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A Performance Evaluation of Pennsylvania's Organ and Tissue Donor Awareness Program

Conducted Pursuant to HR 698 of 2006

June 2007

Table of Contents

	<u>Page</u>
Report Summary	S-1
Summary of Findings	S-5
Recommendations	S-15
I. Introduction	1
II. Background Information on Organ and Tissue Donation	5
III. Findings: An Evaluation of the Implementation and Performance of Pennsylvania’s Organ and Tissue Donor Awareness Program	14
A. Program Definition and Administration	14
B. The Promotion of Organ and Tissue Donation Through Statewide Public Awareness and Education Activities	43
C. The Introduction of Organ and Tissue Donation Awareness Programs in the Commonwealth’s Secondary Schools	77
D. Donor Designation and the Development and Maintenance of a Statewide Donor Registry.....	100
E. Payments to Donors or Donors’ Families for Hospital, Medical, Funeral, and Incidental Expenses	111
F. Hospital Compliance With Required Request and Routine Referral Requirements Related to Organ Donation	137
G. Organ and Tissue Donation and Transplantation Activity in Pennsylvania Since the Passage of Act 1994-102.....	144
H. Transplant Waiting Lists and the Continued Need for Program Services and Expansion of the Organ and Tissue Donor Registry.....	162
I. Program Funding From Voluntary Contributions and Other Sources	171
J. Program Planning, Budgeting, and Expenditures.....	183
K. Expenditure Management and Compliance With Statutory Spending Requirements.....	201
L. Trust Fund Financial Condition	213
M. Review and Update of the State’s Anatomical Gift Act.....	219
N. Compliance With Annual Reporting Requirements	225

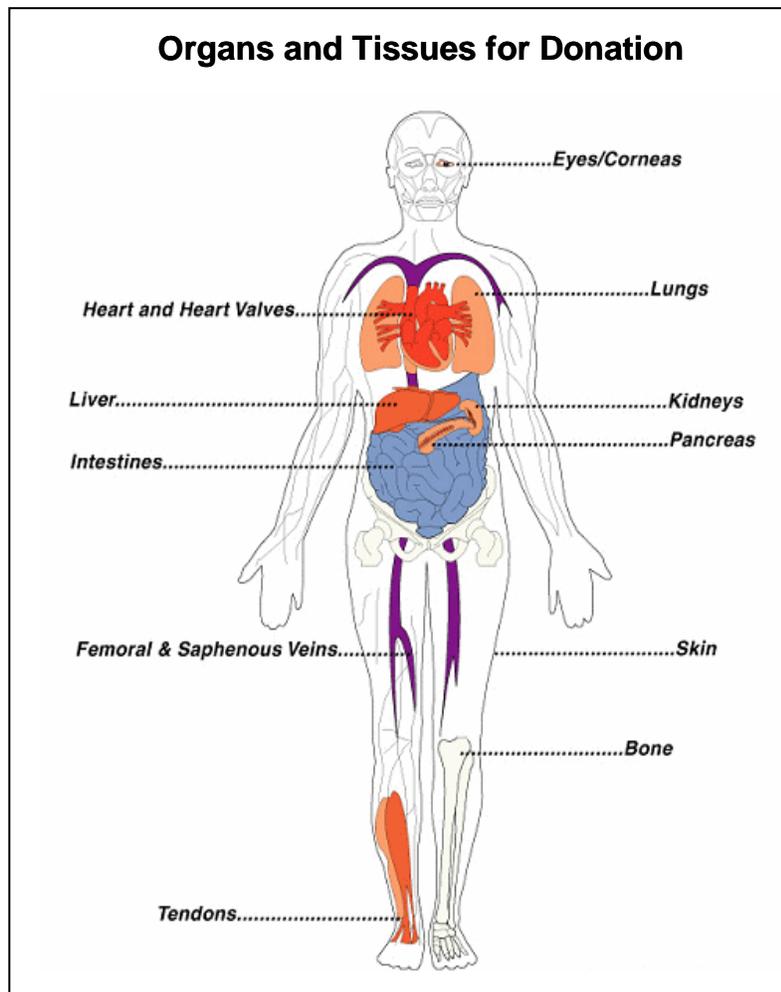
**Table of Contents
(Continued)**

	<u>Page</u>
IV. Appendices	227
A. Copy of House Resolution 698 of 2006.....	228
B. A Summary of Act 2006-65, The Pennsylvania Organ and Bone Marrow Donor Act	230
C. Responses to This Report.....	231

Report Summary

Organ and Tissue Donation

Organ and tissue donation involves the removal of specific organs and tissues of the human body from a person who has recently died, or from a living donor, for the purpose of transplanting or grafting them into persons in need of such organs and tissues. Transplantable organs that can be donated include: the heart, intestines, kidneys, lungs, liver, and pancreas (referred to as solid organs). Tissues that can be donated include: bone marrow, bone grafts, corneas, heart valves, skin grafts, veins, and tendon grafts.



Anyone of sound mind age 18 or older may decide to be an organ and tissue donor. Parents and guardians must consent to that decision by anyone between the ages of 16 and 18, and must also make that decision for other minor donors. There are, however, no age limitations on who can donate. The deciding factor on whether a person can donate is the person's physical condition, not the person's age.

Advances in medical science and technology have made organ and tissue transplantations increasingly common and successful medical procedures. Each year, thousands of persons have their lives extended and their health improved by transplantation. For many individuals, these procedures literally provide them a “second chance at life.”

Since 1988, more than 390,000 organs have been transplanted nationwide and, in 2006, a record 8,022 deceased donors provided 22,200 transplanted organs. Most transplants are deceased donor transplants, involving a donor who has experienced irreversible cessation of cerebral and brain stem function (referred to as neurologic determination of death). In attempting to deal with growing transplant waiting lists, the organ procurement and transplant community is seeking to expand the pool of potential donors to also include donors whose death resulted from the cessation of heart function (referred to as circulatory determination of death).

Living donation has also become more common in recent years. Living donation occurs when a living person donates an organ for transplantation, such as a kidney or a segment of the lung, liver, pancreas, or intestine. Living donors may be blood relatives, emotionally-related individuals, or altruistic strangers. Nationally, there were 6,726 living donors in 2006.

Information on how to register as a donor in Pennsylvania is shown below.

How to become a designated donor? Any adult may complete and have properly witnessed an organ and tissue donor card and/or ask that the “Organ Donor” designation be placed on a new or renewed Pennsylvania Driver’s License or Photo ID Card at the Photo License Center. All three are considered legal documents for the purpose of organ and tissue donation. Pennsylvanians can now also register as an organ donor through a link to a secure PennDOT web page on the “Donate Life-PA” website (<http://www.donatelifepa.org>).

Call 1-877-PA HEALTH or 1-877-DONOR-PA to get a free organ and tissue donor card to sign and carry with you. For more information regarding Organ Donation Designation on your Driver’s License, contact the Pennsylvania Department of Transportation.

Pennsylvania’s Organ and Tissue Donor Awareness Program

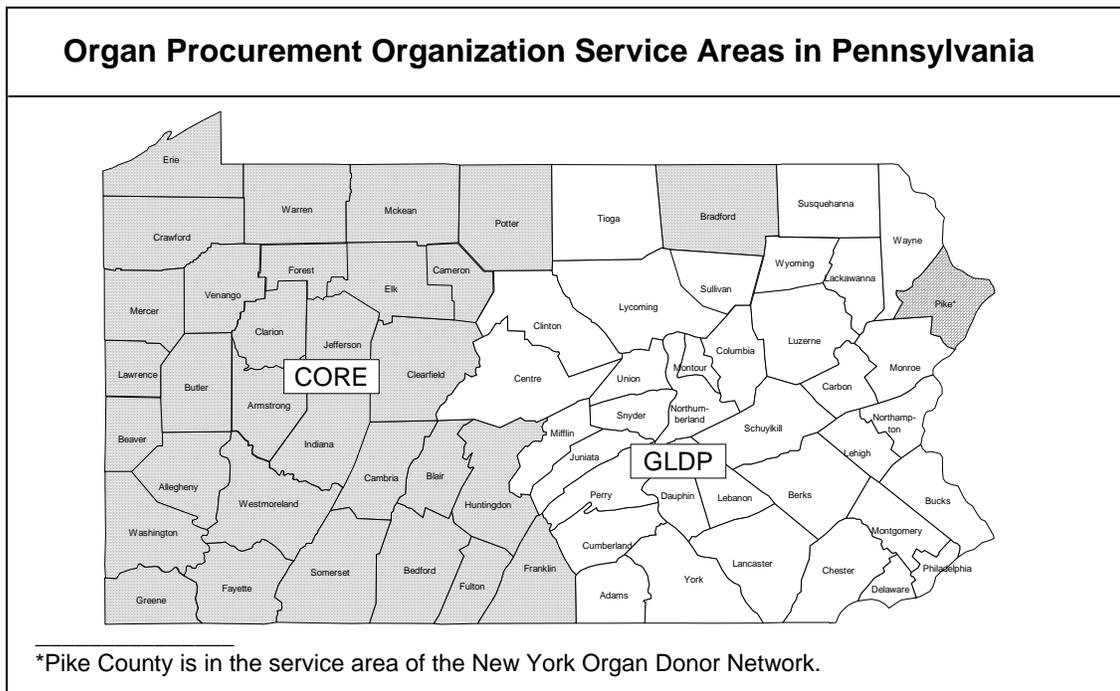
Over the past 25 years, a concerted national effort has been underway to raise awareness of the need for more donors and improved donation practices. At the state government level, governors, legislators, and policy officials are playing a key role in supporting these goals. To this end, many states have initiated special organ and tissue donation awareness programs to heighten public knowledge and awareness of the need for and benefits of organ and tissue donation and transplantation.

With the passage of Act 1994-102, the Pennsylvania General Assembly established the statutory framework for such a program. Known as the “Organ and Tissue Donor Awareness Program” (OTDAP), this program seeks to increase donation rates in the Commonwealth through the implementation of a number of specific provisions contained in Act 102. The primary focus of the program is to increase organ and tissue donation by means of conducting and coordinating public education and awareness programs and activities. Act 102 went into effect on March 1, 1995.

At the state government level in Pennsylvania, four agencies work with the Organ Donation Advisory Committee and the Commonwealth’s two federally-designated organ procurement organizations (OPOs) to administer the state’s Organ and Tissue Donor Awareness Program. The four involved state agencies are the Department of Health, which serves as the lead state agency, and the Departments of Education, Revenue, and Transportation.

The two organ procurement organizations that serve Pennsylvania are the Gift of Life Donor Program (GLDP) headquartered in Philadelphia and the Center for Organ Recovery and Education (CORE) located in Pittsburgh. These OPOs serve as the vital link between the donor and recipient and are responsible for the identification of donors and the retrieval, preservation, and transportation of organs for transplantation. Each OPO also provides public education in the community on the critical need for organ donations.

The service areas for the GLDP and CORE are shown on the map below. Together the two OPOs work with approximately 300 hospitals and 16 transplant centers in 66 of Pennsylvania’s 67 counties.



Pennsylvania OPO Contact Information

Center for Organ Recovery and Education (CORE)
204 Sigma Drive
RIDC Park
Pittsburgh PA 15238
1-800-DONORS-7 www.core.org

Gift of Life Donor Program (GLDP)
401 N. 3rd Street
Philadelphia PA 19123-4101
1-800-DONORS-1 www.donors1.org

The Organ Donation Advisory Committee is a 15-member body that is charged with reviewing progress within the state in the area of organ and tissue donation. The Advisory Committee also provides recommendations on education and awareness training programs and program spending priorities, advises the Secretary of Health on program matters, and recommends legislation.

Together, these agencies and organizations work with the transplant centers, donor hospitals and various other partners in the overall statewide transplantation network, including statewide hospital and healthcare associations, donation advocacy groups, the business community, medical examiners, coroners and district attorney's offices, faith-based communities, and the media.

The OTDAP, which has an annual budget of approximately \$800,000, is funded primarily from voluntary donations that are deposited in the Governor Robert P. Casey Memorial Organ and Tissue Donation Awareness Trust Fund.

House Resolution 698

House Resolution 698 of 2006 directed the Legislative Budget and Finance Committee (LB&FC) to conduct a performance evaluation of the Organ and Tissue Donor Awareness Program. This evaluation focused on the implementation and funding of OTDAP and an assessment of the extent to which the program has been successful in increasing organ and tissue donations in the state by means of education and public awareness programming.

It also reviewed and evaluated the efforts of the Departments of Health, Education, Transportation, and Revenue, the Organ Donation Advisory Committee, and Pennsylvania's two federally-designated organ procurement organizations (OPOs) in carrying out their respective responsibilities under the enabling legislation (Act 1994-102). Finally, the evaluation examined program spending priorities and expenditures from the Governor Robert P. Casey Memorial Organ and Tissue Donation Awareness Trust Fund and surveyed strategies and approaches being used in similar programs in other states.

Summary of Findings¹

Over the past decade, many states have established an “organ and tissue donor awareness program.” With the passage of Act 1994-102, an amendment of the state’s Anatomical Gift Act, Pennsylvania was at the forefront of this movement and, today, is a national leader both in state government programming of this type and in organ donation and transplantation. Moreover, the many accomplishments that have been made through OTDAP in Pennsylvania since 1994, and the influence it has had on legislation and policies nationally, qualifies Act 102 as landmark legislation in the organ and tissue donation field. The program’s record of success and accomplishment as a “best practices” state does not, however, negate the fact that much remains to be done and that legislative and operational improvements to the Organ and Tissue Donor Awareness Program are both possible and necessary, especially to address the widening gap between the supply of transplantable organs and the number of patients on the waiting list.

1. Since 1994, significant progress has been made in implementing Pennsylvania’s Organ and Tissue Donor Awareness Program. Through a strong, multi-agency, collaborative effort, many agencies, organizations, and individuals have effectively combined to promote awareness and increase donation and transplantation. Included in this group are the state Departments of Health, Transportation, Education, and Revenue, the Organ Donation Advisory Committee, the state’s two federally-designated organ procurement organizations, the Gift of Life Donor Program and the Center for Organ Recovery and Education, the state’s acute care hospitals and transplant centers, tissue procurement providers, statewide health associations, and the many thousands of individuals who have authorized the “gift of life.”

Overall, program implementation has been characterized by a strong team effort among involved agencies and organizations. The Department of Health has performed well as lead agency for OTDAP even in the absence of a clearly recognizable program structure and full-time program staff. The Organ Donation Advisory Committee is a dynamic and proactive advisory body whose members demonstrate an intense personal commitment to the program. The Advisory Committee has been very instrumental in OTDAP policy-making, direction, and implementation. Pennsylvania’s two OPOs, the Gift of Life Donor Program and the Center for Organ Recovery and Education, have also played a very prominent role in OTDAP through aggressive implementation of the provisions of Act 1994-102 and active participation and involvement on the Organ Donation Advisory Committee.

PennDOT has also played an important role in program implementation. As required by Act 102, this involved making modifications to the Pennsylvania driver

¹Please refer also to the individual finding statements located at the beginning of each program area, A through N, found in Section III.

license and state identification card system in 1994, providing opportunities for driver license applicants (beginning in 1995) and vehicle registration applicants (beginning in 1999) to make voluntary contributions to OTDAP, and maintaining the state's donor registry as part of the PennDOT driver licensing database. The state Departments of Education and Revenue also participate in the multi-agency effort, PDE through its coordination of the OTDA Education Project under contract to IU-13, and the Department of Revenue through its activities related to monetary contributions to the program.

2. Act 102 and the Organ and Tissue Donation Awareness Program have provided the means by which the state's organ procurement organizations, in concert with the Organ Donation Advisory Committee and involved state agencies, have mounted a concerted statewide public education and awareness campaign with a common theme and unified message. Since 2000, three separate campaigns have been conducted, and more than 773,000 Pennsylvanians have added their names to the statewide donor registry.²

The current campaign, entitled "Ordinary People, Extraordinary Power," conveys the message that each individual has an extraordinary power to save and enhance lives. For example, one organ donor can save up to eight lives and one tissue donor can improve more than 50 lives. To spread this message statewide, the campaign was to tell the true stories of donors, transplant recipients, and families, through multi-media resources and techniques. The campaign involved a combination of public relations, special events (such as promoting Donate Life Month), news releases, radio public service announcements, brochures, and posters. Also included in the campaign was the development of the website www.donatelife-pa.org as a gateway page and the activation of a toll-free telephone number, 1-877-DONORPA.

Through this campaign, a number of special activities such as minority donor awareness and faith-based initiatives have also been undertaken, and system enhancements such as the initiation of an on-line donor designation portal have been made. As a result of such efforts, Pennsylvania now has a solid strategic foundation to further promote organ and tissue donor awareness and build on a donor registry that has more than 4.0 million registered donors, or 43 percent of the state's total population of licensed drivers and state I.D. card holders.

Other awareness activities are targeted to the Commonwealth's secondary schools. The provision in Act 1994-102 that authorizes funding for the development of organ donation awareness programs for the state's secondary schools has resulted in a comprehensive and highly regarded OTDA "Curriculum Framework" and

²Donor registries have been developed in many states as a means by which an individual's consent to be a donor is recorded, stored, and readily retrievable by authorized parties. Pennsylvania's donor registry is maintained by PennDOT as part of the driver licensing database. Officially, however, PennDOT contends that it does not maintain a "donor registry" but rather a database of individuals who hold a driver's license or identification card on which they have registered their decision to be an organ and tissue donor.

“Classroom Toolkit.” In addition to receiving several statewide awards, the products produced by the contractor, Lancaster-Lebanon Intermediate Unit 13, have been distributed and received recognition both nationally and internationally.

Also, through OTDAP, organ donors and donor family members have received limited benefits through a pilot project that helps defray lodging and meal expenses associated with making a vital organ donation. Additionally, a grief counseling benefit program was under development as of spring 2007.

3. While certainly not the sole contributing factors, Act 102 and OTDAP have contributed substantially to Pennsylvania’s leadership position among the states in terms of deceased organ donors coordinated and transplants performed. The directors of Pennsylvania’s OPOs credit both Act 102 and the OTDAP with creating the statutory framework, funding mechanisms, and collaborative relationships that have significantly advanced organ and tissue donor awareness and transplantation activity in the Commonwealth.

Two Act 102 initiatives, in particular, have been influential in increasing organ and tissue donation rates. The first, “required request,” ensures that all potential donor families are asked about donation; the second, “routine referral,” requires that hospitals notify OPOs of all imminent deaths. Pennsylvania pioneered the concept and practice of “routine referral,” and the inclusion of these provisions in Act 102 was the impetus for it being adopted by other states and by the federal government in its 1998 federal “Conditions of Participation Final Rule.” In short, Act 102 changed hospital participation and how the health care community views and participates in the donation process.

In 2006, a total of 996 donors were coordinated in Pennsylvania (including 587 deceased donors and 409 living donors), and a total of 2,249 transplants were performed. Among the 15 most populous states, this ranks Pennsylvania first in both the number of deceased organ donors recovered per million population (47.2 per million population in 2006) and the number of deceased donor transplants performed per million population (149.4 per million population in 2006). (See Section G for a further discussion and explanation of the basis of these calculations.)

Also, the Commonwealth’s two OPOs, the Gift of Life Donor Program and the Center for Organ Recovery and Education, rank at or near the top in the number of donors coordinated and transplants performed per million population among the nation’s most populous OPOs. In all but two years between 1990 and 2006, the Philadelphia-based Gift of Life Donor Program coordinated more organ donations than any other OPO in the country and in 2006 exceeded the 400 donor mark.

4. Through June 30, 2006, a total of \$6.2 million had been spent to develop and implement OTDAP. We found that program spending has

been in compliance with statutory requirements and that, to date, program expenditures have provided a solid return on investment.

The program is funded through a combination of voluntary contributions, General Fund appropriations, and interest with about two-thirds of total revenues coming from voluntary donations made by Pennsylvanians when they: (1) apply for a driver's license, state I.D. Card, or vehicle registration renewal; or (2) contribute a portion of their State Income Tax refund to the Governor Robert P. Casey Memorial Organ and Tissue Donation Awareness Trust Fund. Of the \$6.2 million spent for OTDAP since 1994, \$4.5 million, or 72 percent, was funded from the Trust Fund; the remainder, \$1.7 million, was paid from the state General Fund.

Trust Fund monies are expended according to a statutory spending formula that prescribes spending purposes and maximum percentage amounts of corresponding annual expenditure. After the payment of implementation and Advisory Committee costs, (1) up to 10 percent of the total Trust Fund may be spent annually for "reasonable hospital and other medical expenses, funeral expenses, and incidental expenses"; (2) up to 50 percent may be granted to OPOs for organ donation awareness programs; (3) up to 15 percent may be expended for Project-Make-A-Choice; and (4) up to 25 percent may be used to implement organ donation awareness programs in the Commonwealth's secondary schools.

Based on an analysis of expenditures between FY 2000-01 and FY 2005-06, we found that the majority of OTDAP expenditures have been made through contracts and grants to the OPOs to finance the statewide education and awareness campaigns. During this period, \$2.2 million, or about 73 percent of total spending, was for this purpose. Spending in other expenditure categories was: secondary school awareness, \$697,795; donor/donor family benefits, \$93,871; and program implementation costs, \$20,796.

From our analysis, we found the program to be fully in compliance with the statutory spending caps for voluntary benefits, grants to OPOs, Project Make-A-Choice, and secondary school awareness. In fact, the expenditures for most of the categories were significantly less than their spending cap in almost all of the years examined.

While difficult to quantify the impact of OTDAP in dollar terms, it is possible to make a "cost-per-donor" calculation (that is, the amount spent for each of the more than 4.0 million Pennsylvanians who joined the state registry since the program began). Even when the full \$6.2 million amount spent in the program is used in this calculation, the amount spent per donor is only \$1.55. In contrast, one recent analysis reported by the Institute of Medicine found that with the cost savings of transplantation, society should be willing to spend up to \$1,900 to register a single organ donor. Pennsylvania's accomplishments are all the more significant

considering that about two-thirds of the money invested in the program comes from voluntary donations made by Pennsylvania citizens.

The significance of the impact and benefit of transplantation is evident from a 2005 study of the number of “additional life years” given to patients by deceased donors. The study, reported in the *American Journal of Transplantation*,³ found that an average organ donor provides 30.8 additional life-years distributed over an average 2.9 different solid organ transplant recipients, whereas utilization of all solid organs from a single donor provides 55.8 additional life-years spread over six organ transplant recipients. Approximately 250,000 additional life-years could be saved annually if consent for potential deceased donors could be increased to 100 percent. The study, therefore, concludes that increasing organ donation should be considered among our most important public health concerns.

5. Despite recent increases in donation, the growing demand for donated organs and tissues for transplantation is a pressing public health issue. The success of organ transplantation as a treatment option, the aging of the baby boom generation, increasing life expectancies, and improvements in immunosuppressive medications are among the factors which have resulted in a rapid escalation in the waiting list for transplantation in recent decades.

As of March 9, 2007, 94,857 people were waiting to receive an organ transplant in the United States, and approximately 18 persons die each day because too few organs are available. Every 13 minutes a new name is added to the national waiting list. Pennsylvania’s waiting list as of March 9, 2007, was 6,672, nearly double its size when Act 102 was enacted in 1994.

While OTDAP’s statewide education and awareness efforts have had a positive impact in Pennsylvania, substantial room for improvement remains. At 43 percent of total driver population, Pennsylvania ranks 17th in donor designation among 27 states for which information is available. Eleven of these states, led by Utah at 70 percent, reported “actionable donor designation rates” of 60 percent or higher.

As of March 1, 2007, 5.3 million of Pennsylvania’s 9.3 million licensed drivers and state I.D. card holders were not registered as organ and tissue donors. Applying the two-thirds estimate from a 2005 Gallup survey of Pennsylvanians who have not yet registered but who support organ donation for themselves would indicate a potential pool of approximately 3.4 million new drivers that the OTDAP can conceivably reach and bring onto the donor rolls. This gap between those who support organ and tissue donation in theory and those who actually become donors is

³*The Life-Years Saved by a Deceased Organ Donor* *American Journal of Transplantation* 5(9):2289-2296, September 2005, Schnitzler, Mark A.; Whiting, James F.; Brennan, Daniel C.; Lentine, Krista L.; Desai, Niraj M.; Chapman, William; Abbott, Kevin C.; Kalo, Zoltan.

significant and must be addressed, both in Pennsylvania and in other states, if the growing need for organs and tissues is to be met.

Following the 2003 to 2006 “Ordinary People, Extraordinary Power” statewide campaign, the theme is being continued through at least the first year of the 2006 to 2009 promotional campaign period. A new contractor was selected, and plans are in place to continue and enhance the existing campaign, further develop and enhance a minority outreach campaign, and promote the on-line portal. The overall goal of the campaign is to increase the percentage of the state’s registered drivers who are designated as donors to 46 percent by June 30, 2009.

However, as occurred in 2003 and 2004, the start-up of the 2006 to 2009 phase of the campaign has been held up by contract and grant processing delays at the state level. As a result, the statewide campaign has been on hold, and about eight months of the three-year campaign have essentially been lost.

6. In addition to getting the statewide public education and awareness campaign restarted and on track, the Department of Health, the Organ Donation Advisory Committee, the state’s two organ procurement organizations and, to varying degrees, the other state agencies involved in the program have before them numerous other issues and administrative and operational matters that need to be addressed. Among these are matters that will also require legislative action. The following is a brief discussion of these program-related issues and matters of concern (additional detail is available in Section III of the report).

- *The “Organ and Tissue Donor Awareness Program” is not specifically established in Pennsylvania state law or regulations. The term has evolved since 1994 and is used to refer to the collective efforts and activities of numerous governmental and private-sector agencies and organizations in implementing multiple related provisions in Act 1994-102 contained in Pennsylvania’s Anatomical Gift Act (AGA). Further, the implementing agencies have not established written policy statements, program guidelines, or regulations that define the program or provide a formal basis upon which the program is to be conducted.*
- *The program, which is not officially recognized in statute or in the Department of Health’s organizational structure, does not have a dedicated full-time staff person assigned to it even though it is a program for which the Department has assumed lead agency responsibilities. The individual assigned to OTDAP on a part-time basis also serves as the Department’s Manager of Health Education and Information Programs. This position has many other major competing program responsibilities, primarily in the areas of statewide health education and information programming, worksite health promotion, and women’s health initiatives that prevent*

the level of focus and time that OTDAP merits and requires. This hampers program implementation, communication, continuity of effort, and completion of program initiatives.

- Although OTDAP funding has resulted in the development of a comprehensive and highly regarded “Curriculum Framework” and “Classroom Toolkit,” significant inroads have not yet been made in introducing organ and tissue donor awareness programs in the Commonwealth’s secondary schools. The OTDA “Curriculum Framework” and “Toolkit” have not yet received extensive use in the state’s secondary schools. While nearly \$1.0 million has been expended for the development and implementation of the concept, fewer than 14 percent of all school districts have, to date, adopted it for use. Further, in schools in which it has been used, there are no reliable measures of the sustainability of the instruction or its impact on students’ understanding of and attitudes toward organ and tissue donation.
- Despite making notable strides in increasing the percentage of the state’s licensed drivers who are registered as organ and tissue donors, Pennsylvania, at 43 percent, ranks 17th among the 27 states for which information is available for this measure. Fourteen states, led by Utah at 70 percent, report that over 50 percent of their licensed drivers are organ and tissue donors. Through continued statewide education and awareness efforts, Pennsylvania’s OTDAP will seek to increase this percentage. The goal of the 2006 through 2009 statewide campaign is to increase Pennsylvania’s numbers to 46 percent.
- The spending categories and caps established by Act 1994-102 to govern the allocation of monies from the Trust Fund are administratively cumbersome and do not provide program administrators enough flexibility in program spending; and some authorized spending areas (for example, implementation costs and incidental expenses) are inadequately defined. Additionally, the manner in which the Fund has, until recently, been administered, using separate restricted expenditure accounts or “silos” for each of the four Act 102 statutory spending categories, made expenditure prioritization time-consuming and difficult.
- The component of the program under which Act 102 authorizes the provision of certain types of expense benefits to donors and donor family members is unsettled, with several major questions to be resolved.
 - Although the program is designated as the “Organ and Tissue Donor Awareness Program,” the law currently excludes tissue donors from eligibility for donor and donor family benefits.
 - Although Act 102 authorizes the Organ Donation Advisory Committee to establish a pilot program to reimburse a portion of organ donors’ funeral expenses, the Committee’s proposals to proceed have not been approved by the Secretary of Health. The Secretary’s denials stem

from concerns that such payments would violate the National Organ Transplant Act (NOTA) that prohibits transfers of human organs for “valuable consideration.” While no test cases are available and the federal government has not issued any specific advisories or opinions on the legality of such a program, there are indications that a proposal could be crafted that would not violate the federal law. Within the transplant community, positions vary. There are indications, however, of a fairly recent shift in attitudes toward support of the idea that, at a minimum, pilot projects should be undertaken to help gather data as to the feasibility and effectiveness of financial incentives (e.g., a funeral expense benefit) in increasing organ donation rates.

- While the Advisory Committee was seeking to implement a benefit to benefit deceased donor families, the “Organ Donation Expense Benefit Pilot Program” is almost exclusively benefiting living donors and their families. This benefit was introduced in 2002 as a three-year pilot “in recognition and appreciation of the gift of life.” From its inception through June 30, 2006, 473 donors or their families received expense benefits for lodging and meal expenses associated with making a vital organ donation. These payments, which are paid directly to transplant hospitals or referral hotels, have totaled \$93,781 over five fiscal years and have, with one exception, exclusively benefited living donors. As of early 2007, it continued to operate as a “pilot program.”
- In an effort to provide a Trust Fund benefit to the families of deceased organ donors, the Organ Donation Advisory Committee is planning to implement a Trust Fund-supported family grief counseling and bereavement support benefit through community-based service providers. The timeline originally established for the program called for services to begin in July 2007, but the pilot is currently behind schedule. Initial start-up costs are budgeted at \$30,000 with annual costs thereafter estimated at approximately \$165,000 annually.
- Despite recent increases in donation among minority populations, organ and tissue donation education and awareness deficiencies remain and key issues such as misperceptions about donation and mistrust of the health-care system require continued attention. Moreover, there is an increased need for transplants and, in particular, kidney transplants, in minority populations because of the higher incidence of end-stage renal disease among the members of these populations. Almost 88 percent of African-Americans on Pennsylvania’s waiting list are candidates for a kidney transplant.
- While the Organ Donation Advisory Committee has operated very effectively, there are several membership and administrative matters that require attention. We found, for example, that the Advisory Committee has

not adopted bylaws to govern its operation and has not instituted a formal policy to track the status of the motions it adopts or to formally communicate and transmit advisories and proposals to the Secretary of Health. In terms of membership, the current composition of the Committee is lacking representation from the north central region of the state (a statutory requirement) and includes nine members whose terms have expired. Also, although infrequent, the Committee has not taken action to address attendance problems when they arise.

- The program lacks an overall, multi-year planning process, and program spending priorities are formulated in the absence of an annual program plan or work statement with specific goals and objectives. The Advisory Committee has, on occasion, attempted to identify and formalize operational objectives for the program. For example, in 2002, the Committee held a planning session intended to identify and develop program and Committee goals. While this and a follow-up session were held, nothing was formalized in terms of a program or advisory committee planning process that could be tied to the budget. Planning of this type would, however, require more than the limited DOH staff resources currently available to the program.
- Although the Trust Fund had a balance of \$2.2 million as of the end of FY 2005-06, increasing revenue demands are facing the program. Such factors as growing funding requirements for education and awareness efforts, a planned expansion of donor family benefits to include grief counseling, and the need to address the issue of tissue donor eligibility and other pending initiatives could quickly deplete the available Fund balance.
- While voluntary contributions from driver license, state I.D. card and vehicle registration applicants are the lifeblood of OTDAP funding, the percentage of the total potential contributor population which actually makes a contribution to the Trust Fund is relatively low. Voluntary contributions have sustained the program and, in the case of voluntary contributions from vehicle registration applicants, have increased each year since the option to make a contribution was put into effect. However, the contribution rate (i.e., the number of driver license, state I.D. card, and vehicle registration applicants who actually make a contribution of the total number who apply) is relatively low. We found that between 2003 and 2006, the percentage of vehicle registration applicants ranged from 3.5 percent to 4.2 percent meaning, for example, that in 2006, only 460,590 of the 11,086,810 vehicle registration applicants opted to make a \$1 contribution to the Trust Fund. This is at substantial variance to the results of statewide surveys that indicate that the percentage of Pennsylvanians who report that they support organ and tissue donation is as high as approximately 65 percent. The percentage of driver license and state I.D. card applicants who made a \$1 contribution is somewhat higher at 9.1

percent to 12.5 percent during the period examined, but still substantially below indicated levels of public support. The differential between these currently contributing and potential additional contributors as reflected in reported public support represents a revenue source that will need to be increasingly drawn upon to keep the program viable in upcoming years.

- Despite being faced with growing revenue demands, the program has been lapsing a substantial portion of its General Fund appropriation. During the period FY 2000-01 through FY 2005-06, the OTDAP returned, or lapsed, \$187,257, or 27.4 percent of the total amount appropriated from the General Fund to the Department of Health for the program. These lapses occurred even though the total amount of the General Fund appropriation entitled “Organ Donation” was reduced during this period from \$120,000 in FY 2000-01 to \$109,000 in FY 2005-06, and the Department used a portion of the General Fund appropriations to supplement Trust Fund monies granted to the OPOs.
- Pennsylvania has not yet addressed or taken a formal position on the adoption of any or all of the proposed revisions contained in the updated Uniform Anatomical Gift Act (UAGA) which was adopted by the National Conference of Commissioners on Uniform State Laws in 2006. While the revised AGA makes changes in nine key areas of the act, Pennsylvania’s two OPOs do not believe there is a need for their wholesale incorporation into Pennsylvania law.

7. Our evaluation also included an examination of similar programs in other states to identify program features or approaches that may have potential applicability for the Pennsylvania program. We found that although many states have established an “organ and tissue donor awareness program,” there is no single organizational model or standard set of program components that are common to all programs.

However, by surveying program officials and OPOs in other states and examining pertinent statutes and website program materials, we compiled comparative information in the following areas that is pertinent for consideration for OTDAP: advisory committee composition and bylaws, revenues sources and designated funds/subaccounts, living donor support, medical examiner/coroner policies, minority awareness, organ donation instruction in schools, program staffing, specialized educational programs for legal and medical professionals, websites, workplace partnership for life, and other miscellaneous provisions.

The results of our examination of these areas of organ and tissue donor awareness programs in other states are not included in the report but have been provided to the Department of Health and the Organ Donation Advisory Committee for their reference and use.

Recommendations

Program Definition

- 1. In order to increase program visibility and better define the Organ and Tissue Donation Awareness Program, the General Assembly should consider amending Pennsylvania’s “Anatomical Gift Act”⁴ to specifically reference and establish the program in statute.**

Although the term “Organ and Tissue Donation Awareness Program” is not used in state law, a grouping of selected related provisions in Act 102 has, for practical and operational purposes, been collectively designated as “the Program.” Established and defining it in the Anatomical Gift Act (AGA) would formalize the program and elevate it to official program status. At the same time, the General Assembly should identify those provisions of the act that collectively comprise “the program,” including, for example, all pertinent sections pertaining to required hospital protocols and participation; promotion of organ donation education and awareness; driver’s license designation; creation of an Organ Donation Advisory Committee; establishment of the Governor Robert P. Casey Memorial Organ and Tissue Donation Awareness Trust Fund; authorized expenditures and spending caps; and reporting requirements.

In related actions, the Legislature should (a) formally designate the Department of Health as the “lead state agency” for administering and coordinating the program and specify the lead agency’s duties and responsibilities; and (b) add language to expressly authorize the Department of Health to promulgate any rules and regulations necessary to carry out those provisions that the AGA designates as constituting the Organ and Tissue Donor Awareness Program (for example, to define the meaning of certain terms such as “implementation costs” and “incidental expenses” and clarify what activities are to be funded under each of these terms and to establish the eligibility criteria and application and award procedures for donor and donor family benefits).

Program Staffing

- 2. To enhance program implementation and continuity, the Department of Health should request authorization to create and fill a full-time “Organ and Tissue Donation Awareness Coordinator” position to take the lead for the Department in administering OTDAP and serving as a full-time liaison to the Organ Donation Advisory Committee, the OPOs, other state agencies involved in the program, and program contractors and grantees.**

⁴Pennsylvania’s statutory chapter relating to anatomical gifts (20 Pa.C.S.A. Chapter 86).

This position would serve as the primary departmental contact and administrator for all organ and tissue donation promotion efforts and would provide full-time support in addressing statewide organ/tissue donation awareness issues in partnership with the Organ Donation Advisory Committee and the state's two organ procurement organizations. The Department should pursue General Fund support for this position through its "Organ Donation Appropriation."⁵ The individual in this position would report to the Director of the Bureau of Health Promotion and Risk Reduction and the Deputy Secretary for Health Promotion and Disease Prevention.

The following are examples of job duties and responsibilities that could be considered for inclusion in the job description for the position of state coordinator for the Organ and Tissue Donor Awareness Program:

- assists in planning, developing, organizing, and ensuring the overall implementation of the OTDAP, including the formulation of program policies and procedures;
- assists in administering the Governor Robert P. Casey Memorial Organ and Tissue Donation Awareness Trust Fund;
- maintains program records and files and compiles all materials necessary to meet statutory reporting requirements;
- assists the Organ Donation Advisory Committee in developing statewide programs and initiatives, projects, funding proposals, and expenditure priorities;
- in conjunction with the Bureau Director and Committee co-chairs, prepares the agenda for all Advisory Committee meetings, and makes all necessary meeting arrangements;
- staffs the Organ Donation Advisory Committee meetings (e.g., attends committee meetings, and coordinates recordkeeping and preparation of meeting minutes);
- works with the Advisory Committee to develop and maintain a strategic plan to promote awareness and improve statewide donation rates;
- ensures that PennDOT photo-license centers comply with agreed upon arrangements to display and provide OTDAP materials and coordinates the replenishment of program materials as needed;
- oversees and submits RFPs for grant proposals, and ensures compliance with all state and program requirements;

⁵Between FY 2000-01 and FY 2005-06, the Department of Health lapsed \$187,257, or 27.4 percent, of the total appropriated from the General Fund for OTDAP. Additionally, the Department allocated \$5,000 in FY 2006-07 to each OPO from this General Fund appropriation to supplement Trust Fund monies awarded for statewide public awareness efforts. This amount is to increase to \$10,000 per OPO in FY 2007-08 and FY 2008-09.

- ensures timely notification and communication with Advisory Committee members and provides information and updates between regularly scheduled meetings;
- coordinates schedules and provides committee members and DOH officials with needed reports and input to aid in decision-making;
- analyzes and evaluates OTDAP policies and procedures to ensure compliance;
- monitors OTDAP grants and contracts to ensure compliance;
- establishes and maintains in collaboration with the OPOs, effective liaisons with the transplant centers, tissue procurement providers, acute care hospitals, health care providers and groups, statewide health associations, professional associations, training programs, and community groups to strengthen state/local collaboration related to organ/tissue donation and access to transplantation;
- researches, compiles, and develops materials for non-routine programmatic and administrative issues (e.g., legislation, budget, funding, grants, contracts, and program policy development);
- responds to requests from the public, recovery agencies, and others; and
- performs other related duties as assigned (e.g., provides input into web page updates as needed).

Program Funding

3. In light of growing funding demands, the Organ Donation Advisory Committee should develop an “OTDAP Revenue Enhancement Strategy” and work, in conjunction with the Department of Health and the pertinent legislative standing committees, to implement the measures in the strategy. Possible revenue enhancement measures that the Advisory Committee may wish to consider including in the strategy follow:

- a. Amending the law to authorize PennDOT to revise driver license and vehicle registration renewal forms to give Pennsylvanians the option to contribute “\$1 *or more*” to the Governor Robert P. Casey Memorial Organ and Tissue Donation Awareness Trust Fund. A number of other states provide this option. Once authorized, the DOH and the Advisory Committee should work with PennDOT to redesign the driver license and vehicle registration renewal application forms to both add the “\$1 *or more*” language and to enhance the visibility and wording of the message on the

forms informing applicants of the option to make a volunteer contribution to the Trust Fund.⁶

- b. Consult with PennDOT on the possibility of also including an organ and tissue donation awareness brochure or pamphlet in the mailing sent to vehicle registration renewal applicants. Such materials are currently included in driver license mailings. By also inserting these materials in vehicle registration renewal packets, it may be possible to increase the number of applicants who become aware of the option and make a voluntary contribution to the Trust Fund. Current statistics on voluntary contributions suggest the inclusion of these materials may be a factor in prompting voluntary contributions.⁷
- c. Making arrangements necessary to enable persons who visit the Donate Life-PA website and the PennDOT on-line donor registry to make on-line donations to the Trust Fund.
- d. Advocating that the General Assembly reinstate the voluntary organ donation awareness check-off provision on the State Income Tax form beyond its scheduled sunset expiration date of January 1, 2008.
- e. More effectively publicizing and informing the public of the various donation options and clarify that people do not have to make a monetary contribution in order to register as a donor.
- f. Tasking the proposed full-time state coordinator (proposed in Recommendation #2) to explore the possible availability of alternative revenue sources such as gifts, bequests, grants, donations from public and private sources, foundation funding for special projects, and assistance from companies that market anti-rejection drugs in sponsoring and funding special events and education and awareness activities.
- g. Requesting that the Department of Revenue, when communicating with accountants and accounting and income tax preparation service companies, remind them that their tax preparers should advise their clients of the options they have to donate all or a portion of their state tax refund or to otherwise make a donation to the Trust Fund.

⁶Based on a preliminary inquiry LB&FC staff made with PennDOT on this subject, changing the amount from, for example, \$1 to \$2 would involve a cost of less than \$50,000 for system/software changes, plus forms modification costs. The Department did not estimate the cost of other form modifications or options.

⁷As discussed elsewhere in the report, the percentage of total state driver license and state I.D. card applicants who receive organ and tissue donor awareness informational materials along with their camera card chose to make a voluntary financial contribution in 9.1 percent to 12.5 percent of the cases between FY 2003-04 and FY 2005-06. For vehicle registration applicants (whose applications did not include the organ and tissue donor awareness materials) the percentage of total applicants who chose to make a voluntary contribution ranged from 3.5 percent to 4.2 percent between 2003 and 2006.

Statewide Public Awareness Campaigns and Related Activities

4. **To further public awareness and promote organ and tissue donation, the Advisory Committee, in consultation with the DOH, the OPOs, and the statewide awareness campaign contractor (Giant Ideas) should examine, and as deemed appropriate, implement the following as part of, or as supplements to, the ongoing 2006-2009 “Ordinary People, Extraordinary Power” statewide public awareness campaign.**
 - a. **While continuing to primarily stress the altruistic and charitable nature and motives for donation, also incorporate and quantify the element of self-interest into OTDAP education and awareness materials on organ and tissue donation.** Although not directly presented as a feature of donation education and awareness, a concept and approach espoused in a 2006 publication issued by the Institute of Medicine (IOM)⁸ appears to have potential for incorporation in future OTDAP education and awareness efforts. We believe that the Advisory Committee should consider recommending that the following conceptual approach and specific points be incorporated into future awareness campaign efforts.
 - Historically, the donation of solid organs has been discussed primarily in terms of charity, compassion, generosity, empathy, and philanthropy. According to the IOM, however, it can also be argued that people have a personal interest in maintaining a community (also referred to as a “common stake in a trustworthy system”) that provides options such as organ donation.

Although this motive is usually discussed in qualitative terms as a philosophic principle, it can also be viewed in terms of a traditional (and more narrowly focused) self-interest. That is, how does this apply to me? From this view, the natural questions are “Could this happen to me?” and, if so, “How likely is it to happen to me?”

- Just as everyone has a personal stake or interest in the availability of enough doctors, nurses, and other healthcare providers, as well as drugs and medical devices, to cure or ameliorate disease, so, too, does everyone have a common interest in ensuring the availability of enough organs to save, extend, and improve their own lives and the lives of their loved ones. The Committee on Increasing Rates of Organ Donation quantified self-interest by roughly estimating the probability that solid-organ donation will touch the life of a given person or someone close to him or her over various periods of time.

The Committee estimates that among the U.S. population as a whole, each person has a 1-in-7,500 chance of needing a transplantable organ

⁸*Organ Donation, Opportunities for Action*, the Institute of Medicine of the National Academies, 2006.

in a given year and a 1-in-100 chance of needing one in a lifetime. If it is assumed that any given individual has meaningful emotional attachments to 20 other people, the annual probability that a person or someone whom he or she cares about will need a transplantable organ in a given year is 1 in 358 and the lifetime probability is 1 in 5. If tissue transplants are also considered, the average risk of the need for a transplant that each person and the individuals in his or her close social network faces over a lifetime rises to more than one person in two.

Making this information known as part of ongoing public education and awareness efforts could provide compelling motivation for many persons who are not currently registered donors and could also generate additional monetary donations to the Trust Fund.

b. The Advisory Committee, along with the OPOs and the statewide awareness campaign contractor, should comprehensively reexamine and improve the direct marketing approach and activities currently used to promote and encourage donor designation at PennDOT's 97 photo-license centers. Steps need to be taken, for example, to improve the visibility and availability of organ and tissue donation brochures and other materials at the photo license centers. Specifically, we recommend that the Advisory Committee, the OPOs, and Giant Ideas do the following:

- To give it an identity and emphasize its importance as a discrete component of OTDAP, the overall direct marketing effort at the centers be designated and referred to as "Project-Make-A-Choice." The term "Project-Make-A-Choice" appears in Act 1994-102 and is closely associated with the statewide organ and tissue donation awareness program. As presently constituted, however, it is not a discrete and meaningful project or component of OTDAP. DOH budget materials state only that Project-Make-A-Choice funding is to be used "in coordination with the statewide public awareness program to be conducted by the certified OPOs to encourage Pennsylvanians to become organ and tissue donors." In actual practice, this simply means that a portion of Trust Fund monies are annually combined with another portion of Trust Fund monies called "grants to OPOs." Together, the OPOs use these monies for the statewide awareness campaign, not for a separately identifiable project called "Project-Make-A-Choice." Because it is a recognizable name and was part of the original statute, it seems that the term could be better used to give identity and emphasis to the program activities that transpire at the photo-license centers. The term is clearly very descriptive of the decision residents are asked to make at the centers and its use for this purpose would seem to be more in line with the language originally associated with it in Act 102.

- Work with PennDOT to incorporate provisions into the contract between the Department and the PA Industries for the Blind and Handicapped (PIBH) that ensure that attention is given to consistently and prominently displaying organ and tissue donor materials supplied by the OPOs and the statewide public awareness campaign contractor and that procedures are in place to periodically replenish the centers' supplies of brochures and other materials.
 - Revisit the concept of making center employees "ambassadors" for the program. Consider negotiating with PennDOT and PIBH to allow for photo-license center employees to receive additional training, permission to state a one-line verbal introduction to the topic and, for those employees who wish to do so, to wear a promotional button.
 - Consider redesigning the brochures, posters, and graphics that are made available for distribution at the photo-license centers. Based on LB&FC staff visits to a sample of centers, the design of the materials and the manner in which they are displayed is not eye-catching and, we suspect, presently go unnoticed by many who visit the centers.
 - Consider seeking authorization from PennDOT to install TV monitors in at least some large photo-licensing centers on a trial basis. The monitors could be used to provide organ and tissue donor information, PSAs, and messages interspersed with regular news and PennDOT informational programming. Seek partnerships with cable companies and/or large electronics retailers to provide monitors on a charitable deduction basis or in exchange for public recognition of their donation.
 - Seek authorization from PennDOT to periodically have the state's OPOs work with volunteers to conduct direct marketing activities at selected photo-license centers.
 - Consider providing funding to enable the OPOs to have Giant Ideas expand its contract or subcontract with another firm to provide specialized services to comprehensively redesign and enhance the direct marketing effort at the photo-license centers.
- c. Reconsider and, where feasible and still relevant, incorporate public education awareness initiatives identified but not completed during the course of the 2003 to 2006 statewide public awareness campaign.**

The Advisory Committee, in coordination and consultation with the Department of Health, Pennsylvania's OPOs, and the current contractor for the statewide public awareness campaign, should reexamine those activities and tasks that were initially deemed important to the campaign but that were subsequently not pursued in the 2003 to 2006 time frame of the

“Ordinary People, Extraordinary Power” campaign. As additional funds may become available, consider the following:

- Engaging the Department of Health district offices and county health departments to promote organ and tissue donation awareness, including development of a collaborative relationship with district office personnel to discuss methods and tactics to promote organ and tissue donation awareness within each district for maximum effectiveness.
 - Developing and marketing of point-of-purchase video spots for use in supermarkets, convenience stores, and other areas to be determined.
 - Developing and marketing of a continuous loop video for placement in hospitals, doctor’s offices, government offices, driver licensing centers, and other areas to be determined.
 - Creating slides for use as public service announcements on movie theater screens.
 - Creating posters featuring prominent Pennsylvanians who are organ donors, in a photo driver license format.
- d. Consider developing a special “Donate Life-PA Recognition Program.”** This program would recognize and thank counties, specific photo-license ID centers, workplace partners, community organizations, and OT-DAP strategic partners and other groups and organizations that make a significant contribution to increasing donor designation in the Commonwealth. Recipients could receive a certificate of recognition issued through the Governor’s Office as well as being featured in the annual program report to the public that is proposed in part m. of this recommendation and/or be recognized at the “Organ and Tissue Donation Advocacy Day” described in part o. of this recommendation.
- e. Explore the creation of one or more Minority Organ and Tissue Transplant Education Project (MOTTEP) Chapters in Pennsylvania.** The Organ Donation Advisory Committee and Pennsylvania’s two organ procurement organizations should explore the feasibility of and potential funding sources for creating one or more MOTTEP affiliated organizations in Pennsylvania. For example, a Philadelphia-based organization of this type could assist the OPOs and the public awareness and education campaign in implementing practices and strategies to promote organ and tissue donation among minorities.
- f. Make modifications/corrections to several aspects of the existing “Donate Life-PA” Website.** Several aspects of the “Donate Life-PA” website (<http://www.donatelifepa.org>) require modification/correction. Specifically, several mathematical and/or typographical errors pertaining to county organ donor designation percentages on county-specific web pages

within the website require correction, so as not to distort or misrepresent county donor designation rankings presented on the website.

In addition, the web link provided to obtain a Pennsylvania “Donate Life” license plate is inoperable and in need of restoration, and while the web link provided for the Department of Health forwards visitors to the Department’s website, the destination page is no longer active. Further, personal stories from organ donor families, friends, and recipients posted on county-specific web pages are not prominently located, and may thus remain unnoticed by visitors to the website. More prominent placement of these stories may greatly enhance the website and better serve the objectives of the current statewide public awareness campaign.

- g. Upgrade and redesign the “Donate Life-PA” website to more effectively present the website as the primary gateway to information on organ and tissue donation in Pennsylvania.** The current website used in support of the statewide awareness campaign, “Ordinary People, Extraordinary Power” (<http://www.donatelife-pa.org>), would benefit from an overall site upgrade and redesign. Notably, several features common to organ and tissue donation awareness websites used in other states could be considered.

Features used in other state awareness websites that are not currently used in Pennsylvania include the use of moving graphics as an introduction to the website; information and answers to frequently asked questions on donor designation, donation, and transplantation; information on the Trust Fund (including how to make a contribution to the Fund); information on ongoing awareness events and projects; and the listing of a state hotline or other contact for further information. The website also may benefit from additional links to organ and tissue donation related organizations and resources and more prominent placement of organ donor, donor family, and transplant recipient personal stories. The redesigned website should also include information on bone marrow donation and links to the National Marrow Donor Program.

- h. Reconnect and reestablish the DonorPA toll-free phone line.** In order to ensure maximum public access to information concerning organ and tissue donation (including how to register as a designated donor), program officials should reestablish the hotline as soon as funding allows. We found that, as of mid-April 2007, the statewide toll-free information hotline utilized as a component of the current public awareness campaign (877-DONORPA) had been disconnected. However, this number remains in informational brochures printed in support of the campaign.
- i. Initiate special activities to encourage and obtain on-line donor registrations.** With an online registry system, opportunities to register to donate can be presented in multiple locations. Mobile organ donor sign-up

operations should be initiated to combine awareness activities with immediate opportunities to make donor designations through PennDOT's driver licensing database. To do so, laptop computers with mobile online access capability could be used to allow individuals to add the organ donor designation to their driver licensing record at awareness events. Such mobile donor designation "stations" could be setup at healthcare facilities, places of worship, and at kiosks at sporting events, malls, and other special public events held in support of the awareness campaign. These events could be staffed and conducted by state agency program personnel, OPO staff volunteers, or the designated contractor charged with implementation of the awareness campaign. Program officials in other states with whom we spoke report success in utilizing such donor designation "stations," and some have targeted efforts at areas with known low proportions of designated donors.

To facilitate this process, consideration should be given to purchasing or leasing a van for each OPO region to transport staff, promotional literature and posters, and necessary equipment (such as laptop computers and other equipment required to obtain access to the Internet) to and from awareness events and other locations. The concept should also be explored of acquiring a vehicle that would be of sufficient size to be outfitted as a "mobile free-standing donor designation station" that could be moved to key events and locations around the state.

- j. **Consider creating an organ and tissue donor "webumentary" and online journals.** To further enhance the "Donate Life-PA" website, consideration should be given to creating an organ and tissue donor "webumentary" to present inspirational stories of individuals whose lives were touched in some way by organ and tissue donation. The "webumentary" may consist of streaming videos of in-depth personal stories centered around organ and tissue recipients, donors, or family members, with special focus on the positive, life-saving, and life-enhancing effects of organ and tissue donation.

To provide an interactive component to the website, an online journal or "blog" could be added (possibly through a third party at little or no cost). This feature would allow website administrators to post news, announcements, and other items of interest regarding the ongoing statewide awareness campaign or organ and tissue donation generally, with links added to other websites where users could obtain further information. Pictures of past awareness events could be added to online journal and blog postings. Visitors to the site could then provide comments on items posted.⁹

⁹The website in support of the "Donate Life Illinois" campaign (<http://www.giftofhope.org/donatelife/default.htm>) contains a blog, "donor diaries," and a link to a MySpace© page to promote the campaign.

k. Develop informational DVDs and use existing public service announcements (PSAs) to show in hospitals and health care facilities and post on YouTube© and other on-line video sharing sites.

In order to further expand the awareness campaign to the video and television medium, informational DVDs on the benefits of organ and tissue donation should be developed to be shown in hospitals and health care facilities. Topics that could be covered in the DVDs include important facts regarding organ and tissue donation, personal stories, and messages from religious leaders or celebrities in support of becoming a designated organ and tissue donor. Existing PSAs developed in support of “Ordinary People, Extraordinary Power” could also be shown.

In order to increase online exposure of the awareness campaign, clips from the informational DVDs and the PSAs should be posted on YouTube© and other online video sharing websites. Such uploads, which may usually be completed at little or no cost, have the potential to reach millions of Pennsylvanians. To increase viewership, links to the videos should be posted on the main section of the “Donate Life-PA” website or the online journal or blog page. Consideration should also be given to creating an awareness campaign MySpace© page, at which further information, videos, pictures, and links could be posted, and discussions could be held in support of the campaign.

l. Recruit a high profile spokesperson or persons. To increase the visibility and impact of the awareness campaign, a high-profile spokesperson or persons should be recruited to publicize organ and tissue donation through PSAs and at public awareness campaign events. Spokespersons could be popular professional or collegiate sports figures (athletes or coaches), elected officials, actors, musicians, or other popular entertainers. Such an effort may provide the awareness campaign with the added benefit of creating a positive association among many Pennsylvanians with organ and tissue donation. Spokespersons with a high degree of popularity in certain regions of the state could be used in targeted awareness efforts. Moreover, the use of high-profile spokespersons may be possible at little or no cost to the statewide awareness campaign.

m. Prepare and distribute an annual report to the public, that is an “Annual Report to OTDAP Stakeholders.”

In addition to the annual reporting to the General Assembly that is required in the Anatomical Gift Act, the Advisory Committee should work with the OPOs and the statewide public education and awareness contractor to produce an annual report to the public that makes OTDAP possible through its voluntary financial contributions and support.

This report should be a high profile/high visibility product that would include basic facts and statistics about donation and transplantation in

Pennsylvania, information on Pennsylvania's leadership status nationally, stories about donors, recipients, donor and recipient families, and other pertinent information (e.g., how to donate, how to use the on-line designation feature). Above all, the purpose of the report would be to connect with those individuals who have made financial contributions to the Trust Fund and inform them of the positive life-saving and life-enhancing actions that have resulted from their generosity.

Release of the report could be made through a joint press release issued by the Department of Health and the Advisory Committee to coincide with a major date on the national organ and tissue donation calendar such as National Donor Day (February 14) or during National Donate Life Month (April). The report should be made available to state media outlets and be placed on the DonateLife PA website.

- n. Produce/run more radio and television public service announcements.** In conjunction with the resumption of the statewide public awareness campaign "Ordinary People, Extraordinary Power," and upon the availability of funding, all reasonable efforts should be made to produce and run an increased number of radio and television public service announcements (PSAs) in major and targeted advertising markets throughout Pennsylvania. Several television PSAs have been produced in support of the campaign, but have not yet been aired on television due to delays in execution of the grant to Pennsylvania's OPOs for campaign commencement. Radio advertisements and short radio spots, including the production of additional radio advertisements, should also continue to be a priority. As additional radio and television PSAs are produced, emphasis should continue to be placed on running advertisements in areas of Pennsylvania with low percentages of designated organ donors, including advertisements containing messages to minority communities. Opportunities to air radio and television PSAs at no cost on certain stations should also be actively pursued.
- o. Plan and hold an annual "Organ and Tissue Donation Advocacy Day" at the State Capitol.** The Organ Donation Advisory Committee should consider sponsoring an annual "Pennsylvania Organ and Tissue Donation Advocacy Day" to provide visibility to and increase legislator awareness and understanding of the issues surrounding organ, tissue, and eye donation. This event could connect legislators with state and OPO personnel, professional hospital and transplant group representatives, as well as constituents from their districts who are either transplant recipients or donor family members. Educational sessions could be held with a focus on familiarizing legislators with current and emerging organ and tissue donation-transplantation issues and related legislation needs. Among the day's events could be a remembrance ceremony in the Capitol Rotunda or on the Capitol grounds in honor of organ and tissue donors and their families.

Those persons who are cited by the “Donate Life—PA Recognition Program” proposed in Recommendation #4c could also be honored at this event.

- p. “Piggyback” With the National “Donate Life America” Campaign – take advantage of the national exposure the Donate Life America campaign will receive.**

In order to align with and benefit from organ and tissue donor awareness activities conducted by Donate Life America (of which Pennsylvania’s OPOs are actively involved), Pennsylvania’s awareness campaign should plan and “piggyback” awareness initiatives to coincide with national initiatives when possible. This may include airing PSAs with an emphasis on promoting minority awareness to coincide with national PSAs of this type, as well as developing special awareness activities suitable for National Donor Day (February 14), National Donate Life Month (April), National Minority Donor Awareness Day (August 1), National Hispanic Heritage Month (September 15 through October 15), and the National Donor Sabbath (November).

- q. Take steps to better assess changes in public behavior and awareness and the overall impact and effectiveness of the ongoing statewide public education and awareness campaigns.** While it may still be too soon to gauge the impact and effectiveness of the approaches and methods being applied as part of the statewide public awareness campaign, the Advisory Committee should consider the need to plan for conducting market research activities at the end of the 2006 to 2009 campaign. For example, targeted exit surveys could be used at PennDOT photo-license centers to determine if respondents had seen the promotional material (brochures, posters, billboards, website), seen the public service announcements, heard the radio adds, or were aware of any local events or public relations efforts, including newspaper stories or radio/TV interviews. The surveys would also be geared to learning whether or not they had signed up, if the campaign had changed their attitudes or perceptions, and whether it had impacted their decision to say “yes” to donation. Telephone surveys could also be used, for example, in the ten targeted counties, to learn if respondents are aware of the campaign, if it has changed their attitudes or perceptions, and if they have or plan to sign up.
- r. Consider establishing donation education and awareness seminars and workshops and a special grant program for hospitals, health-care groups, and other professionals (e.g., healthcare facilities, medical and nursing schools, and law schools).** Additionally, the Advisory Committee should consider coordinating joint efforts between the OPOs, the Hospital and Healthsystem Association of Pennsylvania (HAP),

and PA Medical Society to collaborate on increasing the knowledge and understanding of health professionals.¹⁰

- s. **Take steps to ensure that organ and tissue donation education is a part of the professional educational curricula at all professional schools related to health and also at law schools.** As a first step in this process, the Advisory Committee should consider surveying all such schools in Pennsylvania to determine the extent to which such instruction presently occurs. As a matter of policy, the DOH and the Advisory Committee should promote and encourage professional schools to adopt specific organ and tissue donation instruction, if not already doing so. For example, the discretionary funding proposed as a “second priority” spending category in Recommendation #13, the DOH and Advisory Committee should encourage medical schools and nursing schools to include mandatory organ donation education in the schools’ curricula. For example, medical schools could be encouraged to require a physician in a neurology or neurosurgery residency program to complete an advanced course in organ donation education.

Likewise, law schools could be encouraged to provide organ donation information and instruction to law students so that, as attorneys, they can better provide organ donation information to clients seeking advice for end-of-life decisions. Such instruction would be relevant to courses in elder law, estate planning, and health law.

The OTDA Education Project: Secondary School Awareness Activities

5. **The Organ Donation Advisory Committee should encourage and work with PDE and IU-13, the statewide OTDA contractor, toward implementation of the recommendations made in the 2006 “By the Numbers” evaluation report on the OTDA Education Project, including especially the development of a “quick start guide”¹¹ and marketing the classroom toolkit and curriculum framework directly to teachers and principals.**
6. **In order to more directly market the classroom toolkit and curriculum framework, PDE should follow through on an earlier proposal to create an organ and tissue donation awareness education DVD/video project that would be designed to gain the attention of school superintendents and others in a position to promote and approve the introduction and use of the OTDA Education Project in secondary schools.**

¹⁰See also Recommendation #13.

¹¹IU-13 has since developed a “quick start” guide as part of the 2007 “Classroom Toolkit” update.

- 7. As part of the multi-year strategic planning process proposed in Recommendation #19, the Organ Donation Advisory Committee should work with PDE and IU-13, the statewide OTDA contractor, to:**
- a. Develop a plan under which PDE would undertake a more proactive role in promoting the OTDA Education Projects' "Curriculum Framework" and "Classroom Toolkit" and enhancing the exposure and visibility the project receives on the Department's website and in Departmental communications with sending school officials and teachers. This plan would also include distribution of the DVD/video discussed in Recommendation #6.
 - b. Set specific and measurable annual objectives/targets for expanding utilization of the organ and tissue donor education and awareness materials to additional school districts and schools.
 - c. Work with PDE specialists to design a survey instrument to be administered periodically by IU-13 that will measure the impact the OTDA Education Project is having on student knowledge and perspectives related to general information on organ and tissue donation and transplantation in the United States, Pennsylvania state law relating to anatomical gifts, and how to become an organ donor.
 - d. Create a reporting schedule for mini-grant recipient schools to assess evidence of sustainability of project and educational effort. To monitor "sustainability" IU-13 should establish a formal follow-up assessment and reporting schedule for schools that receive mini-grants. This process would assess the sustainability of awareness activities in mini-grant recipient schools past the school year in which a mini-grant is awarded. This would serve as an additional means by which to assess the integration of awareness education in secondary school curricula to program officials in PDE and IU-13, as well as members of the Advisory Committee.
 - e. Explore the possibility of expanding organ and tissue donation awareness education to universities within Pennsylvania's State System of Higher Education (SSHE). Pending statutory changes that would authorize the expansion of the OTDA Education Project beyond secondary schools, the Advisory Committee and PDE should examine necessary authorizations required and the logistics of expanding organ and tissue donation awareness education to SSHE universities. In this effort, the Advisory Committee and PDE should make necessary contacts with SSHE to explore these options. If successful, options could also be explored to engage private colleges and universities within Pennsylvania. Awareness education could potentially be incorporated into courses taken by students majoring in education.
- 8. The Advisory Committee should endeavor to incorporate organ and tissue donation education into the secondary school curriculum by participating in the process that the State Board of Education**

periodically conducts to consider potential changes to the School Code regulations. The State Board of Education adopts broad policies and principles and establishes standards governing the educational programs of the Commonwealth. For example, the State Board is required to engage in “a constant review and appraisal of education” in the state and to periodically review the state academic standards to determine if they are appropriate, clear, specific, and challenging. The Board makes revisions, as necessary, to the regulations.

In April 2007, a subcommittee of the State Board initiated a series of informal meetings (“study group sessions”) to review and discuss Chapter 4 of the School Code regulations relating to Academic Standards and Assessment. The Organ Donation Advisory Committee could participate as an interested party at these sessions for purposes of advancing the OTDA Education Project for inclusion in the state regulations. To that end, we recommend that the Advisory Committee send correspondence to the State Board of Education requesting that Committee and IU-13 representatives be scheduled to make a presentation to the Board on the OTDA Education Project and otherwise participate in the “study group sessions” that are being conducted to consider potential changes to Chapter 4.

Following these meetings at which public input is allowed, roundtable meetings are held to bring interested parties together with members of the State Board to further discuss and explore policy issues and proposals pending before the Board. These “roundtable” meetings provide an informal, but structured, setting where open discussion and dialogue can occur between State Board members and interested parties.

After the completion of the roundtable meetings, the State Board holds formal hearings. One possible outcome of the hearings is that topics and matters brought before the State Board during the Chapter 4 review could be promulgated as regulations and made part of the state’s School Code regulations. If this were to occur with the OTDA Education Project, secondary schools could be required to incorporate the OTDA Curriculum Framework and Classroom Toolkit.

Changing education regulations, however, is a long, time-intensive process that would require an ongoing effort and commitment from the Advisory Committee to keep the issue before the State Board and to shepherd it through the series of study group sessions and more formal meetings and hearings that would be required.

- 9. As an alternative to Recommendation #8, the Advisory Committee, in its capacity as advisor on potential legislation related to the subject of organ and tissue donation, could consider developing a proposal for the General Assembly that legislation be introduced that would**

require incorporation of organ donation education in the secondary school curriculum, as is currently done in certain other states.¹²

Expense Benefit Programs for Donors/Donor Families

10. **The Department of Health should take steps to determine the legality, under federal law, of a funeral expense benefit for donor families that is authorized in state law and that the Organ Donation Advisory Committee has twice proposed to the Department as a pilot project. Specifically, the Department should reassess—in light of the recent federal Department of Justice opinion relating to kidney exchange programs and its analysis of valuable consideration under NOTA Section 301—whether implementing a pilot funeral benefit program as required by Act 102 necessarily involves a buying and selling, or otherwise commercial transfer of organs that “clearly and definitely” is encompassed by NOTA’s prohibition on the transfer of human organs for valuable consideration. We recommend that:**
 - a. The Organ Donation Advisory Committee place the subject of the funeral expense benefit pilot on the agenda for discussion at an upcoming meeting and obtain the group’s current position on again moving forward with a proposal.
 - b. If it votes to proceed, the Advisory Committee should develop, taking into consideration the suggestions contained herein, a written proposal and justification for a funeral expense benefit pilot project and submit the proposal to the Secretary of Health in the formal proposal submittal format discussed in Recommendation #17. The proposal should underscore the non-commercial nature, purpose, and intent of the funeral expense benefit to be provided. This may include, for example, the following:
 - A description and explanation of the nature, purposes, and intent of the funeral benefit program in a “Program Purposes and Intent” section of the proposal. This should, at a minimum, stress and explain the gratuitous, non-commercial nature and intent of the funeral expense benefit arrangement (1) in that organ donation operates under a gift model as recognized by the Anatomical Gift Act and (2) in that the funeral benefit is made on behalf of a donor as a response or gift in recognition of the organ donation. This provision should also stress that the intent is to reimburse for actual funeral expenses incurred attendant to organ donation; there is no gain or profit to be paid.
 - A requirement that donor families wishing to participate in the funeral expense benefit program must attest to full compliance with Section 301 of the National Organ Transplant Act (NOTA), as amended (42

¹²The federal Advisory Committee on Organ Transplantation (ACOT) has recommended that the states include organ and tissue donation in core curriculum standards for public education.

U.S. C. 274e) which stipulates in part that “[i]t shall be unlawful for any person to knowingly acquire, receive, or otherwise transfer any human organ for valuable consideration for use in human transplantation if the transfer affects interstate commerce.”

- A requirement that contractors implementing the funeral expense benefit program must adequately address the NOTA 301 attestation (discussed above) within the standardized protocol or format, subject to DOH approval, to be used when advising a vital organ donor family of the program.
 - A requirement that DOH periodically evaluate the pilot program to assess its effectiveness and to ensure that Act 102’s provisions for funeral benefits are being implemented so as not to frustrate the purposes of NOTA Section 301, and giving effect to both NOTA and Act 102.
- c. The Department of Health’s legal counsel review the detailed proposal to ensure that it does not violate NOTA’s restriction on commercial activity in organ transfers but still gives effect to the requirements of Act 102 for a pilot funeral expense benefit program. This should involve addressing, at a minimum, the following question: Does the funeral expense benefit program, as proposed to be implemented pursuant to the procedures and pilot program developed by the Advisory Committee, involve a buying and selling, or otherwise commercial transfer of organs that “clearly and definitely” is encompassed by the prohibition of NOTA Section 301?

In evaluating the legality of the detailed proposal, counsel should take into consideration the recent kidney exchange opinion issued by the U.S. Department of Justice and confer with counsel to the state’s OPOs. The recent Department of Justice opinion in the area of kidney exchanges concluded that the kidney exchanges at issue did not “clearly and definitely” fall within the prohibition of NOTA Section 301 as transfers for “valuable consideration.” In reaching this conclusion, DOJ acknowledged that NOTA Section 301 does not define “valuable consideration” but simply provides guidance as to what is not valuable consideration. DOJ then opined that “valuable consideration” as applied to organ donations, involved “some sort of buying and selling, or otherwise commercial transfer, of organs.” Moreover, DOJ declared that the prohibition in NOTA must be read narrowly, or less harshly, because NOTA lacked complete clarity on the issue of what constitutes “valuable consideration” and because as a criminal statute, the rule of lenity required a narrow reading of the prohibition.

- d. The Department of Health should consider seeking a formal opinion from the Pennsylvania Office of the Attorney General as to whether the funeral expense benefit program, as proposed to be implemented pursuant to the procedures and pilot program developed by the Advisory Committee, involves a buying and selling, or otherwise commercial transfer of organs that

“clearly and definitely” is encompassed by the prohibition of NOTA Section 301.

11. **In conjunction with officially establishing the OTDAP in law and changing the name of the advisory committee to the Organ and Tissue Donation Advisory Committee, the General Assembly should extend eligibility for donor/donor family benefits to tissue donors by amending Pennsylvania’s “Anatomical Gift Act” at Section 8622(b)(1) to provide that the expense benefit program shall cover the identified expenses “incurred by the donor or donor’s family in connection with making a vital organ *or a tissue donation.*”** In developing procedures as required by Act 102, the Advisory Committee should develop administrative mechanisms for allocating at least a portion of Trust Fund resources for tissue donors.

12. **Concerning donor and donor family benefits, the Department of Health, in conjunction with the Organ Donation Advisory Committee and the OPOs, should also:**
 - a. Make a determination on whether the organ donor/donor family meal and lodging benefit that has been in operation since 2002 is to be removed from pilot status and made permanent.
 - b. If it is to be made permanent, develop guidelines and regulations governing the “Organ Donation Expense Benefit (Meal and Lodging) Program” and any subsequent programs of this type that are implemented.
 - c. Because the proposal grief counseling program would, like the proposed funeral benefit program, grant assistance of monetary value to or on behalf of a donor’s family in connection with a vital organ donation, an analysis and evaluation should be conducted as to its legality under NOTA §301. This is similar to Recommendation #10 regarding funeral benefits and should be undertaken by DOH prior to implementation of the program.
 - d. If a decision is made to go ahead with the grief counseling benefit, and pending a determination on the continuation of the statutory spending caps, ensure that the planned grief counseling program is funded under the statutory Trust Fund provisions authorizing expenditures for “incidental expenses” rather than bundling the funding for the grief counseling benefit with awareness grants awarded to the OPOs.

13. **To provide for greater flexibility in OTDAP administration and Trust Fund management, the General Assembly should amend the law to modify and expand the statutory expenditure authorizations and eliminate the allocation percentages that are currently imposed on spending from the Governor Robert P. Casey Memorial Organ and Tissue Donation Awareness Trust Fund.** While a rationale for the existing spending limitations and percentage spending caps may have been present in

1994 when the program was established, they now appear arbitrary and overly restrictive and have been administratively cumbersome, especially when the “silo” method of Trust Fund management was in effect.

Instead of establishing specific spending caps for each of the authorized spending purposes, the General Assembly should amend the law to give the DOH and the Advisory Committee discretion to allocate funds from the Trust Fund consistent with an annual program budget and spending priorities that are consistent with an overall strategic program plan.

To provide needed flexibility in program budgeting and spending, the General Assembly should also consider expanding the list of authorized purposes for which Trust Fund monies can be expended (beyond the existing five spending categories). We found that the purposes authorized in statute for the expenditure of trust fund monies in a number of similar programs in other states provide administering agencies and advisory bodies a broader range of spending options.

The following is a revised list of authorized spending purposes that might be considered for OTDAP. They are presented in two categories: “first priority allocations” and “second priority allocations.”

We recommend that the following be considered for “first priority” status (i.e., the DOH and the Advisory Committee would first make allocations from available funds for these purposes):

- program implementation costs and Organ and Tissue Donation Advisory Committee costs;
- grants to certified organ procurement organizations for the development and implementation of organ donation awareness programs in the Commonwealth;
- the development of information pamphlets relating to organ donor awareness and the laws regarding organ donation, public information, and public education about contributing to the fund when obtaining or renewing a driver’s license and when completing a state individual income tax return form (currently designated in state law as “Project Make-A-Choice”);¹³ and
- for reasonable hospital and other medical expenses, funeral¹⁴ expenses, and incidental expenses incurred by the donor or donor’s family in connection with making a vital organ donation. As is presently the case, such expenditures could not exceed \$3,000 per donor and

¹³Recommendation #4a proposes instead naming the donor designation activity at PennDOT photo-license centers and through the on-line registration option as “Project-Make-A-Choice.”

¹⁴Except that the “funeral expenses” language be deleted from Pennsylvania law if it is determined to be illegal under federal law.

would only be made directly to the provider or vendor (e.g., a funeral home). No part of the fund would be transferred directly to the donor's family, next of kin, or estate. The Advisory Committee would continue to develop procedures, including the development of necessary pilot programs.

- Allocations to the Department of Education for the implementation of organ donation awareness programs in the secondary schools in the Commonwealth.

We recommend the following spending categories be considered for “second priority” status and, as such, they would receive allocations from the Trust Fund only if revenues are available after all “first priority” spending allocations have been made. Not all categories would receive funding every year and, the Advisory Committee could consider setting up a competitive grant process to make awards in some of the categories. These categories include the following:

- Development of specialized education and awareness campaigns for Pennsylvania state employees or for other targeted groups such as the Commonwealth's older adult population (through the Department of Aging).
- Grants to hospitals for the development of in-hospital organ and tissue donation awareness programs, or for training hospital personnel in best practices associated with obtaining consent to organ and tissue donation.
- Educational initiatives and cooperation with the state medical board; state medical, osteopathic, and ophthalmological associations; and colleges of medicine and nursing schools to more effectively educate medical and nursing students and physicians and nurses about organ and tissue donation, including best practices for approaching patients and their families and to encourage them to assist their patients in making declarations of anatomical gifts.
- Development of training programs for funeral directors concerning Pennsylvania's Anatomical Gift Act, and encouragement of discussing organ and tissue donation during funeral preplanning conferences.
- Development of educational, outreach, awareness, and training programs for medical examiners and coroners.
- Grants to associations, non-profit organizations, private corporations, or Commonwealth political subdivisions for the development and implementation of organ and tissue donor awareness programs, including employee awareness programs.
- Educational initiatives and cooperation with the Pennsylvania Bar Association and Pennsylvania law schools to more effectively educate law

students and attorneys about the donation of anatomical gifts, and the state Anatomical Gift Act and to encourage attorneys to assist their clients in consenting to organ and tissue donation through the development of anatomical gift declarations, durable powers of attorney for health care, wills, and other appropriate means.

- Special research projects, studies, and surveys related to organ and tissue donation and transplantation and other matters related to OT-DAP.

The Department of Health and the Advisory Committee should also establish, as policy, their practice of maintaining a reserve in the Trust Fund of at least \$500,000.

Organ Donation Advisory Committee

- 14. To accurately reflect the nature and scope of its responsibility, its membership, and the program it advises, the General Assembly should amend the AGA to change the name of the Organ Donation Advisory Committee to the Organ and Tissue Donation Advisory Committee.**
- 15. The Department of Health and the Advisory Committee should monitor its membership appointments to ensure that all regions of the state are represented by at least one member as required in law. Currently, a member to represent the North Central region is needed.**
- 16. The Advisory Committee should establish and adopt such bylaws as may be necessary for its operation, consistent with state and federal law.** Advisory committees, including committees involved in similar organ and tissue donation awareness programs in other states, routinely develop bylaws for the conduct of their operations. For example, bylaws in effect for the Delaware Organ and Tissue Donor Awareness Board contain such topics as: name and authority; purpose; membership; officers; board responsibilities and duties; meetings; committees; personnel; and donor awareness plan. The bylaws adopted by the Virginia Transplant Council are also a good model to examine and consider.
- 17. The Advisory Committee should develop and implement methods and procedures to better document, communicate, and track Committee motions, proposals, recommendations, and other actions.** Specifically, the Advisory Committee should:
 - a. initiate a formal process to document, record, and officially transmit Advisory Committee positions, recommendations, and project proposals to the Secretary of Health and other pertinent DOH officials. Such a process

would formalize and facilitate communication between the Advisory Committee and the Department of Health on matters of importance to the Organ and Tissue Donor Awareness Program. An existing process used by the Pennsylvania Emergency Health Services Council (PEHSC), a state-wide advisory body to the Department of Health on emergency medical services issues, could be used as a model for this process.

While PEHSC provides its advice and assistance to the Department through both formal and informal means, its formal advice is provided in the form of a document referred to as “Votes to Recommend,” or VTRs, that result from a consensus of the PEHSC. VTRs are typically prepared after a standing committee of the PEHSC has reviewed and considered an issue. If accepted or approved by the Council, the VTR is then sent to the Secretary of Health. VTRs are consecutively numbered by year and their status can be readily monitored and assessed.

Although we do not recommend that the VTR process be duplicated exactly for use by the Organ Donation Advisory Committee, the essential concept of using a more formal process to record and track advisories of high importance should be considered and tailored to the Committee’s particular needs.

- b. task the DOH staff person assigned to the program (i.e., as recommended in Recommendation #2, the “Organ and Tissue Donation Awareness Coordinator”) (1) to set up and maintain a numeric log of all motions the Advisory Committee adopts during the course of their meetings along with a record of responsible parties, action steps, and target completion dates; (2) to monitor and track the status of all actions provided for in the motions and to document actions taken/outcomes; and (3) to periodically issue reports to the Committee on the status of pending motions.

18. To broaden the representation on the Advisory Committee and facilitate additional input, coordination, and perspectives without increasing the official size of the Committee, the General Assembly should amend the Organ Donation Advisory Committee membership provisions in the AGA to extend nonvoting, associate membership on the Committee to representatives of other organizations, agencies, or experts, public or private, who (a) are directly involved in or (b) provide education or information on organ, tissue, or eye donation, procurement, or transplantation.

For example, associate membership could be extended to a representative of the faith community, local public schools, funeral directors, medical examiners/coroners, and other state agencies. While representatives of PennDOT and Education already attend Committee meetings, they could be given associate member status. The Committee may also wish to extend associate membership to the Department of Aging. Department of Aging awareness of and

involvement in OTDAP would appear to be helpful for a number of reasons. The agency cohort (61 and over) has the lowest donor designation rates in the state donor registry and the Department could assist in increasing rates in this group. With increasing use of “expanded donor criteria” (for example, for kidneys, any deceased donor over the age of 60 years), there is potential to draw new program volunteers from among the Department’s constituency.

Program Planning and Budgeting

- 19. To coincide with the three-year education and awareness grants and contracts awarded in the program, the Advisory Committee should work with the Department of Health to develop a strategic planning process and a three-year “OTDAP Strategic Plan,” including a program mission statement and goals and objectives.** The Advisory Committee should consider engaging the assistance of a management consulting specialist to define and facilitate this process, including relating the strategic plan and annual work statement to the OTDAP budget.

Single Executive Authorization

- 20. Rather than requesting a separate executive authorization for each OTDAP line-item, the Department of Health should request concurrence from the Governor’s Budget Office of the acceptability of requesting one single annual executive authorization for the program as a whole.** Program operations and administrative flexibility could be improved through the receipt of a single annual executive authorization for all program expenditures (that currently total less than \$800,000 annually) from the Trust Fund. The Department of Health, in consultation with the Advisory Committee, would continue to be required to submit adequate supporting detail and justification for proposed Trust Fund expenditures. This approach would, for example, reduce administrative processing time and deliberations at Advisory Committee meetings. It could also have the effect of reducing delays in program implementation caused by the current need to request reallocation of authorized expenditures between expenditure purposes and separate authorizations, while preserving the level of documentation and accountability required by the Office of the Budget.

Living Donor Support

- 21. In order to help living organ donors and potentially increase the number of people willing to donate, the Advisory Committee should work with the Governor’s Office to develop a legislative proposal to further promote living donations. As has been done in a number of other states, consideration should be given to proposing legislation to:**

- a. Allow state employees that undertake living organ donation to be eligible for paid time off from work for a certain period of up to 5-7 days for bone marrow donation and up to 30 days for organ donation.
- b. Provide tax credits or deductions to living donors for non-reimbursed expenses related to living donation.¹⁵

Nineteen states have attempted to address living donor issues through legislation providing for paid time off of work for living donations. Typically, an employee maintains employment rights and benefits during the period of absence related to a living donation. Additionally, since most employers and private insurers do not reimburse the expenses that individuals incur when donating, some states have enacted legislation to issue tax credits or deductions for non-reimbursed expenses related to living donation. Such expenses may include lodging and travel expenses, childcare, and medical costs. The financial impact of lost wages during a living donor's retrieval period can be a major barrier to living organ donation.

Pennsylvania State Employees Workplace Initiative

- 22. The Advisory Committee should collaborate with the Governor's Office to develop and conduct a "Pennsylvania State Employees Organ and Tissue Donation Awareness Workplace Initiative."** Such an initiative, which would be based on the national workplace Partnership for Life model, could reach more than 130,000 state employees and their families.

The Advisory Committee should work with the Governor's Office and the Office of Administration to develop and conduct an "Organ and Tissue Donation Awareness Campaign Workplace Initiative for State Employees." Such a program could be established by an Executive Order that could emphasize the critical importance of organ and tissue donation, stress the urgent need for donors as evidenced by the widening gap between the number on the Pennsylvania waiting list and the number of available transplantable organs, and encourage state employees and their families to consider donation. The Advisory Committee, the OPOs, and the statewide awareness campaign contractor (Giant Ideas) should work with Administration officials on the design and implementation of this workplace campaign, stressing the availability of the on-line portal.

The Statewide Donor Registry

- 23. The General Assembly should establish Pennsylvania's state organ donor registry in Pennsylvania's Anatomical Gift Act and designate it**

¹⁵Act 2006-65, the "Pennsylvania Organ and Bone Marrow Donor Act," authorizes every business firm providing paid leaves of absence to employees for the specific purpose of organ or bone marrow donation to qualify for a tax credit. See Appendix B for further information.

as the “Donate Life-PA Registry.” This statutory amendment should assign responsibility for the maintenance of the registry to PennDOT, which currently maintains the database, and should reference and incorporate standards for its operation, including those contained in the NCCUSL’s proposed AGA revision. The donor registry provisions should allow for a statement or symbol on the registry indicating that a person has made an anatomical gift; allow for access by OPOs 24 hours per day, seven days a week; limit the usage of the information contained in the registry to determining potential organ donors at or near the time of death; and allow for disenrollment and removal of those who are deceased or have moved from the state.

Medical Examiner/Coroner Involvement

24. **The Advisory Committee should consider recommending that the General Assembly amend Pennsylvania’s Anatomical Gift Act to allow for greater cooperation between OPOs and coroners where potential organ or tissue donors are under a coroner’s jurisdiction by providing, at a minimum, that if a coroner is considering denying an organ or tissue donation for any reason, the coroner must be present during the removal of the organs or tissue and may request a biopsy of the organs or tissue, or deny their removal, with a written explanation to the OPO. The Advisory Committee should make appropriate recommendations to the Department of Health for amendments to Pennsylvania’s Anatomical Gift Act.**

Collaborative working relationships between medical examiners/coroners and OPOs are important to facilitating organ and tissue donation. In those cases where donation is possible, coroners are encouraged to work closely with organ procurement organizations to allow the donation of vital organs and tissues to proceed while still obtaining necessary investigative information. Typically, a coroner, when involved, can allow the surgical team to remove organs with permission from the patient’s family. The federal Advisory Committee on Organ Transplantation has recommended that legislative strategies be adopted that will encourage medical examiners and coroners not to withhold life-saving organs and tissues from qualified procurement organizations and noted that medical examiners and coroners are not uniform in their approach to making organs available to procurement organizations resulting in many unnecessarily withheld organs and tissues. As of 2005, 32 states, not including Pennsylvania, had specifically addressed these matters by codifying the role of the medical examiner and coroner in these areas in statute.

The Uniform Anatomical Gift Act

25. **The Advisory Committee should develop a recommendation for the General Assembly on whether and to what extent the provisions of the revised and updated national Uniform Anatomical Gift Act should be adopted in Pennsylvania. The Committee should work with the state's two OPOs and the Department of Health in developing this recommendation.¹⁶**

Contract Administration

26. **As the lead state agency for OTDAP, the Department of Health should take steps to ensure the timely award and execution of all contracts, especially those related to the statewide education and awareness campaigns and the secondary school organ and tissue donation education project. The processing, award, and administration of such contracts would be assigned to the Organ and Tissue Donation Awareness Coordinator position cited in Recommendation #2.**

¹⁶Nationally, as of early May 2007, the UAGA had been adopted in 11 states and introduced in 14 others.

I. Introduction

House Resolution 698, adopted on April 25, 2006, directs the Legislative Budget and Finance Committee to conduct a performance evaluation of the Commonwealth's organ and tissue donor awareness program established under Act 1994-102.

Study Objectives

1. To review the structure and operation of the program and the performance of the Departments of Health, Education, Transportation, and Revenue in carrying out their respective responsibilities under the program's enabling legislation.
2. To review and evaluate the role and activities of the Organ Donation Advisory Committee and Pennsylvania's two designated organ procurement organizations in the program.
3. To examine revenues to and expenditures from the Governor Robert P. Casey Memorial Organ and Tissue Donation Awareness Trust Fund, and to test compliance with the statutory requirements for how fund monies are to be used.
4. To assess the extent to which the program has been successful in increasing organ and tissue donations by means of education and public awareness activities.
5. To examine similar programs in other states in order to identify any program elements or approaches that may have applicability and potential benefit for Pennsylvania's program.
6. To develop findings and recommendations, as appropriate.

Scope and Methodology

This evaluation focused on the implementation, funding, and administration of Pennsylvania's "Organ and Tissue Donor Awareness Program (OTDAP)" and assessed the extent to which the program has been successful in increasing organ and tissue donations in the state by means of education and public awareness programming.

To do this, we reviewed and evaluated the efforts of the Departments of Health, Education, Transportation, and Revenue, the Organ Donation Advisory Committee, and Pennsylvania's two federally-designated organ procurement organizations (OPOs) in carrying out their respective responsibilities under the enabling legislation (Act 1994-102). Additionally, the evaluation examined program

spending priorities and expenditures from the Governor Robert P. Casey Memorial Organ and Tissue Donation Awareness Trust Fund and surveyed strategies and approaches being used in similar programs in other states.

In the initial phase of the study we reviewed the legal development of organ and tissue donation both nationally and in Pennsylvania. While Act 1994-102 is the focus of the study, it was also necessary to review related key legislation, such as the Uniform Determination of Death Act, the Uniform Anatomical Gift Act (both current and proposed revisions), and the National Organ Transplant Act.

Throughout the project, we met with officials and staff of each of the state agencies involved in the program as well as with the co-chairpersons and other members of the Organ Donation Advisory Committee. Through these contacts, we obtained basic program information, statistical data, meeting minutes, and other materials pertinent to the HR 698 evaluation objectives. We also attended three meetings of the Organ Donation Advisory Committee.

We took a comprehensive approach to evaluating all aspects of the program as reflected in Act 102. Although the OTDAP is not specifically referenced in statute, we interpreted numerous related provisions that are contained in Act 102 as constituting the “Program.”

In examining OTDAP implementation, we sought to determine and document what the program had accomplished since its inception and gauge the “return on investment” to the citizens of the Commonwealth. We also closely examined the means in which the donor/donor family benefits provisions of Act 102 are being implemented and the actual and potential financial impacts of these benefits on the Trust Fund balance.

To gain further perspective on the operation of OTDAP within the context of the statewide organ and tissue donation and transplantation system, we worked with the two federally-designated organ procurement organizations operating in Pennsylvania: the Gift of Life Donor Program (GLDP), located in Philadelphia, and the Center for Organ Recovery and Education (CORE), in Pittsburgh. We toured the facilities of both OPOs, met with the OPO directors and staffs, and requested statistical data concerning organ and tissue donation and transplantation and information on the OPO’s respective roles in the statewide awareness program. We had follow-up communications with staff members of both OPOs throughout the project.

We used a variety of OPO-specific statistical data as well as federal databases to assess the levels of organ and tissue donation and transplantation activity in Pennsylvania since the passage of Act 1994-102. The federal National Organ Transplant Act of 1984, among other provisions, established the Organ

Procurement and Transplantation Network (OPTN). We used data available from the OPTN¹ to compare key measures of organ donation and transplantation activity, both within Pennsylvania and with other states.

We conducted an in-depth examination and historical profile of OTDAP revenues and expenditures and the financial condition of the Governor Robert P. Casey Memorial Organ and Tissue Donation Awareness Trust Fund. We focused on DOH's management of the Trust Fund, including the specific limits which Act 102 imposes on specified expenditure categories, and the continued appropriateness of these caps. We also reviewed program expenditures made from General Fund appropriations.

To assess the extent to which the program has succeeded in increasing the number of designated organ and tissue donors by means of education and public awareness activities, we examined and analyzed PennDOT trend data on the size of the state's donor registry. We also reviewed the pertinent contracts, proposals, and other planning documents including the periodic reports of the contractors and sub-contractors in relation to the 2003-2006 awareness campaign. We also conducted an assessment of the contractor's efforts in relation to contractual requirements and objectives. We conducted interviews with a key official involved in managing the 2003-2006 campaign as well as officials of the firm selected to implement the ongoing public awareness campaign through June 2009.

We also examined organ and tissue donor awareness programs in other states. We considered information from other state programs, as well as their relevant state statutes, in order to identify program approaches or strategies that could be recommended as having potential applicability in Pennsylvania. We also examined proposed changes to the national Uniform Anatomical Act (UAGA) and its possible implications for possible revisions to current Pennsylvania law.

Acknowledgements

The LB&FC staff gratefully acknowledges the cooperation, assistance and contributions of numerous agencies and individuals during this evaluation. In particular, we would like to thank Department of Health officials and staff including the Deputy Secretary for Health Promotion and Disease Prevention, Joanne C. Grossi; Leslie Best, Director, Bureau of Health Promotion and Risk Reduction; and

¹The United Network for Organ Sharing (UNOS), a non-profit, scientific and educational organization located in Richmond, Virginia, has been the designated federal contractor responsible for the administration of the OPTN since 1986. UNOS requests that the following acknowledgment be provided concerning use of its data: This work was supported in part by Health Resources and Services Administration contract 234-2005-370011C. The content is the responsibility of the authors alone and does not necessarily reflect the views or policies of the Department of Health and Human Services, nor does mention of trade names, commercial products, or organizations imply endorsement by the U.S. Government.

Terri A. Matio, Director, Bureau of Administrative and Financial Services. We also received valuable assistance from staff of the PA Department of Education, Lancaster-Lebanon Intermediate Unit 13, the Bureau of Driver Licensing within the Department of Transportation, and the Department of Revenue.

Completion of this project would not have been possible without the support and assistance of both the Organ Donation Advisory Committee and Pennsylvania's two federally-designated organ procurement organizations, the Gift of Life Donor Program in Philadelphia, and the Center for Organ Recovery and Education (CORE) in Pittsburgh. We thank all of the Advisory Committee members and offer special thanks to Dawn Reese, Co-Chair of the Advisory Committee for her input and assistance. While a number of OPO staff assisted us throughout this project, we wish to particularly acknowledge the contributions of Howard Nathan, President and CEO, GLDP, and his staff, especially John Green, Director of Community Relations, and Jan Weinstock, Vice President for Administration and General Counsel, as well as Susan Stuart, President and CEO, CORE, and her staff, especially Cherie Peters, Community Relations Coordinator.

We also acknowledge the assistance provided by program contractors, Toplin and Associates, Inc., Giant Ideas, and Intermediate Unit 13, and persons associated with the organ and tissue donor programs in the various states we contacted and the representatives of other state OPOs and the various state and national organizations whom we contacted during the project.

Important Note

This report was developed by Legislative Budget and Finance Committee staff. The release of this report should not be construed as an indication that the Committee or its individual members necessarily concur with the report's findings and recommendations.

Any questions or comments regarding the contents of this report should be directed to Philip R. Durgin, Executive Director, Legislative Budget and Finance Committee, P.O. Box 8737, Harrisburg, Pennsylvania 17105-8737.

II. Background Information on Organ and Tissue Donation

A. Key Federal Statutes and National Initiatives

Many of the current laws and regulations for making anatomical donations and encouraging the public to do so are state specific. However, several federal laws and national policies provide the basic framework for organ and tissue donation. The following is a brief chronology and overview of selected key events and statutes in the overall timeline of federal and national activity.

1968: *The National Conference on the Commissioners of Uniform State Laws (NCCUSL) passed the Uniform Anatomical Gift Act (UAGA), establishing the legal framework for anatomical donation. The UAGA provides for the donation of anatomical gifts for individuals over the age of 18 and others according to relational priority at the time of death. By 1972, the UAGA in some form had been adopted in all 50 states and the District of Columbia.*

1980: *The NCCUSL drafted the Uniform Determination of Death Act (UDDA). This act, which codified and extended the existing common law basis for determining death, was subsequently codified into state laws in various forms. The UDDA states that: an individual who has sustained either (1) irreversible cessation of circulatory and respiratory functions, or (2) irreversible cessation of all functions of the entire brain, including the brain stem, is dead. A determination of death must be made in accordance with accepted medical standards.¹*

1984: *Federal oversight of the National Transplant System began in 1984. At that time, Congress passed the National Organ Transplant Act (Public Law 98-507) establishing, among other things, a national system for the uniform matching of organs with potential recipients. This system, the national Organ Procurement and Transplantation Network (OPTN) includes all federally-certified organ procurement organizations (OPOs) and transplant centers that receive Medicare and Medicaid funding. The OPTN is administered by the United Network for Organ Sharing (UNOS), a private nonprofit entity located in Richmond, Virginia, under contract with the Health Resources and Services Administration (HRSA). The OPTN is primarily responsible for administration of the national waiting list of transplant candidates and the development of equitable policies for organ allocation. The National Organ Transplant Act provided grants to expand regional organ procurement organizations and also prohibited commercial transactions in organs.*

1986: *Subsequent federal legislation (the Omnibus Budget Reconciliation Act of 1986) mandated a “required request” policy under which hospitals*

¹Pennsylvania adopted the UDDA in 1982 in substantially similar form as was drafted by the NCCUSL.

participating in Medicare or Medicaid are required to develop procedures that systematically identify patients as potential donors and approach families about the opportunity of organ and tissue donation.

1987: *The Omnibus Budget Reconciliation Act of 1987 amended the Uniform Anatomical Gift Act.* It also provided explicit authority to the intentions of donors over that of their relatives, prohibited the sale of body organs, and, included required request provisions.

1989-90: *Amendments to the Organ Transplant Act occurred in both 1989 and 1990.* The 1990 amendments provided for the establishment and maintenance of a National Bone Marrow Donor Registry.

1998: *Federal Conditions of Participation for Medicare and Medicaid Participating Hospitals.* Among numerous other provisions, the Conditions of Participation mandate that hospitals have an agreement with the federally designated OPO in its service area to which it must notify, in a timely manner, of individuals whose death is imminent or who have died in the hospital to determine medical suitability for organ donation (referred to as “routine referral”).

1999: *The federal Organ Donor Leave Act increased the amount of paid time allotted for federal employees to serve as organ donors from 7 days to 30 days per calendar year.* In the same year, the OPTN Final Rule established broad performance goals to guide OPTN organ allocation policy development.

2000: *The Organ Procurement Organization Certification Act added to the list of requirements and performance standards to be met by qualified OPOs.* These included recertification no more frequently than once every four years and the use of multiple outcome measures as part of the certification process.

2003: *The introduction of a major new initiative took place in 2003 with the launch of a series of Organ Donation Breakthrough Collaboratives.* Directed by HRSA, the collaboratives attempt to increase rates of organ donation by encouraging hospitals and OPOs to use methods of continuous quality improvement to enhance the process of deceased organ donation. The goal of the collaborative was to bring together key national leaders and practitioners from the nation’s transplantation and hospital communities to work in collaborative teams to spread best practices in order to achieve donation rates of 75 percent or higher in the nation’s largest hospitals.

2003: *The first two collaboratives (2003 to 2005) focused on organ donation. The third collaborative (2006) is focused on increasing organ utilization and is referred to as the Organ Transplantation Breakthrough Collaborative.* This initiative targets transplant centers, surgeons, and OPO and hospital administrators to evaluate how their institutions can increase the number of organs recovered and transplanted, with a goal of 3.75 organs per donor.

2004: *The Organ Donation and Recovery Improvement Act authorized the federal Secretary of Health and Human Services to award grants to states, transplant centers, and qualified OPOs to reimburse travel, subsistence, and incidental nonmedical expenses incurred by individuals making living donations. Among other provisions, the act also establishes an education program to increase awareness about organ donation and the need to provide for an adequate rate of donations.*

2006: *A newly revised UAGA was drafted by the NCCUSL which seeks to update the act in light of changes in federal law providing for an allocation system through hospitals and procurement organizations in securing organs for transplantation as well as related developments in the field of organ donation.*

2006: *The new revision to the UAGA was approved on July 13, 2006, by the NCCUSL at its annual meeting. Some key changes in the proposed revised UAGA include an expanded list of persons, in priority, who may make an anatomical gift on behalf of the deceased, and now includes agents acting under a health-care power of attorney or other record, adult grandchildren, or a close friend. The revised act would also strengthen language that bolsters the rule that a donor's decisions are to be honored and not subject to change by others, permit an individual to sign a refusal that bars all other persons from making an anatomical gift, and allow for the making of anatomical gifts on donor registries.*

2006: *Revisions to CMS Medicare Conditions of Participation for organ procurement organizations, further regulating and defining OPO performance benchmarks.*

2006: *Pennsylvania Organ and Bone Marrow Donor Act (Act 2006-65) signed into law. The act, sponsored by State Representative Robert W. Godshall, provides a tax credit for businesses that grant a paid leave of absence to employees for the purpose of bone marrow or organ donation. The credit is equal to the amount of the employee's compensation during the leave of absence, the cost of any temporary replacement help, and other miscellaneous expenses incurred in connection with the leave of absence. (See Appendix B for a summary of Act 2006-65.)*

B. Questions Frequently Asked About Organ and Tissue Donation

The following series of questions and answers provides the framework for a summary of basic information about organ and tissue donation.²

²These are questions individuals often ask regarding organ and tissue donation along with responses as contained on various federal, state, and transplant organization websites.

What can be donated?

Transplantable organs that can be donated include: the heart, intestines, kidneys, lungs, liver, and pancreas (referred to as solid organs). Also, the following tissues can be donated: bone grafts, corneas, femoral veins, great saphenous veins, heart valves, skin grafts, small saphenous veins, and tendon grafts.³

Who can become a donor?

Anyone of sound mind age 18 or older may decide to be an organ and tissue donor. Parents and guardians must consent to that decision by anyone between the ages of 16 and 18, and must also make that decision for other minor donors. There are, however, no age limitations on who can donate. The deciding factor on whether a person can donate is the person's physical condition, not the person's age. Medical suitability for donation is determined at the time of death.

What is the difference between organ and tissue donation?

Organ (heart, lungs, kidneys, liver, and pancreas) donation most typically occurs after a patient has been determined dead due to cessation of all brain function but whose other organs are kept functioning by sophisticated hospital machinery. Because brain death is not a common occurrence, viable organ donors are rare. Tissue donation (eyes, bone, skin, veins, heart valves, tendons) can occur even after the heart has ceased beating. Most deaths are potential tissue donors (depending on medical and other factors and social history). Organ donors can also be tissue donors.

How is it determined who gets priority for transplants?

There is a standard system which doctors and transplant centers use to rank transplant candidates solely based on severity of illness and medical criteria. When a donated organ becomes available, a list is generated from the United Network of Organ Sharing (UNOS) which ranks recipients based on proximity to donor (because of time constraints on donated organs), blood type, length of time on waiting list, severity of illness, size compatibility of organs, tissue types (for kidneys). Things such as income, name, gender, age, race, are never considered and are not published on the UNOS list.

Are there age limits for donors?

There are no age limitations on who can donate. The deciding factor on whether a person can donate is the person's physical condition, not the person's age. Newborns as well as senior citizens have been organ donors. Persons younger than 18 years of age must have a parent's or guardian's consent.

³This listing is what can be donated after death. Bone marrow is not listed because such donations are made by living donors.

How do I express my wishes to become an organ and tissue donor?

You can include your decision to be an organ and tissue donor on your driver's license, identification card, advance health care directive or power of attorney. Most importantly, discuss your decision with family members and loved ones.

If I sign a donor card or indicate my donation preferences on my driver's license, will my wishes be carried out?

Even if you sign a donor card, it is important, but not essential in all states, that your family know your wishes. Your family may be asked to sign a consent form for your donation to occur. If you wish to learn how organ donation preferences are documented and honored where you live, contact your local organ procurement organization (OPO). The OPO can advise you of specific local procedures, such as joining donation registries, that are available to residents in your area.

If I sign a donor card, will it affect the quality of medical care I receive at the hospital?

No, every effort is made to save your life before donation is considered. The transplant team is completely separate from the medical staff working to save your life. The transplant team does not become involved with you until doctors have determined that all possible efforts to save your life have failed.

Will donation disfigure my body? Can there be an open casket funeral?

Donation does not disfigure the body and does not interfere with having a funeral, including open casket services.

Are there any costs to my family for donation?

The donor's family does not pay for the cost of the organ or tissue donation. All costs related to donation of organs and tissues are reimbursed indirectly by the recipient, usually through insurance, Medicare, or Medicaid.

Can I sell my organs?

No. The National Organ Transplant Act (Public Law 98-507) makes it illegal to sell human organs and tissues. Violators are subject to fines and imprisonment. Among the reasons for this rule is the concern of Congress that buying and selling of organs might lead to inequitable access to donor organs with the wealthy having an unfair advantage.

Do major religions support donation?

Most religions support and consider donation an act of charity. It is a way to affirm a deceased person's generosity and goodness. If you have any questions about the beliefs of your religion regarding donation, you should discuss them with your spiritual leader.

Can I be an organ and tissue donor and also donate my body to medical science?

Total body donation is an option but not if you choose to be an organ and tissue donor. In Pennsylvania, individuals wishing to donate their entire body to medical science should contact the Humanity Gifts Registry headquartered in Philadelphia. Medical schools, research facilities, and other agencies need to study bodies to gain greater understanding of disease mechanisms in humans. This research is vital to saving and improving lives.

Can non-resident aliens donate and receive organs?

Non-resident aliens can both donate and receive organs in the United States. For example, during 2002 and 2003, 513, or less than 2 percent of the 26,090 organ donors, were non-resident aliens. Policies developed by the Organ Procurement and Transplantation Network (OPTN) allow up to 5 percent of recipients at a transplant center to be from other countries. From 1995 to 2002, non-resident aliens accounted for only about 1 percent of more than 20,000 transplants performed annually. Organ allocation is based on the principles of equity and medical utility with the concept of justice applied to both access (consideration) as well as allocation (distribution).

Regardless of any pre-existing medical circumstances or conditions, determination of suitability to donate organs or tissue may be based on a combination of factors that take into account the donor's general health and the urgency of need of the recipient. This determination is usually done by the medical staff that recovers the organs or by the transplant team that reviews all of the data about the organ(s) or tissue that have been recovered from the donor.

What is the process for receiving an organ for transplantation?

- a. If you need an organ transplant, your doctor will help you get on the national waiting list.
- b. To get on the list, you need to visit a transplant hospital. Every transplant hospital in the United States is a member of UNOS. You can use the United Network for Organ Sharing (UNOS) directory at www.unos.org/members/search.asp to find a transplant hospital.

- c. A doctor will examine you and decide if you meet the criteria to be put on the list. You also can get on the waiting list at more than one transplant hospital. Each hospital has its own criteria for listing patients. If you meet their criteria, they will add you to the list.
- d. The hardest part of this process is waiting. There is no way to know how long you will wait to receive a donor organ.
- e. Your name will be added to a pool of names. When an organ donor becomes available, all the patients in the pool are compared to that donor. Factors such as blood and tissue type, size of the organ, medical urgency of the patient's illness, time already spent on the waiting list, and distance between donor and recipient are considered.

The organ is offered first to the candidate who is the best match. The organ is distributed locally first, and if no match is found, it is offered regionally and then nationally until a recipient is found.

Who manages the distribution of organs?

The United Network for Organ Sharing (UNOS) maintains the Organ Procurement and Transplantation Network (OPTN). Through the UNOS Organ Center, organ donors are matched to waiting recipients 24 hours a day, 365 days a year.

C. An Overview of the Organ Matching and Allocation Process

During the earliest days of solid organ transplantation, the hospital in which the donor resided was responsible for locating a recipient. Gradually, a system of independent organizations known as Organ Procurement Organizations, (OPOs) developed to optimize the matching of patients with donated organs.

The origin of the current system is the National Organ Transplant Act of 1984, which created a national transplant system to be operated by transplant professionals, with oversight by the Department of Health and Human Services (DHHS) to ensure an equitable allocation system. The act created the Organ Procurement and Transplantation Network (OPTN), a nonprofit private-sector network to be operated by a contractor to DHHS. The United Network for Organ Sharing, or UNOS, has held this contract since 1986.

As of late 2006, the U.S. organ procurement system included 58 OPOs, which provide all of the deceased donor organs for the nation's 287 transplant centers. Each OPO is required to be a member of OPTN and each has a contiguous service area designated by the federal government for recovering organs in all hospitals in that region. Thus, in each service area, only one OPO coordinates activities relating to organ procurement and allocation, and that OPO is required to have a working arrangement with all hospitals in its designated area. OPOs evaluate potential donors, discuss donation with family members, and arrange for the surgical removal of

donated organs. OPOs also are responsible for preserving organs and arranging for their distribution according to nationally, regionally, or locally agreed upon organ-sharing policies.

The following is an overview description of the organ matching and allocation process as provided by the United Network for Organ Sharing.

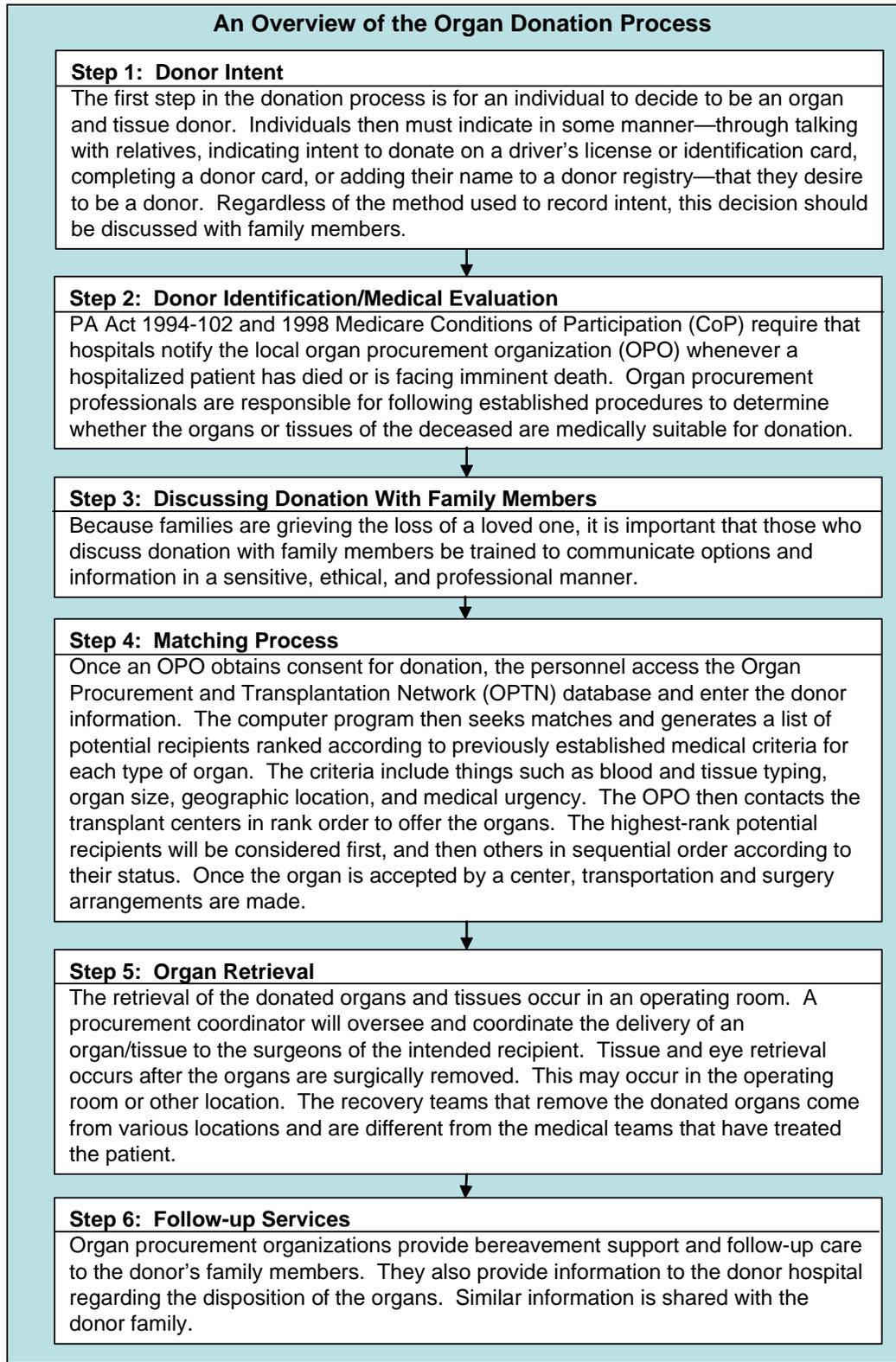
Under contract with the U.S. Department of Health and Human Services' Health Services & Resources Administration (HRSA), UNOS maintains a centralized computer network, UNetsm, which links all organ procurement organizations and transplant centers. This computer network is accessible 24 hours a day, seven days a week, with organ placement specialists in the UNOS Organ Center always available to answer questions.

Within UNet, every organ sharing institution is electronically linked in a secure, real-time environment over the Internet so that donated organs can be placed as quickly as possible. While UNet utilizes the Internet for common access to UNOS members, it employs secure password access to protect confidential medical data.

The rules for organ allocation are set by OPTN/UNOS, and a computer algorithm for distribution of each type of organ is programmed to fulfill this function. All patients waiting for an organ from a deceased donor are required to be placed in the waiting list database. Each time an organ is donated within an OPO service area, the allocation system matches the donor with the database of waiting transplant candidates. The system then generates an ordered list of the potential recipients based on the algorithm for that organ system. Each organ is then offered by the OPO in sequence by communicating the donor's medical and social history to the medical professional (most often the transplant surgeon) at the transplant center where that patient is wait-listed. The transplant center may accept or decline the organ on behalf of the candidate, based on the medical professional's judgment. Extrarenal organs are typically matched and allocated before the organs are recovered in order to limit cold ischemic time. The organs are surgically recovered at the donor hospital and preserved in cold solution via static or pulsatile preservation for transport to the recipient's transplant center.

The current allocation algorithm prioritizes the matching patients in the local OPO service area, then regionally, then nationally. Policies for allocation also consider such factors as medical status (heart and liver), blood type, tissue type (kidneys only), donor weight (nonrenal organs), and time spent on the waiting list. Additional points are given to children under age 18 and to candidates who have previously donated an organ (kidney); other organ-specific allocation rules also exist. An overview of the organ and tissue donation process is shown in Exhibit 1 on the next page.

Exhibit 1



Source: American Journal of Transplantation.

III. An Evaluation of the Implementation and Performance of Pennsylvania's Organ and Tissue Donor Awareness Program

A. Program Definition and Administration

Findings

- A-1. *The “Organ and Tissue Donor Awareness Program” (OTDAP) is not specifically established in Pennsylvania state law or regulations. The term has evolved since 1994 and is used to refer to the collective efforts and activities of numerous governmental and private-sector agencies and organizations in implementing multiple related provisions in Act 1994-102, Pennsylvania’s Anatomical Gift Act. Further, the implementing agencies have not established written policy statements, program guidelines or regulations that define the program or provide a formal basis upon which the program is to be conducted.*
- A-2. *Despite the absence of a well defined program structure and definition, the Organ and Tissue Donor Awareness Program is a successful multi-agency collaborative effort that has significantly enhanced organ and tissue donation awareness and contributed to increased levels of organ donation and transplantation activity in the Commonwealth.*
- a. *The Department of Health has performed well as lead agency for OTDAP even in the absence of a clearly recognizable program structure and full-time program staff.*
- b. *The Organ Donation Advisory Committee is a very dynamic and proactive advisory body whose members demonstrate an intense personal commitment to the promotion of organ and tissue donation and transplantation. The Advisory Committee has been instrumental in OTDAP policy-making, direction, implementation, and related legislation.*
- c. *Pennsylvania’s two OPOs, the Gift of Life Donor Program and the Center for Organ Recovery and Education have played a prominent role in OTDAP through aggressive implementation of the provisions of Act 1994-102 and active participation and involvement on the Organ Donation Advisory Committee. (The state’s two OPOs are national leaders among the most populous OPOs in the nation—see also part G of this section.)*
- d. *PennDOT has successfully implemented several provisions related to organ donor designation and revenue generation for the state’s organ and tissue donor awareness program. As required by Act 102, this was accomplished through modifications to the Pennsylvania driver license and state identification card system in 1994 and the provision of opportunities for driver*

license applicants (beginning in 1995) and vehicle registration applicants (beginning in 1999) to make voluntary contributions to OTDAP.

- e. The Pennsylvania Department of Education contracts with Lancaster-Lebanon Intermediate Unit 13 in attempting to introduce organ and tissue donation awareness studies into secondary school curricula.*
- f. The Department of Revenue's role in OTDAP relates primarily to the state income tax refund check-off and publication of a general notice informing taxpayers of the opportunity to make voluntary contributions to the Trust Fund.*

A-3. The program lacks a full-time support staff capability. Although considered a program for which the Department of Health has assumed lead agency responsibilities, OTDAP does not have a recognized program office or designated full-time staff in the Department of Health. The staff person assigned to the program has numerous and varied other responsibilities that prevent the level of focus and time that OTDAP merits and requires. This hampers program implementation, communication, continuity of effort, and completion of initiatives, especially during the periods between Advisory Committee meetings.

A-4. While the Organ Donation Advisory Committee has operated effectively, there are several membership and administrative matters that require attention. We found, for example, that the Advisory Committee has not adopted bylaws to govern its operation and has not instituted a formal policy to track the status of the motions it adopts or to formally communicate and transmit advisories and proposals to the Secretary of Health. In terms of membership, the current composition of the Committee is lacking representation from the north central region of the state (a statutory requirement) and includes nine members whose terms have expired. Also, although infrequent, the Committee has not taken action to address attendance problems when they arise.

Program Definition

Although the “Organ and Tissue Donor Awareness Program” (OTDAP) is not specifically referenced in Pennsylvania state law, the term is generally used to refer to the collective efforts and activities of various governmental and private-sector agencies and organizations in implementing the provisions of Act 1994-102. The essential purpose of this collective, multi-agency effort is to increase organ and tissue donation by means of a systematic pursuit of educational and public awareness activities and a corresponding coordination of governmental and private sector organ and tissue donation initiatives.

Efforts to increase rates of organ and tissue donation involve the collective work of numerous governmental and private-sector organizations. At the state government level in Pennsylvania, four agencies work with the Organ Donation Advisory Committee and the Commonwealth's two federally-designated organ procurement organizations (OPOs) to administer the state's Organ and Tissue Donor Awareness Program. The four involved state agencies include the Departments of Health, Education, Revenue, and Transportation.

These agencies and organizations work along with the state's hospitals and transplant centers, tissue banks, and numerous other partners in the overall state-wide transplantation network. Other partners include statewide hospital and healthcare associations, donation advocacy organizations, the business community, medical examiners, coroners and district attorney's offices, faith communities, and the media.

The passage of Act 102 in 1994 readopted the state's Anatomical Gift Act (AGA). It also included multiple additional provisions intended to increase organ and tissue donation. Although the term "Organ and Tissue Donor Awareness Program" is never used in the statute, a grouping of selected related provisions in Act 102 has, for practical and operational purposes, been collectively designated as the "Program." The specific provisions that together comprise the "Program" are listed in the following seven categories:

1. Required Hospital Protocols and Participation:

- Requires that hospital protocol be in place for identifying potential organ and tissue donors.
- Mandates that a routine referral system be established by all Pennsylvania acute-care hospitals. Under "routine referral," hospitals must notify one of the state's two OPOs of all deaths or impending deaths. Referral of impending deaths is designed to ensure that referrals for organ donation are made prior to changes in supportive measures that would eliminate organ donation as a viable option.
- Requires that requests be made of all suitable candidates for anatomical donation either by an OPO representative or by an OPO-trained "designated requestor" within the hospital personnel.
- Provides for compliance reviews of acute care hospitals to ensure compliance with the Act's "required request" and "routine referral" provisions.

2. Promotion of Organ Donation Education and Awareness:
 - Authorizes the expenditure of program funds for the development and implementation of statewide organ donation awareness programs; for “Project Make-A-Choice”; and for the implementation of organ donation awareness programs in the Commonwealth’s secondary schools.
3. Driver’s License Designation:
 - Allows the front portion of the state driver’s license or state identification card to be used for indicating an individual’s preference for donation. When a person consents to donation, “ORGAN DONOR” is listed underneath the photo. The license or state identification card then may serve as valid evidence of an individual’s consent for donation that is to be relied upon during the organ donation process.
4. Creation of an Advisory Committee:
 - Creates a 15-member Organ Donation Advisory Committee to, among other things, recommend education and awareness programs, review organ and tissue donation progress in the state, recommend spending priorities, and advise the Secretary of Health and the General Assembly on legislation and program-related matters.
5. Establishment of a Trust Fund:
 - Sets up the Governor Robert P. Casey Memorial Organ and Tissue Donation Awareness Trust Fund into which voluntary donations and other revenues are deposited and from which Program expenses are to be paid.
 - Directs PennDOT to provide applicants for an original or renewal driver’s license or state identification card the opportunity to make a \$1 contribution to the Trust Fund. (Subsequent legislation, Act 1998-74, directed PennDOT to provide the same opportunity to applicants for a renewal vehicle registration.)
6. Authorized Expenditures and Spending Caps:
 - Specifies the manner in which Trust Fund monies are to be allocated to the Departments of Health, Transportation, Education, and Revenue and the purposes for which expenditures can be made. Program implementation costs, including the costs of the Organ Donation Advisory Committee are paid first. Remaining Fund monies may be spent for the purposes and subject to the limitations cited below:
 - reasonable hospital and other medical expenses, funeral expenses, and incidental expenses incurred by the donor or donor’s family (up to 10 percent of the total Fund);

- grants to certified organ procurement organizations (OPOs) for statewide organ donation awareness programs (up to 50 percent of the total Fund);
- “Project Make-A-Choice” (up to 15 percent of the total Fund); and
- the implementation of organ donation awareness programs in the Commonwealth’s secondary schools (up to 25 percent of the total Fund).

7. Reporting Requirements:

- Requires the submission of periodic activity and progress reports to the General Assembly by involved state agencies, OPOs, and tissue procurement providers.

Program definition is also not available in the form of regulations or written policy statements and guidelines. In the absence of definitions in law, regulations or guidelines could be very helpful in providing for the operation of donor/donor family benefit programs and in defining terms such as “implementation costs,” “incidental expenses,” and “Project Make-A-Choice.”

Program Administration

Department of Health

Although not specifically designated as such in law, the Department of Health serves as the lead agency for the program. In this capacity, the Department is responsible for the statewide coordination of organ and tissue donation initiatives. The Department performs various other functions in its “lead agency” program role. These include:

- providing support services and oversight to the Organ Donation Advisory Committee (arranging meetings, preparing and distributing meeting minutes and agendas, attending to concerns and questions of Committee members);
- administering grants to the organ procurement organizations (OPOs), which includes funding for Project Make-A-Choice;
- administering the food and lodging expense benefits program;
- administering miscellaneous projects including: grief counseling proposed pilot program, pediatric organ donation pilot program, online designation program, research projects, and minority initiatives;
- preparing organ donation communication-press releases and response to constituents; and

- administering a state appropriation for educational brochures that are distributed in conjunction with the Department of Transportation as well as funding for other educational initiatives as necessary.

DOH program responsibilities are not concentrated in a single Department bureau or designated program office. Rather, four bureaus have been involved in various aspects of the program. These include: the Bureau of Health Promotion and Risk Reduction, the Bureau of Administrative and Financial Services, the Bureau of Family Health, and the Bureau of Facility Licensure and Certification.

Of these four bureaus, the Bureau of Health Promotion and Risk Reduction (formerly the Bureau of Chronic Diseases and Injury Prevention) is the focal point of the Department's lead agency role. An individual within this bureau (classified as a Public Health Educator) performed program-related duties, including liaison and staff support to the Organ Donation Advisory Committee, on a part-time basis. The person in this position also had responsibility for women's health issues, "work-site wellness," and various other health education initiatives. She left state government employment in November 2006, and the position remained vacant until February 2007.

In addition to this position, the Deputy Secretary for Health Promotion and Disease Prevention and directors of the Bureau of Health Promotion and Risk Reduction and the Bureau of Administrative and Financial Services also devote some time to OTDAP. (The Deputy Secretary represents DOH and serves as co-chair on the Advisory Committee.) Staff of the Bureau of Facility Licensure and Certification perform program-related work during the course of their biennial license surveys.

Department of Education

Under Act 102, the Pennsylvania Department of Education (PDE) is responsible for implementing organ donation awareness programs in the Commonwealth's secondary schools. Following the payment of program implementation costs and all costs of the Organ Donation Advisory Committee, PDE may annually expend 25 percent of the total Trust Fund balance to implement organ donation awareness programs in secondary schools.

Upon availability of funding, and in cooperation with the Department of Health and the state's organ procurement organizations (OPOs), PDE is to establish a program that can be used for secondary education purposes, which is to include: (1) information about state law relating to anatomical gifts, including how to become an organ donor; and (2) general information about organ transplantation in the United States.

Staff of both the PDE Headquarters and Lancaster-Lebanon Intermediate Unit 13 are involved in activities specified in Act 102 and funded from the Organ Donor Awareness Trust Fund. These relate primarily to the “OTDA Education Project” that has been developed by IU-13 under contract to the PDE. The goal of this project is to institutionalize organ and tissue donation awareness studies into secondary school curricula.

At the headquarters level, the PDE has designated an OTDA education program director and program coordinator (both are organizationally located in PDE’s Bureau of Teaching and Learning Support). The current program director reportedly spends approximately 10-15 percent of her time on OTDA responsibilities, with periodic increases in obligated time required in periods surrounding contract renewal with the Department of Health. The program coordinator spends approximately 5 percent of obligated time on OTDA responsibilities. The program coordinator’s main responsibility is overseeing communication with IU-13.

PDE officials maintain communication with the Department of Health, responsible IU-13 staff, and members of the Organ and Tissue Donation Advisory Committee (OTDAC) as appropriate. At IU-13, a project director, project coordinator, and support staff are assigned to the “OTDA Education Project.” The project director has spent approximately 5 percent of her time on project-related duties, while the coordinator has reportedly averaged 80 plus percent of obligated time on the project. Beginning in FY 2007-08, the project coordinator will work on the project on a full-time basis.

The PDE does not receive any funding for implementation costs but administers contract funding from the Trust Fund for services provided by IU-13. In FY 2006-07, the amount of the IU-13 contract was \$150,000; the distribution from the Trust Fund for this purpose beginning in FY 2007-08 will be \$225,000.

Department of Transportation

PennDOT plays a key role in the Commonwealth’s organ donor awareness and recruitment efforts. In response to statutory mandates, the Department has implemented several provisions that are integral to the program. These include a redesign of its driver license and identification card system for purposes of organ donor designation and the maintenance of an organ donor registry in conjunction with its driver licensing database. The Department is also responsible for collecting dedicated program revenues from voluntary contributions made by persons applying for driver licenses and vehicle registrations.

PennDOT officials report that, although more staff resources were assigned to OTDAP-related activities during project start-up and major system enhancements, no Departmental staff perform OTDAP work on a full-time basis. As of late

2006, three staff members, a management analyst in the Office of Information and Fiscal Services and a program manager and contract compliance manager from the Photo License Program, reported spending work time on OTDAP. Each reported that these duties require less than 1 percent of their time.

In addition to developing and maintaining the statewide organ donor registry, PennDOT provides organ donor information to the state's organ procurement organizations (OPOs) and compiles statistical data related to the registry. PennDOT regularly provides this data to the Organ Donation Advisory Committee, the involved state agencies, and the OPOs for program management and assessment purposes.

During the course of this evaluation, PennDOT was working with the Department of Health, the Organ Donation Advisory Committee, and the state's OPOs on system enhancements, including the initiation of an on-line donor registration capability and the direct linkage of the state's two OPOs to the registry database. Beginning in July 2006, Pennsylvania residents who have a driver's license or state I.D. card can go online to a secure page within PennDOT's website to add the donor designation to their record rather than waiting until they renew their driver's license or state I.D. card to register.

Department of Revenue

While also not involved directly in the administration of the Organ and Tissue Donor Awareness Program, state law assigns the Department of Revenue specific duties related to the collection of voluntary contributions to the Governor Robert P. Casey Memorial Organ and Tissue Donor Awareness Trust Fund. Primary among these is the placement of a space on the face of the state individual tax return form whereby an individual may voluntarily contribute any amount of their state income tax refund to the Trust Fund.¹

Subsequent legislation requires that the Department of Revenue also provide on its income tax forms, or in its instructions, information regarding the Trust Fund, including an address (provided by the Organ Donation Advisory Committee) to which contributions may be sent by taxpayers who do not receive refunds but still wish to contribute to the Trust Fund.² The Department annually determines the total amount designated as donations on state individual income tax returns and reports that amount to the State Treasurer, who in turn transfers that amount to the Trust Fund.

¹The amount designated by an individual on the state individual tax return form is to be deducted from the tax refund to which the individual is entitled and does not constitute a charge against the income tax revenues due the Commonwealth.

²Direct contributions to the Trust Fund are to be sent to the Department of Health's Bureau of Administrative and Financial Services.

The Department of Revenue’s involvement in OTDAP does not require a substantial staff commitment. The Bureau of Individual Taxes utilizes a software package to process individual income tax returns for amounts designated to the Trust Fund. Upon identification of all such amounts, a memorandum is submitted to the Comptroller’s Office for transfer to the State Treasurer. The Department’s Bureau of Fiscal Management oversees the process.

The Taxpayer Service and Information Center handles any questions that individual taxpayers may have regarding the Trust Fund refund contribution or direct contributions. For all such questions, individuals call an automated telephone hotline that is used generally for state income tax-related questions.

The Organ Donation Advisory Committee

Statutory Provisions. Act 1994-102 establishes an Organ Donation Advisory Committee for the state’s Organ and Tissue Donor Awareness Program. The Committee consists of 15 members appointed by the Governor for five-year terms. Pursuant to Act 102, appointments are to be made “in a manner that provides representation of the northwest, north central, northeast, southwest, south central, and southeast regions of the Commonwealth. Committee membership is outlined on Exhibit 2.

Exhibit 2

Member Composition of the Organ Donation Advisory Committee

<u>Representatives of:</u>	<u>No. of Members</u>
Organ, Tissue and Eye Recipients, Families of Recipients and Families of Donors.....	6
Acute Care Hospitals.....	3
Organ Procurement Organizations.....	2
Tissue Procurement Providers.....	2
Department of Health.....	1
Eye Banks.....	<u>1</u>
Total.....	15

Source: Act 1994-102.

The Governor appoints Advisory Committee members to five-year terms and members may be reappointed for successive terms. Members remain in office until a successor is appointed and qualified. If vacancies occur prior to completing a term, the Governor is to appoint another appropriate member to fill the unexpired term.

The Advisory Committee is required to meet at least biannually to perform the following duties:

- review progress in the area of organ and tissue donation in the state;
- recommend education and awareness training programs;
- recommend priorities in expenditures from The Governor Robert P. Casey Memorial Organ and Tissue Donation Awareness Trust Fund;
- advise the Secretary of Health on matters relating to the administration of the fund;
- recommend legislation as it deems necessary to fulfill the purposes of the program; and
- submit a report concerning its activities and progress to the General Assembly within 30 days prior to the expiration of each legislative session.

The Department of Health is required to reimburse members of the advisory committee for all necessary and reasonable travel and other expenses incurred in the performance of their duties.

Membership, Meeting, and Administrative Matters. Act 1994-102 sets forth requirements related to committee size, composition, geographic representation, the length of member terms, and the frequency of meetings. The following presents the results of our review of statutory membership and related administrative matters of the Organ Donation Advisory Committee.

Committee Size. Act 102 sets the size of the Organ Donation Advisory Committee at 15 members. As of January 2007, all 15 positions were filled.

Committee Composition. Act 102 prescribes that the Advisory Committee composition include: two representatives of organ procurement providers; two representatives of tissue procurement providers; six members representing organ, tissue and eye recipients, families of recipients, and families of donors; three representatives of acute care hospitals; one representative of the Department of Health; and one representative of eye banks. As illustrated on Exhibit 3, we found that, as of January 2007, the composition of the Advisory Committee was in compliance with these statutory membership provisions.

Geographic Representation. Act 102 also provides that appointments to the Advisory Committee “shall be made in a manner that provides representation of the northwest, north central, northeast, southwest, south central and southeast regions of this Commonwealth.” (The reference is to the six Health Department regions.)

As of January 2007, all regions of the state, except the North Central,³ appeared to be represented by at least one member. (See Exhibit 4.)

³The North Central region includes the counties of Bradford, Centre, Clinton, Columbia, Lycoming, Montour, Northumberland, Potter, Snyder, Sullivan, Tioga, and Union.

Exhibit 3

Members of the Organ Donation Advisory Committee
(As of December 2006)

	<u>Name</u>	<u>Position/Title</u>	<u>Affiliation</u>
Organ Procurement Providers (2)	Howard Nathan	President & CEO	Gift of Life Donor Program
	Susan Stuart	President & CEO	Center for Organ Recovery and Education
Tissue Procurement Providers (2)	Hans Burchardt, Ph.D	V.P., Scientific Affairs	Musculoskeletal Transplant
	James Quirk, III	Exec. V.P.	Lions Eye Bank of Delaware Valley
Organ Tissue Recipients/ Donors/Family Members (6)	Edward D'Agostino		Donor Family
	Rev. Paul Johnson	Clergy	Recipient Family
	Hon. Joseph Petrarca	PA House of Representatives	Donor Family
	Dawn Reese	Legislative Staff	Donor Family and Recipient Family
	Cheryl Eshenour		Donor Family
	Melinda Emerson	President, Quintessence Entertainment, Inc.	Donor Family
Acute Care Hospitals (3)	Cynthia Corbin	Director, Advocacy & Outreach Svcs.	St. Christopher's Hosp. for Children
	Cheri Rinehart	VP, Integrated Delivery System	Hospital & Health Systems Assn. of Pennsylvania
	Vincente H. Gracias, M.D.	Asst. Professor of Surgery	Hospital of the University of Pennsylvania
Department of Health (1)	Joanne Corte Grossi	Dep. Sec. for Health Promotion and Disease Prevention	PA Department of Health
Eye Banks (1)	Thomas Phillips, Jr.	Vice President	Lions Eye & Organ Bank of Erie County.

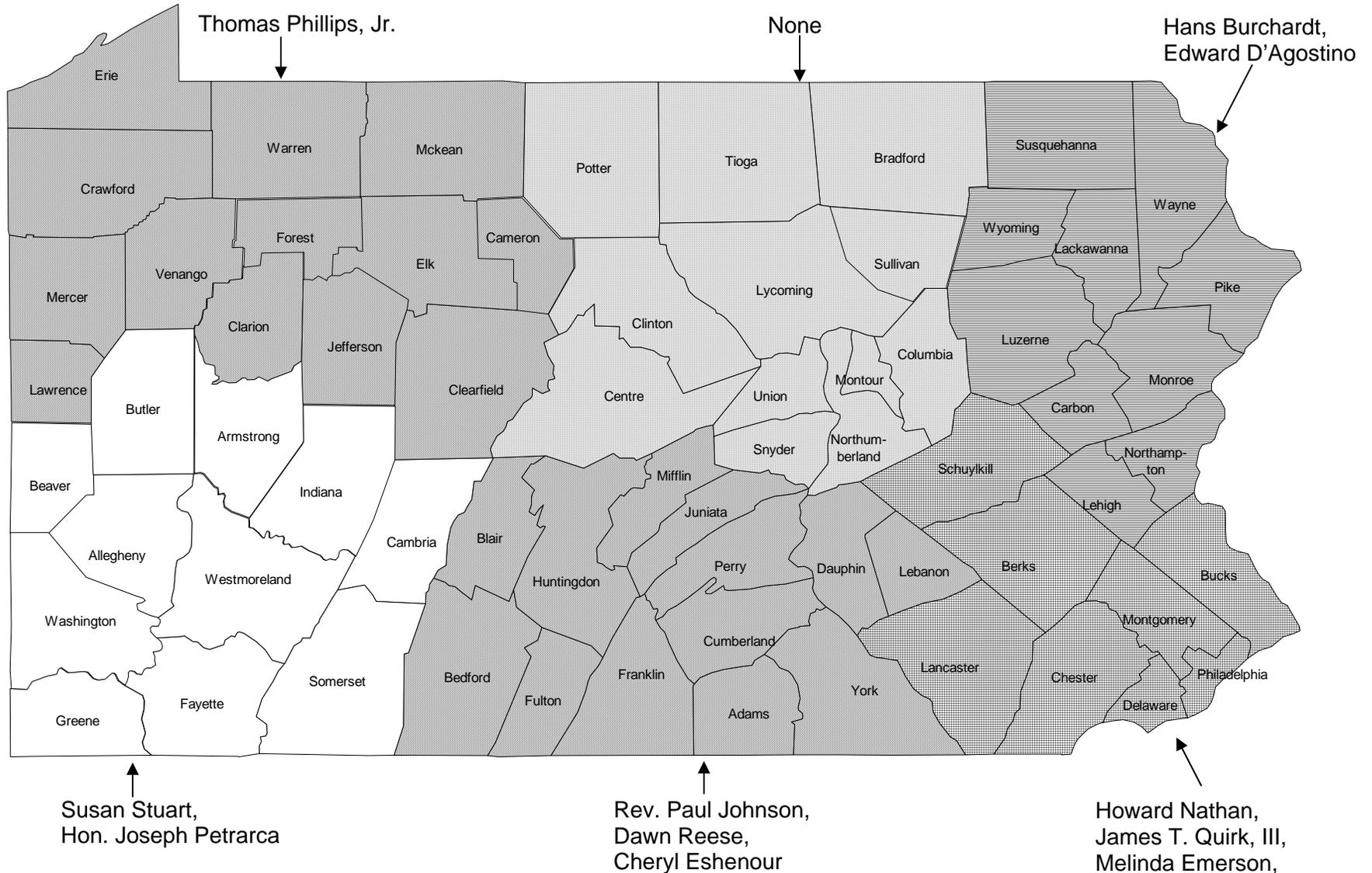
Source: Developed by LB&FC staff using information obtained from the PA Department of Health and the Organ and Donation Advisory Committee.

Member Terms. Act 102 provides that Advisory Committee members are appointed by the Governor to serve five-year terms. The Governor may reappoint members for successive terms. Members of the Advisory Committee remain in office until a successor is appointed and qualified.

We found that, as of April 2007, the terms of nine members had expired (six members' terms expired in November 2006 and three members' terms expired in January 2007). At an Organ Donation Advisory Committee meeting held on April 4, 2007, current members with expired terms were surveyed as to their interest in being reappointed. Those members present each indicated a continuing interest. Several members not present were to be contacted following the meeting by Department of Health staff, who would further draft a formal list of names to submit to the Governor's Office for reappointment.

Exhibit 4

Geographic Representation of Organ Donation Advisory Committee, by Health Department Region



Note: Two members, Joanne C. Grossi and Cheri Rinehart are considered to be "statewide members."

Source: Developed by LB&FC staff using information obtained from the Pennsylvania Department of Health.

However, as of April 2007, two positions on the Advisory Committee required replacement, and the Department of Health planned to solicit current members for names of possible candidates. Before any recommended names are submitted to the Governor's Office, the Department of Health staff will examine the candidates in accordance with the organizational and geographical requirements of Act 102.

Frequency of Meetings. Act 102 requires the Committee to meet at least two times a year. The Advisory Committee met a total of 21 meetings during calendar years 2001 through 2006 (including 3 meetings each in 2001, 2002, and 2006, and 4 meetings each for 2003 through 2005). Meetings are generally scheduled in March, June, September, and December.

Meetings of the Organ Donation Advisory Committee are frequently held in the Health and Welfare Building in Harrisburg. However, meetings have also been held at other locations such as the Gift of Life Donor Program in Philadelphia, the Center for Organ Recovery and Education in Pittsburgh, the headquarters of the Hospital and Healthsystem of Pennsylvania in Harrisburg, the Hershey Medical Center, and the Civil War Museum in Harrisburg.

Although not specifically referenced in Act 102, we also examined other related matters of a meeting/administrative nature. These include the following:

Member Attendance. Based on the records for the 20 meetings examined (from June 2001 through September 2006), and the tenure dates of the current members, we calculated the overall attendance rate for the period at 67 percent. Three members had attended less than 50 percent of the meetings they were scheduled to attend, whereas 7 members had attendance rates higher than 70 percent. During the March 10, 2004, meeting, a motion was made and endorsed by the Committee "that a letter be sent to any Committee member who misses two meetings consecutively." We observed that one member did not attend any of the meetings held in 2006 and was not in attendance at the Committee's first meeting in April 2007. The policy adopted at the March 2004 meeting has not been implemented.

Structure of the Meetings. The Advisory Committee meetings follow a fairly standard format. Among other business, reports are given and discussion and deliberations occur on areas specified by Act 102 as being under the Advisory Committee's purview, such as organ donor status reports (PennDOT report), education curriculum status report (Department of Education or IU-13), status of the Trust Fund (Department of Health), and the public information campaign (DOH, OPOs, and the contractor).

Meeting Protocol. The Committee appears to use a modified parliamentary or Robert's Rules framework to conduct the meetings. The use of formal motions has become more common in recent years, especially in relation to budgetary plans and

initiatives. Voice votes are taken but no roll call or written record of votes is maintained.

A review of the Organ Donation Advisory Committee minutes from June 2001 through December 2006 suggests that overall the procedures followed by the Committee could be described as promoting “consensus decision-making.” The will of those Committee members present is recorded in motions that are moved and seconded. No formal roll call vote is taken or recorded, but members may indicate their opposition to or exclusion from voting on motions. Standard motions are made to approve and adopt the minutes from the previous meeting and also to approve the financial status report on the Trust Fund.

Based on a review of meeting minutes, it appears that the use of formal motions has become more frequent since 2004, especially in regard to budgetary plans and initiatives that would require disbursement from the Trust Fund. A great deal of information is presented, shared, and discussed during the meetings. Members as well as non-member attendees may provide information and advice as appropriate and personal commitments to follow up on issues may be offered and recorded in the minutes, but do not rise to the level of a motion.

Additionally, matters are often researched and further discussed through subcommittees informally appointed. There is no formal subcommittee structure in place. Rather, such committees are established on an as needed basis and are disbanded when their work is completed, although Committee meeting minutes do not always indicate that a topic or topics assigned to a subcommittee (s) have been addressed and reported back to the full Committee.

Committee Officers. The Advisory Committee has co-chairpersons but no other designated officers. The co-chairs at the time of this evaluation were the Health Department’s Deputy Secretary for Health Promotion and Disease Prevention and the Committee member who represents a donor family and is a staff member of the PA House of Representatives. The Committee does not have a formal policy pertaining to Committee officers or written procedures pertaining to officer selection.

Committee Bylaws. The Advisory Committee does not have written by-laws. The drafting and adoption of bylaws could be of assistance to the Committee in dealing with administrative matters such as member attendance and the selection of Committee officers. Bylaws could also provide guidance for new members on committee operations and member duties and responsibilities.

Programmatic Functions and Activities. The Organ Donation Advisory Committee has had a leading role in the multi-agency collaborative that constitutes the Organ and Tissue Donor Awareness Program. Many program initiatives and improvements have been the direct result of discussion and action taken by

members of the Advisory Committee. In addition, the Advisory Committee has been instrumental in the formulation of legislation that has served to increase the effectiveness of the program.

The Organ Donation Advisory Committee is charged with six main duties under provisions of Act 102. These duties, and an assessment of each, follows.

1. Meet at least biannually to review progress in the area of organ and tissue donation in this Commonwealth.

The Advisory Committee meets at least biannually, as required, and closely reviews and monitors progress in the area of organ and tissue donation in Pennsylvania. A review of progress made is a structured part of each committee meeting. The Advisory Committee assesses progress made both in terms of advances made in the number of persons who are designated as organ donors on their state driver's license or identification card and the actual level of donation and transplantation activity occurring in the Commonwealth.

While the Committee has often met at the Health and Welfare Building in Harrisburg, many meetings have been held off-site, including at the headquarters of CORE in Pittsburgh, the headquarters of GLDP in Philadelphia, the Musculoskeletal Transplant Foundation in Jessup, the headquarters of the Hospital and Healthcare System of Pennsylvania, and at the Hershey Medical Center. In some cases, following meetings, Advisory Committee members are given a tour of the host facility, which may provide members a deeper understanding of the operations of key organizations in healthcare and the organ donation, transplantation, and awareness field in Pennsylvania.

At each meeting, reports are presented by representatives of various state agencies involved in the program. These reports, which also enable members to review progress made in the area of organ and tissue donation, cover information on the statewide public awareness campaign (DOH, Pennsylvania's OPOs, and designated subcontractor(s)), status reports on the financial condition of the Trust Fund (DOH Bureau of Administrative and Financial Services), the number of designated organ donors added to the state driver license database (PennDOT), education curriculum status reports (PDE and IU-13), updates on hospital compliance survey results (DOH's Bureau of Facilities Licensure and Certification), and an update on the voluntary expense benefit pilot program.

Routine status reports given at Advisory Committee meetings have also led to discussion of initiatives to be considered further by the Committee. For

example, during the December 2004 Advisory Committee meeting, information presented regarding an increase in actual organ donations over the previous year led to a discussion of plausible reasons for the increase, which identified a possible increase in the number of coroner office referrals to OPOs. As a result, the option of mandating referrals by coroners was discussed.

Although PennDOT does not hold a membership position on the Advisory Committee, the Department has assigned staff to work closely with the Committee and a PennDOT representative is usually in attendance at Committee meetings. This individual provides the Committee a statistical status report on the size and composition of the state donor registry and serves as a liaison between the Department of Health, the Advisory Committee, and PennDOT.

Also, by virtue of having the directors of both the Gift of Life and CORE OPOs as members of the Advisory Committee, there is also a direct link to operational, programmatic, and statistical data on organ donation and transplant activity in the state. Both the PennDOT representative and the OPO Directors (and members of their staffs who also attend meetings) enable the Committee and the Department of Health to closely monitor program activity.

These status reports are frequently accompanied by questions and discussion by Advisory Committee members, which provide members the opportunity to obtain clarification on any aspect of the activities and to articulate concerns, provide suggestions for the improvement of activities, and offer feedback to program implementers. The Advisory Committee has on some occasions also welcomed guests to meetings, including donor families, persons awaiting organ transplants, and transplant recipients. Also, from time to time, the Committee has hosted guests from other state agencies and civic organizations.

2. Recommend education and awareness training programs.

During the period we examined, the Advisory Committee was also active in advising on and recommending various specific education and awareness initiatives. The Committee plays an integral role in helping to shape and define the direction of the overall statewide public education and awareness campaigns and the “Organ Tissue Donation Education Project.”

For example, in this capacity, the Advisory Committee has been active in the development and review of minority awareness programs, as well as the passage of motions affirming their commitment to focus the resources of the statewide awareness campaign in an effort to increase minority organ donor

designation. Through a subcontract executed by Pennsylvania's OPOs for implementation of minority awareness initiatives, a "Barnstorming Bus Tour," faith-based pilot program and brochure, and the launch of the "Community Covenant Program" were completed. The Advisory Committee considered and approved minority outreach campaign proposals and related budgets (including proposed media buys in support of minority donation awareness).

In regard to secondary education awareness, the Committee has been involved with and advised on an ongoing basis on the development and dissemination of the "OTDA Curriculum Framework" and "Classroom Toolkit."

Advisory Committee involvement was also apparent in the production of a faith-based pilot program and brochure developed as a component of the "Ordinary People, Extraordinary Power" in 2005, as well as a pediatric organ donation program to educate health professionals in discussing donation with families of potential pediatric donors.

The Committee has also worked with the OPOs to facilitate training and awareness programs for employees at PennDOT photo-license centers.

3. Recommend priorities in expenditures from the Governor Robert P. Casey Memorial Organ and Tissue Donation Awareness Trust Fund

While the Department of Health has final authority to set executive authorization request levels, the Advisory Committee plays a key role in this process. The Advisory Committee is very active in recommending Trust Fund expenditure priorities. While the Department of Health has worked with the Advisory Committee to concentrate on identifying Trust Fund expenditure priorities at one meeting each year (generally the June meeting), motions have been made at other Advisory Committee meetings during the course of discussions on various ongoing and proposed activities. Often, when discussing activities and associated costs to be incurred from the Trust Fund, the Advisory Committee has ranked identified priorities by importance and, in some cases, members propose and consider motions which assign specific dollar amounts to activities.

In some cases, the Advisory Committee considers funding for program activities through a multi-year framework. These include multi-year contracts and work plans with GLDP and CORE for the implementation of statewide organ and tissue donation public awareness campaigns, and multi-year contracts and work plans executed by the PDE with IU-13 for the implementation of organ and tissue donation awareness programs in Pennsylvania's secondary schools.

The Committee also routinely engages in discussions that impact budget and funding decisions. For example, in 2003 the Advisory Committee passed a motion regarding the introduction of an online donor designation portal through PennDOT's driver licensing website. Through initiatives taken by the Advisory Committee, representatives from the Department of Health, GLDP, and CORE met with representatives from PennDOT to discuss the cost and logistics of launching an online donor designation website. This culminated in the Advisory Committee agreeing to fund the upgrade costs from the Trust Fund, and the eventual launch of the portal in July 2006.

In another example, a discussion occurred at the December 8, 2004, Advisory Committee meeting regarding potential programs that may be initiated to utilize unexpended Trust Fund monies. This session produced several ideas for additional programs, as well as potential uses for unexpended Trust Fund monies.

4. Advise the Secretary of Health on matters relating to administration of the fund.

The Advisory Committee does not have a formal mechanism through which it directly advises the Secretary but does communicate directly with Department officials, including at the deputy secretary level, during the course of regular Committee meetings.

While not a result of direct advice provided to the Secretary, the Advisory Committee was instrumental in initiating the change in the method of Trust Fund financial management employed by the Department of Health. The minutes of Advisory Committee meetings we examined for the period 2000 through 2006 contain numerous references to the "silo system," including discussion of whether it was necessary and the need to consider alternatives. Discussion ensued among members of the Advisory Committee regarding the constricting nature of the "silo" method of Trust Fund financial management (in which monies allocated to each Trust Fund expenditure purpose, or "silo," retained their identity from year to year), contributed to the change in the method of Trust Fund financial management (See also Section K). This method, in the view of at least some members, limited amounts available for other important program initiatives.

In late 2005, the co-chair of the Advisory Committee worked with DOH officials on a proposal to modify the financial management of the Trust Fund to allow for the most effective expenditure of Fund monies. Subsequently, the Department requested that its Legal Counsel review the law to determine whether it provides for an alternative method of Trust Fund financial management.

In some cases, the Committee has met with or otherwise communicates directly with the Secretary. For example, the Advisory Committee has considered the option in the law of using Trust Fund monies to cover a portion of funeral expenses incurred by organ donors or their families in connection with making a vital organ donation. A subcommittee of the advisory committee was formed to evaluate the issue and provide recommendations for the program. The Advisory Committee subsequently developed a program proposal and delivered it to the Secretary of Health for review in 1999. Members of the Advisory Committee again met with the Secretary of Health in 2006 regarding the possible implementation of a funeral expense benefit pilot program. (For a complete discussion of the consideration of reimbursement for funeral expenses, see Section E).

Because the organ donation expense benefit pilot program is primarily serving living donors, the Advisory Committee sought another avenue to provide a Trust Fund benefit to families of deceased donors. To accomplish this objective, the Committee finalized a proposal in 2006 which would provide a family grief counseling and bereavement support benefit through the Trust Fund. (For a complete discussion of the development of a pilot grief counseling program, see Section E.)

5. Recommend legislation as it deems necessary to fulfill the purposes of the program.

The Advisory Committee has been very active in the development of several pieces of legislation related to various aspects of OTDAP.

Act 1998-74 directed PennDOT to provide applicants for a renewal vehicle registration the opportunity to make a contribution of \$1 to the Trust Fund. This Act was sponsored by a state representative serving on the Advisory Committee, and was developed as a result of Advisory Committee's advocacy to create an additional source of Trust Fund revenue.

In an effort to enable more efficient OPO determination of patients' organ donor designation status, the Advisory Committee passed a motion to investigate the cost of direct OPO access to the PennDOT driver licensing database in September 2003. This eventually led to the introduction of House Bill 1834 of 2006 (co-sponsored by a state representative serving on the Advisory Committee), which later became of Act 48 of 2006. Act 48 granted Pennsylvania's OPOs 24-hour-a-day electronic access to the PennDOT driver licensing database to determine the organ donor designation status of hospital patients who are at or near death.

Members of the Advisory Committee have also been active in monitoring the status of statutory authorizations of various components of the program. For example, the Committee has discussed the need to renew the statutory authorization for taxpayers to donate a portion of their state individual income tax return refund to the Trust Fund (which is set to expire on January 1, 2008). The Advisory Committee also often examines and advises on potential amendments to Pennsylvania's Anatomical Gift Act (see Section M).

Although it did not require specific legislation, the Advisory Committee was also instrumental in the introduction of the Pennsylvania Organ and Tissue Donor Awareness license plate, with the inscription "Organ Donors Save Lives" introduced in 2004. This was the result of a motion made by the Advisory Committee in 2003.

6. Submit a report concerning its activities and progress to the General Assembly within 30 days prior to the expiration of each legislative session.

The Advisory Committee is to submit a report to the General Assembly within 30 days prior to the expiration of each legislative session concerning its activities and progress. Act 102 also created several annual reporting requirements to the General Assembly for the state agencies, OPOs, and tissue procurement providers involved in the implementation of the Act's provisions.

To satisfy these requirements, the Department of Health, in the name of the Organ Donation Advisory Committee, annually compiles required and supplementary information from each state agency of responsibility and the state's OPOs.

We reviewed the annual reports for the period 2000 through 2005, and found that the reports satisfy each of the reporting requirements stated in law. (See also part N of this Section.)

Federally-Designated Organ Procurement Organizations

OPOs Defined. OPOs serve as the vital link between the donor and recipient and are responsible for the identification of donors and the retrieval, preservation, and transportation of organs for transplantation, and for providing public education in the community on the critical need for organ donations.

As stated in federal regulations, an organ procurement organization (OPO) is "an organization that performs or coordinates the procurement, preservation, and transport of organs and maintains a system for locating prospective recipients for available organs." As of September 2006, there were 58 OPOs operating within 11 regions nationwide.

Of the 58 OPOs (now collectively referred to as “donate life organizations”), 50 are independent and 8 are hospital or university based. Each OPO serves a unique geographic area known as a donation service area (DSA)⁴ with specific donor hospitals and transplant centers as designated by the federal government. The designated geographic areas served by the various OPOs range in size from a few counties, to entire states, to multi-state areas covering parts or all of several states.

In order to be certified as a qualified organ procurement organization, an entity must have received an authorized grant from the Secretary of the federal Department of Health and Human Services (HHS) or have been certified or recertified by the Secretary within the previous four years as being a qualified OPO.

HHS has designated the Centers for Medicare and Medicaid Services (CMS) as the entity responsible for certifying qualified OPOs as per federal law and regulation. OPOs must enter into an agreement with CMS in order for the organ procurement costs attributable to the OPO to be reimbursed under Medicare and Medicaid. The CMS makes OPO designations every four years. Each OPO is required to be a member of the national Organ Procurement and Transplantation Network (OPTN).

Two OPOs serve Pennsylvania: The Gift of Life Donor Program (GLDP) and the Center for Organ Recovery and Education (CORE). Together, GLDP and CORE share the responsibility of serving hospitals in 66 of Pennsylvania’s 67 counties. The New York Organ Donor Network serves Pike County.⁵

Gift of Life Donor Program (GLDP). GLDP is a nonprofit organization dedicated to promoting donation, education, and research for the purpose of saving and improving the quality of life through organ, tissue, and corneal transplantation. GLDP’s service area includes the eastern half of Pennsylvania, southern New Jersey, and Delaware. (See Exhibit 5.) In Pennsylvania, GLDP serves 35 counties, covering approximately 7.8 million Pennsylvania citizens. Gift of Life Donor Program is headquartered in Philadelphia with a satellite office located in Harrisburg.

GLDP was founded in 1974 by the Greater Delaware Valley Society of Transplant Surgeons. First named the Delaware Valley Transplant Program with an unforgettable phone number (1-800-KIDNEY-1), the organization’s name was officially changed to Gift of Life Donor Program in 1999. Gift of Life is one of 58 non-profit, federally designated organ procurement organizations in the United States and is a

⁴The DSA is the geographic area that is served by one OPO, one or more transplant centers, and one or more donor hospitals. As of 2003, the populations served by individual OPOs ranged from 1 million to 17 million people and the OPO coverage areas ranged from approximately 3,600 to more than 850,000 square miles.

⁵The New York Organ Donor Network, an OPO covering the greater New York metropolitan area, is also the designated OPO for organ and tissue procurement and transplantation in Pike County. According to Department of Health officials, the New York Organ Donor Network receives no state or Trust Fund monies for operations, and has no interaction with DOH.

member of the nationwide Organ Procurement and Transplantation Network (OPTN).

Exhibit 5

Service Area Information for the Gift of Life Donor Program (GLDP)

Pennsylvania Counties Served:			
1. Adams	10. Dauphin	19. Mifflin	28. Snyder
2. Berks	11. Delaware	20. Monroe	29. Sullivan
3. Bucks	12. Juniata	21. Montgomery	30. Susquehanna
4. Carbon	13. Lackawanna	22. Montour	31. Tioga
5. Centre	14. Lancaster	23. Northampton	32. Union
6. Chester	15. Lebanon	24. Northumberland	33. Wayne
7. Clinton	16. Lehigh	25. Perry	34. Wyoming
8. Columbia	17. Luzerne	26. Philadelphia	35. York
9. Cumberland	18. Lycoming	27. Schuylkill	
Pennsylvania Organ Transplant Centers Served:			
1. Albert Einstein Medical Center	7. St. Christopher's Hospital for Children		
2. Hahnemann University Hospital	8. Temple University Hospital		
3. Children's Hospital of Philadelphia	9. The Milton S. Hershey Medical Center		
4. Geisinger Medical Center - Danville	10. The Lankenau Hospital		
5. University of Pennsylvania Medical Center	11. Lehigh Valley Hospital		
6. Harrisburg Hospital	12. Thomas Jefferson University Hospital		
	13. Geisinger, Wyoming Valley		
Pennsylvania Tissue Procurement Providers:			
1. Gift of Life Donor Program	4. Musculoskeletal Transplant Foundation		
2. CryoLife, Inc	5. National Disease Research Interchange		
3. LifeNet Transplant Services	6. Ohio Valley Tissue & Skin Center		
Pennsylvania Eye Procurement Providers:			
1. Gift of Life Donor Program			
2. Lions Eye Bank of Delaware Valley			
3. Northeast Pennsylvania Lions Eye Bank			

Source: Organ Donation Advisory Committee, 2006.

Gift of Life Donor Program serves 13 organ transplant centers in Pennsylvania and partners with approximately 150 acute care and specialty hospitals in its service region. Gift of Life also serves as a tissue procurement provider and works with tissue processors that release tissue allografts, heart valves, veins, and skin for life-enhancing transplant operations for hospitals in our service area. Additionally, Gift of Life supports eye banking through its collaboration with the Lions Eye Bank of Delaware Valley and the Northeast Lions Eye Bank as well as through its own eye bank which services central Pennsylvania.

Since 1974, GLDP, one of the oldest and largest OPOs in the country, has served as the link between donors and patients awaiting life-saving transplants in the eastern half of Pennsylvania, southern New Jersey, and Delaware. In that

time, the OPO has coordinated more than 25,000 life-saving organ transplants and hundreds of thousands of tissue transplants. GLDP has a staff of more than 125 full- and part-time clinical and administrative personnel. Staff units and services include the following:

Transplant Services Coordinators. The Transplant Services Coordinators staff coordinates the organ and tissue donation process. They provide timely on-site response assessment, evaluation, and coordination of potential donors as well as interacting with the hospital staff regarding the donation process. GLDP staff also generates organ transplant candidate listings on national and local computer systems and oversees the allocation of organs.

Hospital Services. The Hospital Services staff interacts with area hospitals to provide support and education surrounding the clinical aspects of organ and tissue donation and transplantation. These personnel develop collaborative relationships with area hospitals, physicians, and nurses and provide essential information regarding the implementation of the “Routine Referral” laws. Staff of this unit provide professional and educational programs at area hospitals and are instrumental in promoting the National Breakthrough Collaborative in the GLDP service area.

Community Relations. The Community Relations staff provides community outreach and education programs to increase awareness of the critical need for donated organs and tissues to save and enhance the lives of patients in need of transplants. These staff members work closely with volunteers to coordinate grass roots education programs and interact with area media outlets throughout the tri-state region. Specific projects include: programs to target minority communities, advertising campaigns, marketing communications, special events, and public affairs activities.

Family Support Services. The Family Support Services staff provides a variety of grief and bereavement programs to help those whose loved ones have died. Services include individual counseling, group sessions, and monthly support groups and other special programs. The Family Support Services also facilitates communications between donor and recipient families.

In 2005, GLDP moved into a new headquarters building in Philadelphia. The building is designed to support community programming, enhanced services to hospital partners, and the development of clinical services to advance the donation process. It is a full service facility that includes a call center, recovery suites, operating rooms, and a training institute with practicum facilities.

The GLDP facility houses the Transplant Information Center (TIC), an on-site call center that provides support for donor referral triage 24 hours/7 days a week. This center handles 50,000 referrals from hospitals throughout a tri-state

region, obtains consent for tissue donation, preliminarily determines donor suitability, and allocates kidneys and pancreas donations.

In addition, the facility will include a HLA and Serology Testing Laboratory that will be operational in the fall of 2007 that will enable donor HLA identification (tissue-typing), conduct preliminary cross matching for kidney transplantations, as well as serological testing for organ and tissue donors.

The GLDP facility includes a kidney pulsatile perfusion lab. The addition of a pulsatile perfusion lab has made more organs available for those awaiting transplantation by expanding the donor pool. In addition to keeping the kidney viable, this “perfusion” process delivers nutrients to the kidney and, perhaps most significantly, gives doctors data as to the kidney’s ability to function. With pulsatile preservation, doctors can monitor flow through the kidney. When using this method, kidneys from older donors (up to 80 years old) or donors previously considered marginal can be evaluated based on the data obtained while they are being pumped. Prior to putting kidneys on the pump, basic predictors were the only method to evaluate the kidneys, this meant kidneys possibly could have been discarded that would have been effective following transplant.

Gift of Life Donor Program is one of only two organ procurement organizations in the country that have on-site recovery suites, and 25 organ recoveries and 270 tissue recoveries have been performed to date. Coordinating recoveries on-site will enable GLDP to better schedule recoveries while freeing up the operating rooms of donor hospitals for emergency traumas and help reduce costs.

In addition, the facility houses the Gift of Life Institute, an all-inclusive, international training center offering comprehensive interdisciplinary resources for skill-based learning, continuing education, collaborative research, and consulting services for donation professionals. Since its founding in 2004, The Institute has facilitated over 100 workshops nationally on topics of consent, hospital development and procurement and trained more over 700 coordinators and requestors on Dual Advocacy Approach for Consent.

Among other GLDP programs and activities are the following:⁶

- GLDP organizes and participates in donor family recognition ceremonies. Along with regional transplant recipients, transplant support groups, and area Coalitions for Organ and Tissue Donation, the OPO organizes “Thanks for Giving the Gift of Life Ceremonies” throughout the eastern half of Pennsylvania, southern New Jersey, and Delaware. In 2005, approximately 800 donor family members and recipients attended these ceremonies. At these ceremonies, area transplant recipients honored the

⁶See GLDP’s website at www.donors1.org for further information.

- family members of area men, women, and children who died and donated organs and tissue for life-saving and life-enhancing transplants. Family members of donors receive the “Gift of Life Donor Medal of Honor” at these ceremonies. This medal, designed by one of our volunteers, has been used by more than 40 OPOs and received by more than 25,000 donor families in recognition of their loved one. This medal has also been given to families from across the nation who attend the National Donor Family Recognition Ceremony in Washington, D.C.
- GLDP organizes several special events each year to promote public awareness of the critical need for organ and tissue donors. These events include the annual Dash for Organ Donor Awareness, a 3K walk and 5K and 10K run that attracts more than 3,000 participants each April as part of National Donate Life Month, the bi-annual Legacies of Life conference featuring 12 workshops tailored to the specific questions and concerns of donor families, those waiting for transplant as well as those newly transplanted, and minority outreach programs such as our Gospel Concert and Vigil (held in conjunction with National Minority Donor Awareness Day on August 1) and National Donor Sabbath.
 - GLDP and the region’s hospitals with the largest organ donor potential continue to be active participants in the National Organ Donation Break-through Collaborative. In this effort, GLDP works with service area hospitals to implement best demonstrated practices proven to increase organ donation conversion rates to 75 percent or higher.
 - GLDP maintains two informational hotlines (1-800-DONORS-1 for the general public and 1-800-KIDNEY-1 for healthcare professionals). It also publishes two different news letters that are circulated to healthcare professionals, transplant recipients, donor family members, and patients:
 - Gift of Life News* is a quarterly publication available to the general public, transplant recipients, donor family members, funeral directors, coroners, corporations, clergy, schools, etc., within the Gift of Life service region. *News* offers transplant news and features, profiles on donor families, transplant recipients, and details on community donor awareness programs.
 - Clinical Update* is a quarterly publication for healthcare professionals, funeral directors, and coroners who are within the Gift of Life service region. *Clinical Update* provides clinical information on donation and transplantation, case studies, and legislative news directed to the clinical and medical audiences.
 - Gift of Life enlists the support of more than 1,000 volunteers and 15 local coalitions in their outreach activities. GLDP also works with the Clergy Advisory Council, an inter-denominational group of religious advisors who discuss news and issues surrounding donation and transplantation as it

relates to various religious faiths. The Council members serve as an important resource to the community and its members provide support and education to other clergy members.

- GLDP is governed by a Board of Directors, which includes representatives from each transplant center in its service area as well as a neurosurgeon, hospital administrator, histo compatibility expert, ICU/Trauma physician, as well as community members including donor family members and transplant recipients.

The Center for Organ Recovery and Education (CORE). The Center for Organ Recovery and Education (CORE) is a not-for-profit organization dedicated to promoting donation, education, and research for the purpose of saving and improving the quality of life through organ, tissue, and corneal transplantation. The tax-exempt, federally designated organization serves the western half of Pennsylvania, most of West Virginia, and Chemung County, New York, and is responsible for recovering and distributing organs and tissues used in life-saving and life-enhancing transplants. CORE partners with 155 acute care and specialty hospitals and serves a population of over 5.5 million people. Its Pennsylvania service area includes 31 counties covering approximately 4.2 million persons. (See Exhibit 6.)

CORE's staff of more than 90 full-time and part-time clinical and administrative personnel serve six area transplant centers where heart, kidney, liver, lung, intestine and pancreas transplants are performed. In addition, CORE maintains the registry, of designated donors, used in addition to the Pennsylvania Department of Transportation driver's license registry. Currently, there are more than 2,000 patients locally awaiting a life saving organ transplant. CORE also coordinates the recovery of life-enhancing tissue, including maintaining an eye bank. In addition, CORE works with several tissue banks in order to preserve donated tissue until the time it is needed to be transplanted.

Formerly known as Pittsburgh Transplant Foundation, the organization's name was changed to the Center for Organ Recovery & Education in 1992 in an effort to better reflect its mission.

Donor Referral Coordinators. These coordinators are the first step in the life-saving processes of organ and tissue donation. CORE's donor referral office is staffed 24-hours a day, 365-days a year in order to maximize the potential for donation offered through the routine referral program. Donor Referral Coordinators are responsible for first-level screening of potential organ, tissue, and eye donors as they receive and process every call through routine referral. After a donor has satisfied all of the criteria, Donor Referral Coordinators begin the process of organizing all efforts related to the organ and tissue recovery; including scheduling operation room times, transportation of recovery staff, and allocation of organs and tissues.

In addition, Donor Referral Coordinators offer the gift of donation to families of potential tissue donors.

Exhibit 6

**Service Area Information for the
Center for Organ Recovery and Education (CORE)**

<u>Pennsylvania Counties Served (31)</u>			
1. Allegheny	9. Cameron	17. Franklin	25. Mercer
2. Armstrong	10. Clarion	18. Fulton	26. Potter
3. Beaver	11. Clearfield	19. Greene	27. Somerset
4. Bedford	12. Crawford	20. Huntingdon	28. Venango
5. Blair	13. Elk	21. Indiana	29. Warren
6. Bradford	14. Erie	22. Jefferson	30. Washington
7. Butler	15. Fayette	23. Lawrence	31. Westmoreland
8. Cambria	16. Forest	24. McKean	
Pennsylvania Organ Transplant Centers Served:			
1. West Penn Allegheny Health System/Allegheny General Hospital Pittsburgh, PA			
2. Children’s Hospital of Pittsburgh, Pittsburgh, PA			
3. University of Pittsburgh Medical Center, Pittsburgh, PA			
4. Veterans Administration Medical Center, Pittsburgh, PA			
Pennsylvania Tissue Procurement Providers:			
1. Center for Organ Recovery & Education (CORE)			
2. CryoLife Inc.			
3. LifeNet Transplant Services			
4. National Diabetes Research Interchange			
5. LifeCell			
Pennsylvania Eye Procurement Providers:			
1. Center for Organ Recovery & Education (CORE)			
2. Lions Eye Bank of Northwestern Pennsylvania			
3. Rochester Eye and Human Parts Bank			

Source: Organ Donation Advisory Committee, 2006.

Clinical Services. These staff coordinate the organ and tissue donation process. They provide timely on-site response assessment, evaluation, and coordination of potential donors as well as interact with the hospital staff regarding the donation process.

Clinical services staff include Organ Procurement Coordinators, Recovery Coordinators, and Lab Technicians. Organ Procurement Coordinators are on-site at the hospitals in order to coordinate organ recovery efforts. In addition to evaluating the donor, Organ Procurement Coordinators also offer the donation opportunity to families, work with hospital staff to maintain the donor, coordinate recovery efforts while in the operating room, and supervise all recovery processes.

Recovery Coordinators are responsible for the perfusion of organs in the operating room and preparing the organs for transport to the recipient's hospital. In addition, Recovery Coordinators are specially trained to perform surgical recovery efforts of tissue.

CORE maintains a state-of-the-art lab facility that enables serology and microbiology tests to be performed. Lab Technicians are highly specialized and trained clinical service providers that carefully screen for a series of diseases and illnesses that could be transferred from a donor to a recipient.

Hospital Services. Hospital Services staff, also known as Professional Services Liaisons (PSLs), interacts with area hospitals to provide support and education surrounding the clinical aspects of organ and tissue donation and transplantation. These personnel develop collaborative relationships with area hospitals, physicians, and nurses and provide essential information regarding the implementation of the "Routine Referral" laws. In addition, PSLs address all hospital issues including donor chart reviews and educational programming for hospital staff.

Family Support and Education Coordinators (FSECs). These coordinators provide in-house coordination for recovery efforts. They are located in the largest trauma centers and assist in education for hospital staff and counseling for donor families.

Community Relations. Community Relations staff provides community outreach and education programs to increase awareness of the critical need for donated organs and tissues to save and enhance the lives of patients in need of transplants. These staff members work closely with volunteers to coordinate grass roots education programs and interact with area media outlets throughout the tri-state region. Specific projects include: programs to target minority communities, high school awareness initiatives, corporate awareness initiatives, advertising campaigns, marketing communications, special events, and public affairs activities. In addition, the department writes several publications, such as brochures, newsletters, web materials, news releases, and fact sheets.

Among other CORE programs and activities are the following:⁷

- Partnering for Life is an outreach initiative to corporate partners which CORE founded in 2001. The program has grown to include more than 1,000 partners. As a result of CORE's successful program, the Workplace Partnership for Life was founded on a national level.
- Volunteers for Life enables donor families and transplant recipients the opportunity to share their personal experiences with the public. Over 200

⁷See CORE's website at www.core.org for further information.

- volunteers have joined the grassroots initiative, which encourages volunteers to find opportunities to promote donation in their community. Volunteers participate in a variety of programs, including health fairs, special events, educational presentations, in-office assistance, and media.
- A Special Place was dedicated in 1992 to recognize the amazing second chance at life provided by donors and to thank families for their generosity. It is a park-like area outside CORE's office in Pittsburgh. On the graduated, granite walls forming A Special Place, a leaf has been engraved for every CORE donor. The memorial area is inscribed with the words "Let the leaves symbolize the donors. Like softly fallen petals that nourish the earth, they have touched the lives of others." Each year, CORE holds A Special Place ceremony for the families of donors from the previous year.

B. The Promotion of Organ and Tissue Donation Through Statewide Public Awareness and Education Activities

Findings

- B-1. The challenges for organ and tissue donation public education and awareness activities lie both in the complex nature of the information that needs to be communicated and the need to correct myths and misperceptions about donation and transplantation. Pennsylvania's organ procurement organizations (OPOs) do this by providing public education in the community on the critical need for organ and tissue donations. While both the Gift of Life Donor Program (GLDP) and the Center for Organ Recovery and Education (CORE) conduct extensive public information and awareness activities on their own, funding from Act 1994-102 and the Organ and Tissue Donation Awareness Program have provided the means by which the OPOs can mount a concerted, statewide campaign with a common theme and unified message. Since 2000, three separate campaigns have been conducted at a total cost to the OTDAP Trust Fund of approximately \$1.9 million.*
- B-2. Among persons involved in the program, there is a general consensus that although it did not meet targeted increases in enlisting new organ donors, the 2003 through 2006 phase of the "Ordinary People, Extraordinary Power" campaign is considered successful and is the most effective of the three statewide awareness campaigns undertaken to date. The campaign involved a mix of donor education and awareness activities including public relations, billboard and radio advertising, collateral material development, an online presence, special events, and alliances with various organizations throughout the Commonwealth. Also, additional funding for a faith-based brochure and outreach in the minority communities enabled the program to enhance ongoing efforts in those communities. The firm contracted to conduct the statewide campaign received several industry awards for their work related to the organ and tissue donor awareness program.*
- B-3. While the 2003 through 2006 phase of the "Ordinary People, Extraordinary Power" campaign established a solid strategic foundation for future efforts, it encountered an initial delay and did not meet initial campaign targets. The campaign was launched on November 4, 2004, more than one year after the contract was scheduled to begin. In the short-term, the following measures can be examined to determine if the campaign's message was heard and if interest was generated:*
- *Number of Website Hits: The DonateLife-PA website was introduced in November 2004 and registered 9,173 visits during the first eight months of operation. This number increased to nearly 15,000 visits in the subsequent*

twelve-month period. Four of the 10 “low-donor counties” ranked in the top 10 among all counties in terms of number of hits registered.

- *Calls to 1-877-DONORPA: Relatively few calls were made to the OTDAP toll-free telephone line during FY 2004-05 and FY 2005-06, averaging 35 calls per month statewide in FY 2004-05 and 30 per month in FY 2005-06. We found that as of April and early May 2007, this toll-free line was not in service.*

Over a longer time period, changes in behavior can be assessed in terms of the overall statewide increase (both in raw numbers and percentages), of individuals identified as donors and the increases in the ten targeted “low-donor counties.”

- *Increase in Designated Donors: Between 2003 and 2006, the size of the donor registry increased by 236,484 persons. However, the campaign objective of increasing the number of persons who designate “organ donor” on their driver’s license or ID card by a minimum of 3 percent annually was not met in any year during the 2003 to 2006 contract period. (Actual annual percentage increases were 2.3 percent, 1.7 percent, and 2.2 percent.)*
- *Increases In Donor Designations in “Low-Donor Counties”: Between June 2003 and January 2007, the total number of designated organ donors statewide increased by 7.9 percent. Of the 10 counties classified for purposes of the campaign as “low-donor counties,”¹ the rate of increase in donor designation during the same period ranged from a low of 4.7 percent in Allegheny County to a high of 14.4 percent in Luzerne County. Overall, 5 of the 10 “low-donor” counties exceeded the statewide average of 7.9 percent.*

B-4 While the numbers cited in B-3 above relating to campaign effectiveness do not indicate significant gains in increased awareness and numbers of new donors, it is probably still too soon to know the campaign’s actual impact. The bulk of the campaign transpired during a time when the organ and tissue donation awareness campaign presented members of the public with messages without an immediate and easy “call to action.” That is, even if a person made the decision to become a donor, they could not immediately act on that decision because, until July 2006, the only opportunity drivers had to designate as an organ donor was once every four years when they renewed their license.

So, the combination of a delay in campaign start-up due to state contract processing issues and a later-than-expected activation of the on-line registration feature in the state donor registry most likely restricted the sign-up of new donors during the period. The contracted public relations firm’s position is

¹“Low donor counties” were targeted through radio, outdoor and public relations efforts, including the campaign kick-off event.

that, for the vast majority of people, the decision to donate is a deliberate one that is considered over a long period of time, and that attitudes and behaviors among that group, referred to as the “persuadables,” will begin to shift with ongoing public relations efforts.

- B-5. The program is not maximizing the public education and awareness potential at PennDOT photo-license centers. Based on our observations at 16 photo-license centers in 11 counties, program materials are not being consistently and prominently displayed and the organ and tissue donation option is not being sufficiently promoted.*

- B-6. One of the challenges in increasing organ donation rates has been to more fully engage minority populations in organ donation. Further, for many people, issues and beliefs regarding death and donation are closely intertwined with their faith and spirituality.*

- B-7. The OPOs and the Department of Health plan to continue the public awareness campaign theme “Ordinary People, Extraordinary” through, at least, the end of 2007. The initial plan was to begin the second three-year campaign on October 1, 2006, and continue through June 30, 2009. However, delays again occurred at the state level as the relationship between the Department and the OPOs was changed from a contractual basis to a grant basis and, as of early May 2007, the 2006 to 2009 phase of the campaign had not yet been launched. Once initiated, this campaign is to involve a transition from primarily an awareness and education campaign to a motivational and call to action campaign (through a word-of-mouth and “viral e-mail approach”). The established campaign target is to add 277,000 new donors and increase the percentage of the state’s registered drivers who are designated donors to 46 percent by June 30, 2009.*

Pennsylvania’s Statewide Public Education and Awareness Campaigns

The Department of Health has authority under Act 1994-102 (20 Pa. C.S.A. §8622(b)(2) to provide grants to certified organ procurement organizations for the development and implementation of statewide organ and tissue donation public awareness programs.² The purpose of such campaigns is to reach Pennsylvania citizens with current and accurate information about the organ and tissue donation process and the benefits of organ and tissue donation, to dispel myths and misperceptions surrounding organ and tissue donation, and to encourage both the completion of a legal instrument (driver’s license, donor card, living will) designating

²Act 102 provides that, after payment of implementation and advisory committee costs, the Department may annually expend 50 percent of the total Trust Fund for grants to certified organ procurement organizations “for the development and implementation of organ donation awareness programs in this Commonwealth.”

themselves as organ and tissue donors and the commitment to donate at the time of death.

Many factors (for example, religious beliefs, cultural norms, age, ethnicity and socio-economic status) can influence a person's attitude and willingness to become an organ donor. Frequently, strongly held beliefs or fears constitute barriers against a person's affirmative choice to donate. Various myths surrounding organ donation and transplantation—for example, having a donor card may adversely affect the quality and extent of medical treatment one receives—represent a considerable challenge to programs designed to increase donation rates.

To administer the education and awareness component of the program, the Department of Health provides annual funding in equal amounts to each of the Commonwealth's two certified OPOs. The OPOs in turn are required to work in concert with the advice and recommendations of the Organ Donation Advisory Committee and the approval of the Department to jointly select one subcontractor, an advertising/public relations firm, to design and implement the statewide public awareness campaign.

Since 2000, the Trust Fund has financed three separate campaigns. The first two included a campaign entitled "Wanna Make Your License Look Great? Say Yes to Organ Donation" and another entitled "To Be or Not To Be."

Following the experience of these two campaigns (both of which involved the OPOs' use of consultants under a one-year contract), Department of Health officials and the OPOs agreed to alter their approach by developing a sustained campaign over three years. Under this approach, the campaign was carried out through a contractual agreement between the Department of Health and the OPOs extending from July 1, 2003, through June 30, 2006. The OPOs were to then subcontract with an advertising/public relations agency to conduct the three-year campaign.

The 2003-2006 Campaign: "Ordinary People, Extraordinary Power"

Contract Provisions. Through a competitive bid process conducted in 2003, the OPOs selected the firm of Toplin and Associates, as sub-contractor, to develop and carry out the third statewide campaign (entitled "Ordinary People, Extraordinary Power"). Toplin and Associates is a marketing, public relations, and advertising firm headquartered in Fort Washington, PA. For the "Ordinary People, Extraordinary Power" campaign, each OPO had an identical contract, which began July 1, 2003, and expired June 30, 2006, at a cost not to exceed \$615,000 each or up to a total cost ceiling of \$1,230,000.

The “work statement” portion of the 2003-2006 statewide public awareness contract between the Department and the OPOs provided that the following requirements were to be met by the statewide campaign:

- The awareness campaign was to use a combination of public relations, special events, news releases, radio and television public service announcements, brochures, and posters.
- Both English and Spanish versions of all education and information materials were to be created.
- A common theme and supporting messages were to be designed to enhance public understanding throughout the Commonwealth.
- All campaign activities were to be coordinated with the Department’s District Offices which shall provide support activities and the Bureau of Chronic Diseases and Injury Prevention [now the Bureau of Health Promotion and Disease Prevention] which shall provide contract monitoring.
- All printed materials and materials for radio and television were subject to the written approval of the Department’s Press Office (Office of Communications).

The contract also stipulated that the statewide public awareness campaign should have as its objective increasing the number of organ donors designated on the Pennsylvania driver’s license and photo ID by a “minimum of 3 percent annually.” The increase was to be calculated based on the number of persons designating “Organ Donor” on their licenses and photo IDs as documented by PennDOT in their most recent statistical report prior to the date that the contractor is notified to proceed with the contract.

The work statement for both OPOs was identical and tasks assigned in both work statements were to be a comprehensive effort to provide a consistent message across the Commonwealth. All campaign tasks and reports were to be a joint effort and both were to submit identical reports and invoices.

Campaign Design and Start-Up. Although the contract period was intended to begin on July 1, 2003, the contract did not become effective until November 21, 2003, due to delays in obtaining state approvals of the contracts between the OPOs and the Department of Health. (At least some of the delay reportedly involved misunderstandings by the Department of General Services on the sole source nature of the contracts with the OPOs.)

On December 10, 2003, the Department of Health shared a “work statement” for the campaign with the Organ Donation Advisory Committee. At the same time, the OPOs also announced that they would be working with the firm of Toplin and

Associates, that they would soon meet to develop a more finite three-year plan, and that a presentation would be given at a future meeting of the Advisory Committee.

Research conducted by Toplin and Associates in early 2004 (done as the groundwork for building and testing the campaign) demonstrated that the “beliefs around organ and tissue donation are extremely personal and emotional, and are often surrounded by highly charged myths and concerns.” These beliefs and myths dealt with issues such as: the abruptness of making the “yes/no” decision on license application/renewal; the belief that a donor’s life will be sacrificed for a waiting recipient; the myth that religious beliefs prohibit it and an open casket will not be possible; issues involving money; fear of loss of control; and concerns about equity in the allocation process.

Using market research techniques, Toplin and Associates determined that persons’ beliefs regarding organ donation ranged along a continuum from those who were strongly committed to organ donation (the “Yeses”) to those who were strongly against committing themselves to organ donation (the “Nos”). The campaign would focus on those persons whom the subcontractor identified as the “Persuadables.” This group included persons who were open to the idea of organ donation, but had yet to register through their driver’s license, organ donation card, or living will. This group also included persons who were sitting on the fence and possibly in need of more information to help them make an informed decision.

As expressed by the contractor, Toplin and Associates: “We believe that people will feel more positively about organ designation if they feel an emotional connection with and compassion for recipients and their renewed lives.”³ The contractor, therefore, planned to generate a series of on-going publicity stories about donors, recipients and families, especially in low-donor target counties.

A “Preliminary Plan” by Toplin and Associates, dated January 12, 2004, assessed the goals, challenges and assumptions of the campaign, and outlined its major components. At the March 2004 meeting of the Organ Donation Advisory Committee, the President of Toplin and Associates set forth the goals of the campaign as follows:

- increase the overall percentage of organ donor designations across the state;
- increase the percentage in the counties that have been identified as having lower donation designation; and
- steadily increase the number of donor designations being made from quarter to quarter, each year.

³Individuals who are transplant recipients or family members of donors are able to provide valuable perspectives and insights on the personal realities of the impact of donation decisions. Such stories are available on the OPOs’ websites and on the “Donate Life-PA” website.

Based on their market research, Toplin and Associates promoted the use of a broad-based integrated campaign that casts a wide net over the entire market while at the same time targeting specific groups along the continuum, coaxing them through smaller decisions toward the final choice to become a designated donor.

According to a Toplin and Associates officer responsible for the contract's implementation, the contract "work statement" which had been available by late 2003, had not been presented to them until several months after the initial stages of the campaign were underway in 2004. Following formulation of their initial plans for the campaign, the subcontractor also attempted to incorporate components of the work statement and reconfigure a previously developed three-year project into a revised two-year campaign. As such, the work statement of the original contract was, according to a Toplin and Associates employee, perceived and used as a guideline and not as a contractual requirement.⁴

By the end of the summer 2004, it had been determined that "Ordinary People, Extraordinary Power" would serve as the theme for a "highly strategic and integrated advertising and public relations campaign" that would feature photos of real organ donors, stories about those donors and the impact of their decision on their families, as well as the changes that recipients and their respective families experience as a result of their transplants.

Although internal progress reports indicate that a number of initial work products were developed in the remaining months of the first contract year (i.e., July 1, 2003, through June 30, 2004), substantive progress on the campaign did not occur until the second contract year. The "Ordinary People, Extraordinary Power" campaign was launched on November 4, 2004, more than one year after the contract for the campaign was scheduled to begin.

The campaign's "kickoff" event (organized by the Department of Health) was held in the State Capitol Rotunda. Dignitaries, including the Lt. Governor, Health and Transportation Secretaries, and the Auditor General, joined legislators and members of the Organ Donation Advisory Committee to unveil the new statewide campaign. The campaign's theme "Ordinary People, Extraordinary Power", as one speaker noted, "reminds us about the importance of organ and tissue donation and the extraordinary power that people have to save lives."

Following the kickoff event in November 2004, campaign representatives (and two mobile billboards featuring an enlarged driver's license of a donor) traveled for several days across the state to promote the campaign. Stops were made at PennDOT's driver's license centers in Allegheny, Westmoreland, Erie, Berks,

⁴However, a document entitled *OTDA—Campaign Components Updated for FY 2004-2005*, dated July 15, 2004, does provide a campaign timeline with action steps that include many of the specific tasks and objectives outlined in the original work statement.

Luzerne and Philadelphia counties where events were held with local mayors and health commissioners. Donor families and recipients were also invited to attend and speak. The kickoff events were intended to focus media attention on the campaign's theme and the importance of organ donation.

Campaign Implementation.

Deliverables and Outputs. The multi-year “Ordinary People, Extraordinary Power” campaign involved use of multi-media resources and techniques and was multi-dimensional in concept. The entire campaign, ongoing through 2006, involved a combination of public relations, special events (such as promoting Donate Life Month in April), news releases, radio and television public service announcements, brochures (both English and Spanish versions), and posters. Also included in the campaign was the development of the website www.donatelife-pa.org as a gateway page. The campaign also featured a toll-free telephone number 1-877-DONORPA.

Based on quarterly and end-of-year reports that Toplin submitted to the OPOs and the Department of Health for project years 2004-2005 and 2005-2006, it is possible to describe and quantify campaign deliverables and outputs. These are arranged in six categories: (1) Creative/Collateral; (2) Media Buys; (3) Special Events; (4) Direct Marketing at Photo Licensing Centers; (5) Viral E-Mail; and (6) Strategic Alliances/Partnerships.

Creative/Collateral. This involved the development and finalization of specific products to be used during the campaign (replacing items used in the previous campaign) such as billboards, brochures, posters, computer toppers, radio spots, print advertisements and the launching of the web site www.donatelife-pa.org.

The first full project year, 2004-2005, included the development of many of the key promotional and advertising products that would be used throughout the campaign. These included:

- Billboards—six different billboard versions featuring Pennsylvanians who became organ donors. The billboards were later revised to reflect the new PA driver's license and a stronger organ donor message.
- Brochures—created three different versions for use by PennDOT, the OPOs, and a Spanish-language version.
- Poster—featuring three organ donors.
- Computer toppers (point-of-purchase that is visible at the decision-making moment) – distributed to driver's license centers.
- Radio spot—combined two 30-second ads that feature racial diversity to create a 60-second spot.
- Web site—launched www.donatelife-pa.org as a gateway page, including links to CORE, Gift of Life, PennDOT, National Donate Life campaign

and the ability to download a form to request a Donate Life license plate. The site features statistics by county and the location of driver's license centers.

The second project year (2005-2006) witnessed the updating and/or reprinting of many items produced the first year. Several new items were also created, for example, the donor reminder card posted on the web site, and the development of the faith-based brochure.

Media Buys. Different media types were used to carry the message. The availability of funding heavily influences the selection of media for advertising. For this reason, billboards and radio were used more extensively during the campaign than the more expensive use of television.

During 2004-2005, media buys focused mainly on the use of radio and billboards. Regarding radio, a two-week paid buy targeted to reach 35-64 year olds coincided with the campaign's launch (November 7 to 20, 2004) and another buy occurred during Donate Life Month (April 3 to 16) in the low-donor markets.

Billboard buys (generally for three-month exposures) were made during the Fall and Spring, and focused on counties identified as "low-donor" counties. In the Summer billboard buys were arranged near high-traffic entertainment venues such as stadiums and amusement parks in July and/or August. Examples included Philadelphia—sports arenas (July); Dauphin—Hershey Park (July and August); Pittsburgh—Idlewild/Storybook Land (July).

Media attention during the second project year (2005-2006) was more diverse and included the use of radio interviews and free public service announcements, TV coverage, billboard buys, newspaper feature articles, and even online reports.

Special Events. Special publicity was planned for the kick off of the campaign and the launching of the "Donate Life" license plate.

The "Campaign Kickoff" for "Ordinary People, Extraordinary Power" occurred on November 8, 2004. The event was held in the State Capitol Rotunda (organized by the Department of Health) and included: Lt. Gov. Catherine Baker Knoll, Health Secretary Dr. Calvin B. Johnson, Transportation Secretary Allen Biehler and Auditor General Robert Casey Jr. They joined legislators and the Organ Donation Advisory Committee to kick off the organ donation campaign and unveil organ donor materials with the goal of increasing the number of organ donors in Pennsylvania. For the next several days after this event, campaign representatives (and two mobile billboards) traveled to six other low-donor counties and held events at the driver's license centers with local mayors and health commissioners. Donor families and recipients were invited to attend and speak. Events took place in Allegheny,

Westmoreland, Erie, Berks, Luzerne and Philadelphia counties. The event also generated media interest and attention.

Direct Marketing at Photo Licensing Center. An initial concept of enlisting driving license center employees as ambassadors promoting organ donation, and generating a sense of competition among the centers was not wholly adopted. However, the Department of Health and the Department of Transportation agreed that informational materials can be displayed in the centers including “computer toppers”, specially designed to attract attention to the organ donor program, and an annual training program for center employees can be conducted.

During the 2004-2005 project year various campaign materials were developed specifically for use in driver licensing/photo licensing centers. These materials included:

- *P-O-P (Computer Toppers).* These were created and distributed twice to every driver’s license center in the state, along with directions on how to display the computer topper.
- *Brochures.* English and Spanish brochures, where appropriate, were distributed twice to every driver’s license center in the state. Directions were developed and included to enable centers to reorder materials as needed.
- *Posters.* These were distributed through two mailings. A frame was included in the second mailing for centers that needed a new one.

Also, the OPOs requested and received permission to increase training for all PIBH employees. It was conducted in April 2005 by representatives of GLDP and CORE.

Viral Email. Creating viral email campaigns calling upon the first person stories of local recipients who willingly share them with friends, families, and natural connections.

During the first project year, the subcontractor created viral e-mails calling upon the first person stories of donor families who participated in the campaign. Also, an e-mail promoting organ and tissue donation was customized and was sent to Workplace Partnership for Life participants through Akoya. This was part of the initiative carried out under the auspices of the Division of Health & Human Services. The e-mail was distributed to employees of approximately 2,000 Pennsylvania corporations, 75 percent of which are major employers.

Strategic Alliances/Partnerships. Creating strategic alliances and partnerships with “influencers” (especially religious/spiritual) who have regular access to campaign’s target populations and can, therefore, consistently reinforce the message.

An important component over both years of the campaign was the development of alliances and partnerships with organizations who are likely to exercise significant influence in the thinking of potential donors. Relationships were developed with the Saturn Corporation, with AAA, and with faith-based community groups. For example:

- Saturn displayed campaign materials at their booth, and volunteers from CORE and GDLP were present to speak to visitors, at the Pittsburgh, Harrisburg, Philadelphia and Lehigh Valley auto shows held at various times during 2005 and 2006.
- Campaign materials were displayed in all 21 Pennsylvania Saturn dealerships for National Donor Day in February. We requested that the poster, computer topper and brochures be continuously displayed in showrooms and that the Donate Life plate be promoted with the purchase of each new car.
- AAA – (Mideastern Region) distributed “Donate Life” license plate registration forms and campaign information at the Philadelphia Auto show in February 2005 and 2006.

Outreach to faith-based communities was facilitated through the creation of a ministry advisory group for the campaign, including clergy representatives from Episcopal Community Services, Hispanic Clergy of Philadelphia and Vicinity and the chair of Gift of Life’s clergy advisory board regarding faith-based community support and met with them numerous times to get input for outreach efforts. Toplin also met with the Salvation Army in western Pennsylvania to solicit their interest and support, and contacted other religious organizations in CORE’s region. A Ministry Outreach Toolkit was developed with background information, suggested sermons, newsletter articles, advertisements, brochures and other literature. The toolkit addresses how organ and tissue donation relates to stewardship and how faith-based communities can support donation. Toolkits were mailed to 25 clergy members throughout the state.

The 2006 Contract Amendment (Minority Awareness and Faith-Based Education). In 2006, a contract amendment for the Organ and Tissue Donor Awareness campaign was executed to support a minority outreach education and awareness program and a faith-based publication in an attempt to increase the number of organ and tissue donations within the minority and faith-based communities. Additional funds of \$125,000 from the Governor Robert P. Casey Memorial Organ and Tissue Donation Awareness Trust Fund were made available for this purpose. This outreach and education services program was coordinated by the OPOs in partnership with Toplin and Associates and with Brown Partners multicultural marketing firm (subcontractor to Toplin).

The contract amendment recognized that one of the challenges to increasing organ donation rates is to further engage minority populations in organ donation. The complex factors involved in organ donation decisions, including trust and distrust in the healthcare system, seem particularly relevant to minority populations. Past studies found that minority populations expressed less willingness to donate, become designated donors, and had lower consent rates overall.

A national study (Callender et al., 2002) involving community focus groups identified five main “points of reluctance” to organ donation in the African-American community that affect donation rates. These include the lack of community awareness of the need for transplantation, religious myths and misconceptions, a general distrust of the medical community (e.g., healthcare professionals will not do as much to save their lives if they are designated organ donors), fear of premature death, and racism. Together, these factors pose a significant challenge to communicating the organ donation message.

As a whole, some diseases (for example, of the kidneys, heart, and liver) that are best treated through transplantation are found more frequently among African-Americans and other minorities. For example, African-Americans are about three times more likely to suffer from end-stage renal disease than Caucasians. Thus, although it is possible for a candidate to match a donor from another racial or ethnic group, transplant success rates increase when organs are matched between members of the same ethnic background. Consequently, a lack of organs donated by multicultural populations can contribute to longer waiting periods for transplantation and potentially less successful transplant outcomes.

There is, therefore, a continued need to increase organ donation education and awareness efforts in minority communities. Although organ donation designation, by race, is not tracked on Pennsylvania driver’s license/identification card/registry records, it is generally believed that the sign-up rates for organ donation among African-American residents, especially in areas such as Philadelphia, Pittsburgh, Altoona, and Harrisburg, are below the statewide average.

Media campaign and grassroots efforts⁵ to education minority communities about organ donation and dispel associated myths are an important component of Pennsylvania’s current statewide campaign. Nationally, statistics indicate that progress is being made and that minority populations are now donating in proportions equal to or even greater than their proportion of the total population. (See Section G.) Although donations are increasing, educational and awareness

⁵At the national level, a large-scale effort termed National MOTTEP, is also addressing the organ donation issues of minority populations. Begun as an effort focused on organ donation by African Americans, the program has expanded to include Latino-Hispanic, Native Americans, and Asian-Pacific Islander populations. National MOTTEP uses media campaigns and grassroots efforts to disseminate a two-pronged message: preventing chronic diseases (particularly hypertension, renal failure, and diabetes) and increasing awareness of organ donation (with information provided on the options for registering as an organ donor).

deficiencies remain and key issues such as mistrust of the healthcare system require continued attention. Moreover, there is an increased need for transplants and, in particular, kidney transplants, in minority populations because of the higher incidence of end-stage renal disease among the members of these populations.

The contract amendment was approved in March 2006; consequently, most of the work on this phase of the awareness campaign occurred from March through June 2006 (plus a three-month extension through September 2006). The following narrative includes a brief description of the four contract tasks or objectives specified in the contract amendment⁶ plus information regarding activities undertaken.

- Build alliances with African-American community leaders to improve awareness about organ and tissue donation within African-American communities in Philadelphia, Pittsburgh, and Harrisburg.

During the contract period, Toplin created a ministry advisory group for the faith-based campaign, including clergy representatives from Episcopal Community Services, Hispanic Clergy of Philadelphia and Vicinity and the chair of Gift of Life's clergy advisory board regarding faith-based community support, and met with them numerous times to get input for outreach efforts.

In what is referred to as the Community Covenant Program (or the Covenant for Life Program), the African American community is targeted, including:

- Outreach to 12 African American organizations in Philadelphia and Pittsburgh via personal letters and phone calls about joining in a covenant program for organ and tissue donor awareness.
- Meetings were held with the Center for Minority Health at the University of Pittsburgh (CORE), the Urban League of Philadelphia (GLDP), Hamilton Health Center in Harrisburg (GLDP), and Alpha Kappa Alpha sorority, Omega Chapter-Philadelphia (GLDP).
- Alpha Kappa Alpha sorority hosted a half-hour interview/call-in program on WURD-AM with Gift of Life representatives.
- CORE had a second meeting with Dr. Steven Thomas, the Center for Minority Health, University of Pittsburgh, to discuss next steps between the two organizations.

⁶A review by the Department of General Services of a sole source documentation for the 2006 through 2009 period of this contract determined that the agreement should be administered as a grant rather than as a contract. This necessitated a three-month extension to prevent a lapse in contract services.

- Building organ and tissue donation awareness through a statewide bus campaign.

On August 15, approximately 40 African American organ donor recipients, families, and transplant candidates from across the state joined in the Barnstorming Bus Tour to raise awareness for organ and tissue donation among the African-American community. Beginning in Philadelphia, the bus tour traveled to Harrisburg and Altoona picking up participants, and culminated in Pittsburgh for the Eagles v. Steelers preseason NFL game.

- To supplement the existing organ and tissue donation campaign, develop one 60-second radio spot that addresses the lack of awareness of organ and tissue donation within the African-American community.

Radio buys ran on African American radio stations in Philadelphia, Harrisburg, and Pittsburgh. A total of 344 radio spots ran from August 1-14, surrounding minority donor awareness day and the barnstorming bus tour. An additional 336 spots were planned for October 17-30, prior to Donor Sabbath.

- Develop and distribute brochures that describe the religious views of 22 different religious denominations on organ donation and transplantation (printed in both English and Spanish).

Developed the ministry outreach toolkit with background information, suggested sermons, newsletter articles, advertisements, brochures (Spanish and English) and other literature. The toolkit addresses how organ and tissue donation relates to stewardship and how faith-based communities can support donation. Toolkits were mailed to 25 clergy members throughout the state.

Campaign Budget and Contract Costs. The total cost of the original contract for the three-year campaign (2003 through 2006) was budgeted at \$410,000 a year (\$205,000 to each OPO) for a total maximum of \$1,230,000. In a preliminary plan, Toplin and Associates assessed the goals, challenges and assumptions of the campaign, and outlined its major components. One of the challenges identified by the subcontractor related to what the firm perceived to be an inadequate budget for the campaign. Their plan stated as follows: “the Organ and Tissue Donor Awareness program’s \$410,000 annual budget is limited and does not give us adequate resources to concentrate on the entire Pennsylvania population.”⁷

⁷For purposes of comparison, the subcontractor cited the annual statewide public relations campaign budgets for state efforts to combat smoking and for Pennsylvania’s Children’s Health Insurance Program (CHIP). Nearly \$5 million was allocated to media contractors under the statewide contract for the tobacco use prevention and cessation advertising in FY 2005-06 (in addition to county-based service providers and numerous other awareness-related activities funded through the Tobacco Master Settlement Agreement). In addition, the Insurance Department budgeted \$2 million annually from federal funds for the purpose of contracting with media consultants for developing marketing campaigns and related outreach activities for CHIP.

Because the subcontractor considered the funding to be inadequate to concentrate on the entire population of the state, the firm recommended prioritizing targets by criteria (e.g. age, location) to maximize dollars for best results, rather than spending against all targets equally. According to the Toplin and Associates official most directly involved with the campaign, the budget adversely affected their ability to advertise in higher cost media such as television. Had additional funding been available during the campaign, TV buys would have been used to a greater extent.

The amount actually paid to Toplin and Associates, for the period during which the firm was subcontractor to the OPOs for the organ and tissue donor public awareness campaign, totaled \$1,611,300 (through September 30, 2006). The original contract amount of \$1,230,000 was supplemented by a contract amendment for the minority outreach campaign at a cost of \$250,000, and a three-month contract extension through September 30, 2006, at an additional cost of \$133,750. Payments to Toplin and Associates were provided from grants to the OPOs and funding for Project Make-A-Choice obtained through the Governor Robert P. Casey Memorial Organ and Tissue Donation Awareness Trust Fund.

A Toplin and Associates representative told LB&FC staff that Toplin provided a total of \$70,000 in additional services to the campaign for which it did not bill (“extra-value added”). LB&FC staff did not independently verify this calculation.

Campaign Performance Measures.

Attainment of Work Statement Objectives. An examination of various materials and reports pertinent to the “Ordinary People, Extraordinary Power” campaign indicates that many, but not all, of the work statement tasks and objectives were completed. Items not implemented include, for example, “develop point-of-purchase video spot (supermarkets, convenience stores)”; “create a 15-minute continuous loop video for placement in waiting areas of hospitals, doctor’s offices, government offices, photo-center”; “create a media “roundtable in each of the DOH’s six districts and an associated “chat room”; and “create a slide for use as a public service announcement at movie theaters.”

A spokesperson for Toplin and Associates explained that, when viewing the initial work statement, an evaluator must recognize that the work statement was used as a “flexible guideline,” subject to modification either through direction from or consultation with the OPOs and the Department of Health. Additionally, in some cases, certain tasks and activities were reportedly not undertaken for financial reasons.

Increase in the Number of Persons Who Designate “Organ Donor” on Their Driver’s License. One of the primary campaign objectives was to increase the

number of persons who designate “organ donor” on their driver’s license or ID card by a minimum of 3 percent annually. The work statement indicates that calculation of this percentage is to be based on the total increase in the number of persons on the state registry at the end of the annual contract period compared to the number of organ donors designated in the previous PennDOT statistical report prior to the date the contractor is notified to proceed with contract work. This objective applied to each year of the contract period.

Using PennDOT data on the number of donors on the state registry, we analyzed the extent to which this annual 3 percent objective was attained during the 2003-2006 contract period. As Table 1 shows, the campaign did not meet this objective in any of the contract years.

Table 1

**Annual Percentage Change in the Size of Pennsylvania’s
Organ and Tissue Donor Registry**

<u>As of Date</u>	<u>Total No. Of Donors</u>	<u>Percent Change Over Prior Year</u>
October 31, 1998	2,913,517 ^a	-- ^a
August 31, 1999.....	3,094,031	6.2%
May 22, 2000	3,233,003	4.5
May 29, 2001	3,425,335	5.9
June 4, 2002	3,605,128	5.2
June 2, 2003	3,707,763	2.8
June 1, 2004	3,793,596	2.3
June 1, 2005	3,858,606	1.7
June 6, 2006	3,944,247	2.2
March 1, 2007.....	4,006,425	--

^aData is not available from PennDOT on the number of donors on the state registry prior to October 31, 1998. Also, the months for which historical data are available are not consistent.

Source: Developed by LB&FC staff using information obtained from PennDOT.

The above table shows the nine year statewide total number of organ donor designees from 1998 through 2006, as well as the recent nine month period from June 1, 2006 through March 1, 2007. Although the total number of organ donors increases each year when compared with the prior year total, the percentage increase varies from year-to-year but has generally declined. The August 1999 organ donor total was 6.2 percent higher than the October 1998 total, dipping slightly to 4.5 percent between August 1999 and May 2000. Between 2000 and 2001, the increase was about 5.9 percent, declining to 5.2 percent by June 2002 and to 2.8 percent and 2.3 percent respectively in June 2003 and 2004. During the first year of the contract execution (7/1/2004-6/30/2005), the percentage increase declined to its lowest point at 1.7 percent, but then rebounded to 2.2 percent in its second and final contract year (6/1/06).

Another way to analyze the statistics is to calculate the percentage change in the difference between each year's new donors. As shown on Table 2, the decline in the number of new donors was precipitous through June of 2005, but actually became a positive percentage by June of 2006.

As of early January 2007, the total number of Pennsylvanians designating themselves as organ donors on their driver's licenses or photo identification cards passed the 4 million mark. Also, based on statistics as of March 1, 2007, it is possible that the annual number of new donors by June 1, 2007 may closely compare with the prior year's total new donors of 85,641. It appears, however, that achieving annual increases in new donors of 100,000 plus at this stage of the program, as occurred in 2002, and nearly 200,000 annually as occurred in 2000 and 2001, may be difficult to attain.

It is, however, still too soon to accurately gauge the impact of this campaign, especially when, until July 2006, the only opportunity drivers had to indicate organ donor designation was when renewing their licenses once every four years. Other factors that may have directly affected the extent to which expansion of the registry was achieved during this period were the previously discussed delay in contract implementation due to processing delays at the state level and a later-than-expected activation of the on-line registration feature on the state donor registry.

Table 2

Annual Change in the Number of Pennsylvanians Designating as an Organ and Tissue Donor on the PennDOT Registry

<u>As of Date</u>	<u>Number of New Donors</u>	<u>Percent Change Over Prior Year</u>
October 31, 1998	a	a
August 31, 1999	180,514	a
May 22, 2000	138,972	(23.0%)
May 29, 2001	192,332	38.4
June 4, 2002	179,793	(6.5)%
June 2, 2003	102,635	(42.9)
June 1, 2004	85,833	(16.4)
June 1, 2005	65,010	(24.3)
June 6, 2006	85,641	31.7
March 1, 2007	62,178 ^b	NA ^b

^aData is not available from PennDOT on the number of donors on the state registry prior to October 31, 1998.

^bData for nine months only.

Source: Developed by LB&FC staff using information obtained from PennDOT.

Related to this subject, the contractor noted as follows:

Looking at changes in numbers in the early stages of a media campaign, especially when drivers renew their licenses only once every four years, does not necessarily indicate the effectiveness of the campaign in terms of the number of messages that people hear and whether they begin to feel differently. We believe, however, that attitudes will change over time and behaviors will begin to shift with ongoing public relations efforts and support from the paid media campaign.

Organ Donor Designation in “Low-Donor Counties.” One task required by the work statement was to “identify three counties with low designation rates and develop three-year strategic marketing plan.” Documents indicate that at least several months after Toplin and Associates began to develop the campaign, the number of “low-donor” counties expanded from three to ten. The amended concept also involved having an equal number of counties (five each) in both the west (CORE’s area) and the east (Gift of Life area).

However, the identification of a “low-donor county” for the purpose of targeting the various awareness initiatives was not based strictly on the proportion of designated organ donors to driver’s licenses. In other words, the identification of “low donor” counties involved more than just selecting the ten counties with the overall lowest donor designation percentage rates. Rather, various factors including the existence of urban centers and presence of established media were also considered in order that increased campaign concentration might yield many more new donors. Targeted campaign attention in rural areas with low population would generally not be cost-effective.

The ten counties identified as “low-donor counties” based on the Organ Donor Registry maintained by PennDOT (and their statewide ranking as of June 2003) were as follows:⁸

- East: Berks (37), Dauphin (26), Lackawanna (42), Luzerne (61), Philadelphia (67)
- West: Allegheny (34), Butler (12), Erie (5), Fayette (66), Westmoreland (51)

As suggested by Toplin and Associates, two measures of behavioral change resulting from the awareness campaign are the raw numbers and percentage increase of organ donors statewide as well as the raw numbers and percentage increases for each of the targeted low-donor counties. These figures are shown on Table 3. As shown, the total number of designated organ donors statewide increased by 292,918 persons, or 7.9 percent, between June 2003 and January 2007. Five of the seven “low-donor” counties exceeded the statewide percentage increase during

⁸See Table 12 in part D of this section for the complete statewide rankings.

the period, with Luzerne County achieving the greatest increase at 14.4 percent versus the statewide average of 7.9 percent. The county showing the smallest gain was Allegheny at 4.7 percent.

Also, Table 4 provides data on the “low-donor” counties, comparing the number of donors, the percentage of donors to licensed drivers, and the statewide ranking of each of the ten counties based on the percent of donors to licensed drivers. The table presents data for June 2003 (just prior to the intended start of 2003-2006 awareness campaign) as compared with information as of January 11, 2007. The total number of designated organ donors for Pennsylvania as a whole and the relative percentage of total organ donors to total statewide licensed drivers are also presented for the two periods.

As shown on the table, the state total and every one of the ten counties increased between the two periods in terms of number of designated organ donors as well as in the percentage of donors to licensed drivers. However, the situation was mixed in the case of state ranking. Of the ten counties, only two (Dauphin and Lackawanna) improved their ranking: Dauphin—from 26 to 22; and Lackawanna from 42 to 36. Five counties (Butler, Erie, Fayette, Philadelphia, and Westmoreland) maintained the same rank, and four counties (Allegheny, Berks, Dauphin, and Luzerne) saw their statewide rank drop. Comparison of rank is, however, not as significant an indicator in that variation in population size among the counties can result in volatile changes in rank, particularly among counties with smaller populations.

Table 3

The Change in the Number of Designated Organ Donors in “Low-Donor” Counties Before and After the Statewide Campaign					
	“Low Donor” Counties	June 2003	January 2007	Increase	
		Designated Organ Donors	Designated Organ Donors	2007 Over 2003 Number	%
East	Berks	114,177	126,533	12,356	10.8%
	Dauphin.....	82,977	90,228	7,251	8.7
	Lackawanna....	60,926	67,504	6,578	10.8
	Luzerne	84,155	96,249	12,094	14.4
	Philadelphia.....	264,993	280,973	15,980	6.0
West	Allegheny	380,951	398,921	17,970	4.7
	Butler.....	61,563	67,073	5,510	9.0
	Erie.....	95,461	100,421	4,960	5.2
	Fayette	34,554	36,789	2,235	6.5
	Westmoreland.	106,500	114,237	7,737	7.3
	Statewide.....	3,707,763	4,000,681	292,918	7.9

Source: Developed by LB&FC staff using information obtained from Organ Donor Registry reports, PA Department of Transportation.

Table 4

**The Number of Designated Organ Donors in “Low-Donor” Counties
and Their Statewide Ranking Before and After the Statewide Campaign**

		June 2003			January 2007		
“Low Donor Counties		Designated Organ Donors	Percent of Donors to Total ^a	Rank	Designated Organ Donors	Percent of Donors to Total ^a	Rank
East	Berks	114,177	40.7%	37	126,533	42.5%	43
	Dauphin.....	82,977	43.0	26	90,228	45.6	22
	Lackawanna....	60,926	40.2	42	67,504	43.3	36
	Luzerne	84,155	36.0	61	96,249	38.7	62
	Philadelphia....	264,993	29.2	67	280,973	29.3	67
West	Allegheny	380,951	41.3%	34	398,921	45.5%	35
	Butler.....	61,563	44.7	12	67,073	47.3	12
	Erie.....	95,461	47.3	5	100,421	49.9	5
	Fayette	34,554	30.3	66	36,789	32.4	66
	Westmoreland.	<u>106,500</u>	38.6	51	<u>114,237</u>	41.0	51
	Statewide	3,707,763	41.2%		4,000,681	43.2%	

^a“Total” includes both licensed drivers and state I.D. card holders.

Source: Developed by LB&FC staff using information obtained from the PA Department of Transportation.

Number of Website Hits. Introduced on November 2004, in conjunction with the kickoff of the “Ordinary People, Extraordinary Power” campaign, www.donatelife-pa.org is the centralized public access website sponsored jointly by GLDP, CORE, and the Departments of Health and Transportation. The site announces the campaign themes and describes itself as a collaborative educational and outreach effort to encourage Pennsylvanians to say “yes” to organ and tissue donation. Additional information on the website is:

There are more than 6,500 Pennsylvanians awaiting lifesaving transplants. They need ordinary people, like us, to say “yes” to organ and tissue donation. We each have the power to make a difference.

Say “yes” to organ donor on your driver’s license or state identification card. And discuss your commitment with your family.

Clicking the “Enter Site” button displays a statewide map of Pennsylvania. Clicking anywhere on the map activates the cursor such that moving the cursor over any county automatically generates a small window which gives the percentage of the county’s drivers who “have already said “YES” to organ donation.”

A further click on any individual county provides a statistical breakdown of organ designation for that county (by age and gender), the location and hours of the PennDOT Photo License Centers in that county, and an indication of the county's organ designation rank. By clicking on a "sign up now" button, the visitor is taken to the "Online Organ Donor Designation Login" instructional page of PennDOT's Driver and Vehicle Services web site. An additional button on the statewide map page is available for persons wishing to order their PA Donate Life license plate.

Another measure of awareness, as suggested by the sub-contractor, is to track the number of hits on the Web Site www.donatelife-pa.org and the percentage, by county, of those hits that come from the ten counties targeted through radio, outdoor and PR efforts, including the kickoff event.

The subcontractor reported that, from November 3, 2004, (when the website was launched) to 6/27/05, there were a total of 9,173 visits to the website, of which 7,982 were unique visitors. Total visits to the county pages equaled 6,744, with six of the ten "low-donor counties" ranking in the top ten, but all ten counties ranking in the top 20.

From July 1, 2005 to June 30, 2006, there were a total of 14,677 visits to the website, of which 6,907 were unique visitors. During this period, 42 people completed the online reminder form, requesting notification when the online registry launches. Four of the ten counties ranked in the top ten in terms of number of visits. Table 5 presents information on website visits by low-donor county during the two periods reviewed.

Table 5

Number of Visits to Donate Life-PA Website by Residents of "Low-Donor Counties" (November 2004 through June 2006)		
<u>County</u>	<u>Website Hits/Rank 11/3/04 thru 6/27/05</u>	<u>Website Hits/Rank 7/1/05 thru 6/30/06</u>
Allegheny.....	285—(3)	633—(1)
Berks	157—(9)	298—(17)
Butler	110—(Tied for 15)	316—(14)
Dauphin	461—(1)	508—(3)
Erie	138—(12)	450—(5)
Fayette.....	105—(18)	227—(Tied for 37)
Lackawanna	110—(Tied for 15)	206—(52)
Luzerne.....	152—(10)	231—(34)
Philadelphia.....	269—(4)	475—(4)
Westmoreland	<u>372—(2)</u>	<u>290—(18)</u>
Total.....	2,159	3,634

Source: Developed by LB&FC staff from information provided by Organ Donation Awareness Campaign sub-contractor, Toplin and Associates.

Number of Toll-Free Telephone Line Contacts. Toplin and Associates data also provides information on the number of calls to the toll free number 1-877-DONORPA during the campaign period. Table 6 presents data on the number of calls to the toll free line for each month from July 2004 to June 2006. As shown, 415 calls were made during the first twelve month period compared with 361 for the second twelve months. This averages to 35 calls per month versus 30 calls per month. The sub-contractor points out that, prior to the kickoff of the campaign in November 2004, there was an average of 25 calls per month, but the average increased to 39 calls per month for the remaining eight months of the campaign's first year. The decline in the monthly average of calls in the second year of the campaign (especially when compared to the number of visits to the Web site), indicates that the toll free number is not the preferred method for obtaining information about becoming an organ donor.⁹

Table 6

Number of Calls to the Toll-Free Telephone Number
(July 2004 through June 2006)

<u>Month</u>	<u>2004-05</u>	<u>2005-06</u>
July	30	37
August.....	25	25
September	17	35
October	28	42
November	49	30
December	42	27
January	33	19
February	32	26
March.....	32	27
April.....	45	33
May	40	36
June	<u>42</u>	<u>24</u>
Total.....	415	361
Per Month Average.....	35	30

Source: Developed by the LB&FC staff using information obtained from the Organ Donation Awareness Campaign subcontractor, Toplin and Associates.

Industry Awards. While not all campaign objectives were met, the contractor, Toplin and Associates, received several industry awards for their work on the statewide organ and tissue donor awareness campaign. Specifically, Toplin received the following awards from the Public Relations Society of America, Philadelphia Chapter:

⁹As discussed later in this section, LB&FC staff attempted to call the hotline number in mid-April 2007 and early May 2007 and found that it was inoperable.

- Best of Show—2005 – The overall campaign was selected from all entries in the competition.
- First Place Awards—2005
 - *Institutional Program, 4 months or longer*: “Organ and Tissue Donor Awareness” (overall campaign)
 - *Special PR Program*: “Barnstorming Bus Tour for Minority Organ Donor Awareness” (in partnership with BrownPartners Multicultural Marketing)
- Meritorious Award—2005
 - *Special Events & Observances (Seven Days or Fewer)*: “Organ and Tissue Donor Awareness Kickoff Campaign”
- First Place Awards—2006
 - *Institutional Programs, 4 months or more*: Organ and Tissue Donor Awareness Campaign
 - *Single Piece Communications: Radio Public Service Announcement*: Organ and Tissue Donor Awareness Campaign PSAs-Radio
 - *Special Public Relations Program*: Clergy Outreach for Organ Tissue Donor Awareness
 - *Web Site Communications, Established Site*: “Ordinary People, Extraordinary Power” Web Site
- Meritorious Award—2006
 - *Community Relations: Clergy Outreach Toolkit for Organ and Tissue Donor Awareness*

The 2006-2009 Statewide Campaign: “Continuation of the Ordinary People, Extraordinary Power” Theme

The Request for Proposal. The OPOs and the Department of Health plan to continue the public awareness campaign theme “Ordinary People, Extraordinary Power” at least through the end of calendar year 2007. In July 2006, the OPOs issued a request for proposal (RFP) for a three-year (2006-2009) promotional campaign on organ and tissue donation. The Department of Health will award funding for the campaign to the OPOs in the form of annual grants.¹⁰ The agency selected will serve as the subgrantee, interacting directly with the OPOs.

¹⁰The Department of General Services has determined that the agreement between DOH and the OPOs should be administered as a grant rather than a contract.

The RFP involved two components designed to support and enhance this campaign: The first component involved supporting the continuation of the current promotional campaign “Ordinary People, Extraordinary Power.” The initial launch of the campaign was November 4, 2004. The next phase of the campaign will involve media, public relations, and advertising to continue the current campaign. The grant for this component of the campaign was to begin October 1, 2006, and continue through June 30, 2009. The RFP stated that, based on the previous six years, a minimum of \$468,125 should be available in year one of the grant and \$535,000 should be available for each of years two and three of the grant.

The second component of this RFP involved the development and execution of a campaign to promote the new on-line donor designation portal as well as the development of a campaign targeted specifically to minority communities in Pennsylvania. The on-line portal enables Pennsylvanians to go to a secure section of the PennDOT website to add the organ donor designation to their PennDOT record. The minority campaign will be targeted to increase awareness and support among African Americans and Hispanics. The RFP anticipated that this campaign will involve special events to launch this campaign, media and public relations, and web-based marketing. Funds available to support both the on-line portal as well as the targeted minority campaign are estimated to be \$440,000 and are contingent on the approval and availability of state funding. In summary, the RFP discussed the plan and development of three campaigns: (1) a plan to continue and enhance the existing campaign; (2) the development of a minority outreach campaign; and (3) the development of a campaign to promote the on-line portal. These campaigns are to be integrated as well as targeted.

The RFP Evaluation. Following the issuance of the Request for Proposal in July 2006, proposals and supporting documentation were submitted to CORE and Gift of Life for review and selection of finalists to deliver presentations in Harrisburg. Three finalists were selected. A committee composed of staff from Gift of Life, CORE, and the Department of Health evaluated the finalists based on various factors including previous experience with advocacy issues and statewide campaigns, their proposed ideas and tactics for the campaign, demonstrated ability to perform minority outreach, and the strength of their presentation. By October, Giant Ideas, a marketing and advertising firm headquartered in Pittsburgh, had been selected as the sub-contractor to the OPOs for the 2006-2009 public awareness campaign.

The Work Statement. The statement expresses the purpose of the statewide campaign as follows:

The purpose of the Statewide Organ and Tissue Donation Public Awareness Campaign is to reach Pennsylvania citizens with current and accurate information about the organ and tissue donation process

and the benefits of organ and tissue donation, and to encourage both the completion of a legal instrument (drivers license, donor card, living will) designating themselves as organ and tissue donors and the commitment to donate at the time of death.

The public awareness campaign is to use a combination of public relations, special events, news releases, radio and television public service announcements, brochures, and posters. Both English and Spanish versions of all education and information materials are to be created. To enhance public understanding throughout the Commonwealth, a unified theme and supporting messages are to be communicated. The public awareness campaign will provide statewide messages with specific emphasis to ten counties, five in each OPO service area, with the lowest donor designation rate based on PennDOT statistics.

The 2006-09 statewide public awareness campaign has as its objective to increase the number of organ donors designated on their Pennsylvania Drivers License by 277,000 new designations over the three-year grant agreement period. Calculation of this increase is to be based upon the number of persons designated "Organ Donor" on their licenses or state ID cards as documented by PennDOT in its most recent statistical report prior to the start of the grant. By June 30, 2009, the goal is have 46 percent of the state's registered drivers designated as organ donors.

However, as of March 2007, the grant for the 2006-2009 public awareness campaign had not received final approval due to processing delays at the state level. According to the Department of Health, this six-month delay was caused by the necessity to rewrite certain documents to reflect the change from a contractual agreement to a grant agreement between the Department and the OPOs.

We spoke with the president of the contractor (technically, the sub-grantee), Giant Ideas, in late March. He expressed confidence that grant approval was imminent, thus enabling his firm's involvement in the continuation of the "Ordinary People, Extraordinary Power" campaign, including the implementation of plans and strategies already developed to observe Donate Life Month in April. The president of the advertising/marketing firm noted, however, that although his firm has continued to work and prepare for the campaign launch, the delay in contract finalization has reduced the amount of time available to achieve the stated 2006-2009 campaign goal of adding 277,000 new organ donor designees by June 30, 2009.¹¹

¹¹At the Organ Donation Advisory Committee meeting on April 4, 2007, the Director of Community Relations for the Gift of Life Donor Program announced the involvement of Pennsylvania's OPOs in the nationwide Donor Designation Collaborative's goal of increasing the number of registered organ donors to over 100 million by April 2008. Towards this goal, Pennsylvania's OPOs will be working to register 500,000 new organ donors in Pennsylvania by April 2008, in an initiative named "The Pennsylvania 500." This goal is significantly more ambitious than the statewide campaign's target of 277,000 new designations by June 2009.

Public Education and Awareness Efforts at PennDOT Driver License Photo Centers

One aspect of the recent and continuing statewide public awareness campaign entitled “Ordinary People, Extraordinary Power” is the development of informational materials for display at the Driver License/Photo License Centers. These materials consist of a poster and poster frame, brochures in Spanish as well as English, and computer toppers. These items were sent to all Driver License Center supervisors by the consultant to the OPOs on the public awareness campaign with the following instructions:

Thank you for your support of the Organ and Tissue Donor Awareness effort sponsored by the Pennsylvania Department of Health, Pennsylvania Department of Transportation, the Center for Organ Recovery and Education and Gift of Life Donor Program. Your assistance in properly displaying the poster, computer topper and brochure (and keeping a supply of brochures in the display racks) will be a tremendous help in raising awareness and encouraging your customers to say “yes” to organ and tissue donation.

Additionally, the centers were given a visual depiction of how the materials were to be displayed and were also provided contacts for reordering the materials.

To determine if these materials are being consistently and uniformly displayed and made available to state residents who visit the center, LB&FC staff conducted a visual survey of a sample of 16 driver license centers in 11 counties. We found the following.

Posters

Three of the 16 centers we visited, including the main driver license photo center at PennDOT headquarters in Harrisburg, did not have a poster or posters on display promoting organ and tissue donation awareness. Of the 13 centers with posters, 11 displayed framed posters that were mounted on the interior wall of the center.¹² In two of the 11 centers with framed posters, this represented the only form of organ and tissue donation awareness materials available. The other two centers did not frame their posters, instead mounting them with tape on the wall at one center and on a window in the other. Both centers with unframed posters are messenger services that also function as photo license centers.

Despite the high number of driver license centers surveyed with posters on display, many were not conspicuously placed so as to maximize visibility to

¹²Materials sent to each driver license center by the Gift of Life Donor Program and CORE indicate that posters are to be framed. These materials report that poster frames have been sent to driver license centers if needed.

customers. In many centers, their placement was not prominent and immediately obvious to customers who congregate in the waiting areas. As a result, the posters may not be noticed by many customers and especially not before proceeding to the center attendant who will process their application.

Brochures

Brochures promoting the current statewide awareness campaign, “Ordinary People, Extraordinary Power” are to be displayed on wall racks at driver license centers.¹³ Overall, brochures were not readily available on a wall rack, table, or other publicly-accessible area in 6 of the 16 driver license centers visited. Three of the 16 driver license centers visited had no brochures available. This included the main driver license center at the Riverfront Office Center in Harrisburg.

In two other centers, brochures were not stocked on wall racks or in any other publicly-accessible area of the center, but were provided by a staff member upon request. At one of these centers, there appeared to be sufficient space on the wall rack for brochures to be stocked. At the other center, after providing a brochure upon request and being advised that there were no brochures in the wall racks, a staff member indicated that brochures would soon be placed in the racks.

At another center, a staff member indicated that the brochures they currently had at the center were outdated, and added that the center had not yet received updated brochures. The staff member then apologized for the unavailability of a brochure and provided the toll-free state hotline number (1-877-DONORPA) to obtain further information.¹⁴

In total, of the ten driver license centers with brochures readily available, only 5 centers placed brochures on wall racks within the center.¹⁵ We also found that 4 of the 5 centers with brochures available on wall racks had a large quantity of brochures available. Two of the 5 centers with brochures on wall racks also placed brochures on tables in other locations within the center.

Five other driver license centers visited had a large quantity of brochures available, but were placed only on tables within the photo center rather than on a wall rack. Two of these centers stacked brochures on a table with other brochures, and three others placed brochures on a table or counter near the area used to take driver license photos in a location not immediately evident.

¹³According to materials sent to each driver license center, both English and Spanish brochures (where appropriate) were distributed twice to every driver license center in Pennsylvania. Additional brochures, posters, and computer toppers may be reordered by driver license centers.

¹⁴We later found that this telephone number had been disconnected.

¹⁵At one center we found a number of organ and tissue donation awareness bumper stickers and brochures provided by the Gift of Life Donor Program. At most centers, we also heard staff asking driver license applicants to confirm their desire to be an organ donor when so indicated.

Brochures used in the campaign, “Ordinary People, Extraordinary Power” provide photos of three organ donors with the words “Ordinary People” above the photos. The photos are set against a black background and have a yellow border on the top and bottom of the brochure. We found that, in many cases, the brochures that are displayed on wall racks are not immediately recognizable as pertaining to organ and tissue donation upon casual scanning of the wall rack. This results from the layout and design of the brochure and the portions of the brochure that are visible when placed in the racks.

Computer Toppers

Driver license centers also are to display computer toppers on the top of computers used by individuals renewing their driver’s license (and making a decision on whether to register as an organ donor). We found that at least some photo licensing computers at 8 of 16 driver license centers visited did not have such toppers. Where present, the centers placed computer toppers on photo licensing computers, and one center also placed toppers on a number of computers used for driver licensing exams.

Donate Life/Pennsylvania Website and Telephone Hotline

Website

The Donate Life/Pennsylvania website, used in support of the statewide public awareness campaign, “Ordinary People, Extraordinary Power” (<http://www.donatelife-pa.org>), was launched in November 2004 to coincide with the commencement of the campaign. From July 1, 2005, to June 30, 2006, there were a total of 14,677 visits to the website, of which 6,907 were unique visitors.

Upon loading the website, the campaign title, “Ordinary People, Extraordinary Power” is printed above and below a group of 3 driver licenses bearing the “Organ Donor” designation. Also on the start page is the following description of the current statewide awareness campaign:

A collaborative educational and outreach effort to encourage Pennsylvanians to say "yes" to organ and tissue donation. Sponsored by Pennsylvania's Departments of Health and Transportation, the Center for Organ Recovery & Education (CORE), and Gift of Life Donor Program.

Logos and links to respective websites are included on the start page for CORE, the Gift of Life, the Department of Health, and PennDOT. Also included prominently on the start page is a large purple button with the text, “Sign Up Now!”, which provides a direct link to the PennDOT online organ donor designation

website. In addition, the “Donate Life” logo is included at the bottom of the start page.

Upon clicking a web link with the label “Enter Site,” users are taken to an interactive map of Pennsylvania. Included again on this page is a link to PennDOT’s online donor designation website, as well as links to the websites of CORE, GLDP, the Department of Health, PennDOT’s main website, the website of Donate Life America, and a link to a web page where individuals may purchase a Pennsylvania “Donate Life” license plate.

By rolling the cursor over a county on the interactive map of Pennsylvania, a dialog box appears containing summary information on the percentage of licensed driver and state identification cardholders who have become designated organ donors.

Upon clicking on a county on the interactive map, users are directed to a county-specific web page with a table presenting the percentage of male, female, and combined total percentage of designated organ donors divided into 7 age categories. A total average, by gender, is also provided for each county, along with the current percentage of designated organ donors statewide and the corresponding county ranking.

A dialog box located adjacent to the statistical table contains the location, hours of operation, and address for driver licensing exams and photo license services of all PennDOT photo license centers located within the county selected. Along the right column of interactive county map web page is a list of counties (with clickable links to county detail web pages) that may be sorted by the user alphabetically or by comparative statewide rank.

Organ donor families, friends, and recipients may also submit their personal stories via an e-mail link provided below the statistical table. The e-mail link forwards correspondence to the Director of Community Relations for the Gift of Life Donor Program.

Through an examination of the Donate Life/Pennsylvania website current as of mid-April, 2007, the following problems were identified:

- *Some statistics on the website are not accurate.* In reviewing a sample of county-specific web pages within the site, we noticed several mathematical and/or typographical errors in the county organ donor designation percentages.

On the website, Clinton County is currently ranked number 33 of 67 in the percentage of designated organ donors on the interactive map and in the county ranking sidebar menu. However, in the statistical summary

table for Clinton County, the total percentage of designated organ donors in the county is listed as 18.8 percent. This statistic would, if correct, rank Clinton County at number 67 in the number of designated organ donors. It appears that the source of the error may be that the “over 75” female and total percentage amounts are listed twice; once in the designated row and again in the “Total” row for the county.

A mathematical discrepancy was also noticed in the organ donor designation chart for Cumberland County. As shown in the statistical summary table for Cumberland County, the “Total Percentage” of “over 75” male and female designated organ donors (26.2 percent), is less than each of the respective male and female percentages (27.8 percent and 52.1 percent, respectively). This discrepancy may have caused the total percentage of designated organ donors in Cumberland County to be incorrect.

- *The web link to the organ donation license plate is inoperable.* As of mid-April 2007, the web link provided on the website to obtain a Pennsylvania “Donate Life” license plate was inoperable. The link appeared to be a broken connection to a page maintained on the Gift of Life’s website at which the application for a Donate Life license plate can be downloaded (administered through the Transplant Foundation).

In addition, while the link provided for the Department of Health forwards users to the Department’s website, the destination page is no longer active.

- *Personal stories on the website are not prominent.* Organ donor families, friends, and recipients may submit their personal stories via an e-mail link provided below statistical tables on county-specific web pages. As of mid-April 2007, personal stories were posted on 10 of 67, or approximately 15 percent, of the county-specific web pages.

When posted, the personal stories appear at the bottom left portion of the web page. The stories are not immediately visible upon loading the county web pages, requiring the user to scroll down to read the stories. Moreover, the text size of the personal stories is relatively small, and is not eye-catching.

We also found that while ten county web pages contain personal stories, only six unique stories are used, resulting in identical stories appearing on multiple county web pages.

Telephone Hotline

In mid-April 2007, LB&FC called the toll-free hotline and found it to be inoperable and apparently disconnected. However, the hotline number remains in informational brochures printed in support of the campaign.

In addition to the hotline, the Department of Health's Bureau of Health Promotion and Risk Reduction maintains an organ donation awareness web page within the Department's website that informs visitors of the option to call 1-877-PA-HEALTH (the Department's main hotline) for additional information or to obtain a free organ and tissue donor card to sign and carry.

LB&FC staff called the Department's main hotline in April 2007 after finding that the toll-free hotline for organ and tissue donation information (877-DONORPA) was disconnected. The automated menu that callers first hear when calling this number does not include an option for more information about organ and tissue donation. We then requested information on organ and tissue donation from an operator, who advised staff to call the (inoperable) toll-free hotline (877-DONORPA).

Other Education and Awareness Activities

Other GLDP and CORE Activities

In addition to their involvement with the statewide public awareness campaign and Project Make-A-Choice, GLDP and CORE also conduct education and awareness-related activities in their respective service areas (see part A of this Section for further information). Both GLDP and CORE utilize the service of volunteers for outreach. GLDP, for example, enlists more than 1,000 volunteers and 15 local coalitions in their outreach activities, and works with a Clergy Advisory Council, whose members provide education and support to the community and to other clergy members. GLDP has also organized and sponsored community events (e.g. fun runs/walks, conferences/workshops, and concerts) to promote public awareness.

Examples of similar efforts and activities promoted by CORE in the western portion of the state include the enlistment of more than 200 volunteers in "Volunteers for Life" which enables donor families and transplant recipients the opportunity to share their personal experiences with the public in a variety of programs such as health fairs and school/educational presentations. Another CORE initiative, Partnering for Life, is an outreach to corporate partners.

The two OPOs have also developed a variety of different brochures targeted to specific groups. One CORE brochure entitled "Become a Kidney Donor", provides information on choosing to make a living kidney donation. Another brochure done by the GLDP is targeted to the African American population and stresses the importance of donation considering that 35 percent of patients awaiting kidney transplants are African American. One brochure developed in connection with the recent public awareness campaign is entitled "A Faith-Based Decision: Religious Perspectives on Organ and Tissue Donation." In this brochure, specific information is presented on various religions including Judaism, Hinduism, and Islam, as well as a variety of Christian denominations. Another more general brochure states "You

have the power to donate life—Be an organ, eye and tissue donor.” In addition to providing important facts and information in an easy-to-read format, the brochure also provides a few brief personal stories and a “family notification card” to give to one’s family regarding his or her personal decision.

Donate Life America

Donate Life America (formerly the Coalition on Donation) is a not-for-profit alliance of national organizations and local coalitions across the U.S. dedicated to educating the public about organ and tissue donation and inspiring people to save and enhance lives through organ, eye and tissue donation. Founded in 1992, its mission includes assisting the transplant community in educating the public about organ, eye and tissue donation and avoiding duplication of effort. Donate Life America publishes brochures, program kits and other materials; provides technical assistance and referral services; coordinates the national campaign for organ, eye and tissue donation; identifies measurable best practices and leads the Donor Designation Collaborative.

While the reach of Donate Life America is national, the key to success is the involvement of local chapters to distribute and implement relevant messages locally. Local chapters also can provide information and referral services specific to their communities.

The Gift of Life Donor Program (GLDP) supports regional chapters of the Donate Life America. The chapters are an alliance of volunteers from hospitals and affiliated health organizations working with local transplant recipients, donor family members and transplant support groups to increase awareness of organ and tissue donation.

By visiting the Donate Life America website, one can click on the state and the county for any state. When clicking on any county in Pennsylvania, you will get a contact person at one of Pennsylvania’s two OPOs.

Recurring National Organ Donation Key Dates and Events

Nationally, there are a number of recurring annual key dates and events recognizing organ and tissue donors and the need for donation and transplantation. These are listed on Exhibit 7.

**Calendar of Recurring National Organ
Donation and Related Initiatives**

February (Valentine’s Day)	National Donor Day
April.....	National Donate Life Month
June (Even Numbered Years)....	U.S. Transplant Games ^a
July (Odd Numbered Years)	National Donor Recognition Ceremony and Workshop
August (1 st).....	National Minority Donor Awareness Day
November	National Marrow Awareness Month National Donor Sabbath ^b

^aTo be held in Pittsburgh PA in 2008.

^bTraditionally held two weekends prior to Thanksgiving.

Source: Presidential/federal proclamations, resolutions, and other declarations.

National Donor Day is a collaborative effort led by Saturn and the United AutoWorkers to make facilities available nationwide for individuals to make the pledge to be organ and marrow donors and to donate blood.

National Donate Life Month was established in 2003 to celebrate the generosity of those who have saved lives by becoming organ, tissue, marrow, and blood donors and to encourage more Americans to follow their example.

The U.S. Transplant Games, first held in Texas in 1982, is a four-day athletic competition for recipients of organ transplants. Competition in the games is open to anyone whose most recent lifesaving solid organ transplant—heart, liver, kidney, lung, pancreas and/or heterologous bone marrow—has been functioning for at least six months. One of the purposes of the games is to demonstrate the collective and individual successes of the life-restoring therapy of organ transplantation.

The tenth National Donor Recognition Ceremony and Workshop (NDRCW), sponsored by the Division of Transplantation, Health Resources and Services Administration, U.S. Department of Health & Human Services, will be held in the Nation’s capital on July 20-22, 2007. The event will also be assisted by the National Donor Family Council of the National Kidney Foundation. This biennial event, held in odd-numbered years, pays tribute to America’s organ, tissue and marrow donors.

National Minority Donor Awareness Day, each year on August 1, is designed to increase awareness of the need for more organ/tissue donors. The annual observance reaches out to minorities and focuses on the various fears and obstacles associated with donation. The campaign’s goal is to promote health living and disease prevention, as well as increase the number of people who sign donor cards, have discussions with their families about their wishes, and become donors.

National Marrow Awareness Month was established by the National Marrow Donor Program, which facilitates unrelated marrow and blood stem cell transplants for patients with life-threatening illnesses. During November the NMDP's nationwide network of transplant and donor centers spread the news that marrow and blood stem cell transplants save lives and issue the call for persons to become volunteer marrow or blood stem cell donors.

National Donor Sabbath, endorsed by the U.S. Department of Health and Human Resources, occurs annually in November, and is intended to raise public awareness about transplantation and the critical need for donated organs and tissues.

C. The Introduction of Organ and Tissue Donation Awareness Programs in the Commonwealth's Secondary Schools

Findings

- C-1. *The provision in Act 1994-102 that authorizes funding for the development of organ donation awareness programs for the state's secondary schools has resulted in a comprehensive and highly regarded Organ and Tissue Donation Awareness (OTDA) "Curriculum Framework" and "Classroom Toolkit." In addition to receiving several statewide awards, the products produced by the contractor, the Lancaster-Lebanon Intermediate Unit (IU-13), have been distributed and received recognition both nationally and internationally.*
- C-2. *Because OTDA instruction in Pennsylvania's secondary schools is not mandated in law, the OTDA "Curriculum Framework" and "Classroom Toolkit" have not yet received extensive use. While nearly \$1.0 million has been expended for the development and implementation of these concepts, less than 14 percent of all school districts have, to date, adopted it for use. IU-13 does not have records on the actual number of the state's secondary schools in which project materials have been (or are being) used and, for the schools in which they have been used, there are no reliable measures of its impact on students' understanding of and attitudes toward organ and tissue donation.*
- C-3. *As the designated contractor for implementation of the Pennsylvania Department of Education (PDE) responsibilities under Act 102, IU-13 has also administered a program of OTDA mini-grants to selected secondary schools and, in conjunction with PDE, conducted annual OTDA Institute for Educators conferences (attendance at which is mandatory for mini-grant recipients). The Institute for Educators began as a twice annual conference, but was reduced to once per year due to attendance not meeting initial expectations.*
- a. *A mini-grant funding program began in the 2000-01 school year to provide seed monies to encourage school districts to implement the OTDA Curriculum Framework and Toolkit. Through the current year, 26 high schools and one area vocational technical school have received grants.*
- b. *A key objective of awarding mini-grants is the achievement of project sustainability past the school year in which the mini-grant is awarded. Numerous mini-grant implementation schools (or "pilot" sites) have developed high-quality student projects related to organ and tissue donation, and many teachers have reported successful integration of OTDA education into curricula. IU-13 staff looks for evidence of project sustainability when considering mini-grant site applications, completes on-site visits of mini-grant implementation sites, and prepares final evaluation reports. However, no*

- reporting mechanism and/or fixed schedule of implementation site follow-up evaluations is in place to evaluate outcomes and determine if there is evidence of continued use of OTDA educational materials in the classroom.*
- C-4. *As has also been the case with the statewide education and awareness campaign, delays have occurred in the award of contracts to IU-13 for implementation of the OTDA Education Project. Specifically, contracts were not executed at or near the beginning of the fiscal year in the first four years of the Project (FY 1998-99 through FY 2001-02). These delays caused IU-13 to attempt to implement planned activities in a time frame much shorter than a full fiscal year, and resulted in \$108,302 in unexpended contract monies in the period FY 1998-99 through FY 2001-02. Further, in FY 2002-03, no contract was executed with IU-13 for Project implementation. While a single-year contract was again executed in FY 2006-07, PDE and IU-13 are developing a multi-year contract and work plan to ensure future continuity in Project implementation.*
- C-5. *During the course of our OTDAP evaluation, By The Numbers, a data analysis, program evaluation, and statistical research firm based in State College, issued an evaluation report on the OTDA Education Project for the period 2003-2006. Their evaluation found that the first of the OTDA Education Project's three key objectives, to develop educational tools needed by secondary school teachers to implement organ and tissue donation awareness evaluation in their classrooms, had been fully met. The report classified as "largely met" the objective of holding bi-annual OTDA Institutes for Education as a forum for knowledge building and networking among secondary school teachers. However, the objective of making Pennsylvania secondary schools aware of the existence and activities of the project was found to have been only "partially met." The evaluation report also contained five recommendations to enhance and strengthen the OTDA Education Project (see Exhibit 10).*
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Background on the OTDA Education Project

Act 1994-102 provides that, after payment of implementation and Advisory Committee costs, 25 percent of the total Trust Fund may be expended by the Department of Education for the implementation of organ donation awareness programs in the Commonwealth's secondary schools. Upon availability of funding, and in cooperation with the Department of Health and the state's OPOs, the Pennsylvania Department of Education is to establish a program that can be used for secondary education purposes, which is to include (1) information about state law relating to anatomical gifts, including how to become an organ donor; and (2) general information about organ transplantation in the United States.

Purpose and Objectives

Since the FY 1997-98 program year, PDE has contracted with the Lancaster-Lebanon Intermediate Unit (IU-13) to implement the organ and tissue donation awareness component of the program for the state's secondary schools. Known as the "OTDA Education Project," this effort is intended to aid in the implementation of organ and tissue donor awareness into high school curricula so that secondary students can make informed decisions about organ and tissue donation, particularly the choice of whether to be listed as an organ donor on their driver's license.

Project materials note, however, that the project is not targeted at increasing the number of secondary school students who choose to be listed as an organ donor on their driver's license, although that could be an outcome of the project. The Department of Education reportedly takes a position of neutrality on the issue, preferring to simply make the facts available to the students.

Consistent with the provisions of Act 102, the key objectives of the Project are to:

- provide information about OTDA education to secondary educators within the 501 Pennsylvania school districts;
- assist secondary educators in understanding the importance of including OTDA education across the curriculum;
- provide secondary educators with tools they can readily use to implement the OTDA Curriculum Framework; and
- provide both a concrete (hard copy) and web-based format so that teachers can choose the most comfortable and convenient access route to this information.

Contractor Selection and Project Development

Section 9 of Act 1994-102, providing for the initiation of a program for OTDA awareness in the state's secondary schools, became effective on March 1, 1995. By 1997, PDE curriculum developers had designed a baseline curriculum planning framework for secondary education, with the understanding that further research and development would be needed to implement the framework.

To accomplish this, PDE sought to contract with one of the state's 29 Intermediate Units (IUs) to provide educational services supporting organ and tissue donation awareness. In selecting a contractor, PDE first conducted an informal telephone inquiry to identify an intermediate unit with "knowledgeable professional resources." Subsequently, IU-13 was identified.

An e-mail survey was then sent to each of the state's intermediate units to determine if there were other intermediate units working on organ and tissue donation education and to determine the level of expertise in this area within the intermediate units. If an intermediate unit did not respond to the e-mail survey, a telephone call was made to the curriculum directors at the intermediate units.

Twenty-six of the 29 state intermediate units responded to the survey. PDE materials indicate that the survey identified IU-13 as the only intermediate unit with experience in the development of organ and tissue donation awareness curriculum, and implementation and personnel with expertise in this area capable of providing statewide services. PDE subsequently provided sole source justification for designating IU-13 as the contractor.

In April 1998, PDE contracted with IU-13¹ to implement the OTDA Education Project statewide. During FY 1997-98, IU-13 convened a school-based statewide planning group (consisting of OPO representatives, tissue bank representatives, community members, educators, and donor family members) to provide insight and input on the further development of the OTDA curriculum framework and to develop a three-year education workplan to implement OTDA in secondary schools throughout the state. This was followed by the establishment of focus groups of students ages 15-18 to gauge the knowledge, skills, and prevailing attitudes regarding organ and tissue donation.

The focus group results yielded a list of priority topics to be addressed as part of an organ and tissue donation curriculum; representing areas where gaps of knowledge and skills were greatest and where misconceptions were the most severe. Members of the Organ Donation Advisory Committee (ODAC) also met with project staff to discuss the background and history of the educational project, the law governing the project, and steps necessary to proceed with the project.

In FY 1998-99, project staff then began the development of an educational bibliography on organ and tissue donation and a comprehensive database of individuals, groups, and activities related to OTDA. An OTDA website was also launched as an extension of the IU-13 website in FY 1998-99.

IU-13 then contracted with By The Numbers, a data analysis, program evaluation, and statistical research firm based in State College, to survey secondary school teachers to gauge their knowledge, skills, and attitudes regarding organ and tissue donation. This information was used to create a curriculum framework, the first draft of which was completed in FY 1999-00 and "crosswalked" to Pennsylvania academic standards, and later an OTDA Classroom Toolkit. An OTDA Listserv, launched in FY 1999-00, was used to encourage conversation among educators using the OTDA Curriculum Framework. These resources were developed with the

¹IU-13 serves 22 school districts in Lancaster and Lebanon Counties as well as students in nonpublic schools.

assistance of the state Organ Donation Advisory Committee, an OTDA Curriculum Advisory Committee, the state's OPOs and tissue banks, and OTDA Project implementation pilot site schools.

Project Staffing

PDE Staffing. Since PDE initiated the OTDA Education Project in FY 1997-98, a project director² has overseen project implementation and a project coordinator³ has been charged with overseeing the day-to-day project operations. Several Department clerical support staff have assisted the project director and project coordinator as needed.

The current project director spends approximately 10-15 percent of obligated time on OTDA responsibilities, with periodic increases in obligated time required in periods surrounding contract renewal with IU-13. The project coordinator spends approximately 5 percent of obligated time on OTDA responsibilities, and has the main responsibility of overseeing communication with IU-13 on project-related matters as needed.

Both the current PDE project director and project coordinator are organizationally located in the Bureau of Teaching and Learning Support. The project director is in the Division of Early Childhood and Elementary Education, while the project coordinator is in the Division of Middle and Secondary Education.

PDE's Bureau of Budget and Fiscal Management prepares and submits the Department's request for an executive authorization of Trust Fund monies for the OTDA Education Project to the Office of the Budget. The Bureau receives guidance from DOH regarding the amount to be requested for the upcoming fiscal year, based upon the amount recommended by the Organ Donation Advisory Committee. For budget planning purposes related to PDE's multi-year contract with IU-13, PDE also budgets amounts for fiscal years following the budget year as recommended by the Advisory Committee.

Information related to the OTDA Education Project, including a link to the IU-13 OTDA Education Project website, is included in the Health, Safety, and Physical Education section of the Department's website. This content was added in February 2007.

IU-13 Staffing. The IU-13 OTDA Education Project Director devotes approximately 5 percent of obligated time to project-related responsibilities. The IU-13 OTDA Education Project Coordinator devotes nearly 100 percent of obligated

²Identified as the "PDE Contract Officer" in the Department's Intergovernmental Agreement for FY 2006-07 with IU-13.

³Identified as the "PDE Project Contact" in the Intergovernmental Agreement.

time to the project. Pending contract execution, the project coordinator plans to work on a full-time basis on OTDA activities beginning in FY 2007-08.

An additional IU-13 staff member previously devoted a large amount of obligated time to the OTDA Education Project, and several additional staff continue to provide clerical support services. Additional IU-13 staff members are occasionally added, as well as individuals' amount of obligated time on the project modified, as project demands require and available funding allows.

In addition, pursuant to a mandate in Act 102, PDE, in cooperation with IU-13, provides quarterly and annual OTDA Education Project reports to the Organ Donation Advisory Committee. These reports summarize staffing, activities completed, contract status, and other Project developments.⁴

Project Implementation

Among numerous other Project activities, PDE and IU-13 implementation of the secondary education awareness provision of Act 102 can be viewed in terms of three broad initiatives: (1) development and dissemination of an OTDA "Classroom Toolkit," *The Decision of a Lifetime, and an OTDA Curriculum Framework*; (2) administration of a program of OTDA mini-grants to selected secondary schools; and (3) the sponsorship of annual OTDA Institutes for Educators.

The OTDA Curriculum Framework and Classroom Toolkit

The development of the Curriculum Framework and Classroom Toolkit was intended to meet one of the key objectives of the OTDA Education Project: that is, to develop the educational tools needed by secondary school teachers to implement organ and tissue donation awareness education in their classrooms.

The Curriculum Framework. The purpose of the Organ and Tissue Donation Curriculum Framework is to aid the implementation of organ and tissue donation awareness into high school curricula throughout Pennsylvania so that secondary students can make informed decisions about organ and tissue donation. The OTDA Curriculum Framework provides an organizational structure around which instruction can be planned. The Framework is intended to assist educators in determining ways to incorporate a critical topic into existing curricula in a way that addresses the individual needs of their students and community. IU-13 OTDA Education Project staff developed a poster-size OTDA "Curriculum Framework Wheel" that

⁴Towards fulfillment of this mandate, the Lancaster-Lebanon Intermediate Unit (IU-13) updates PDE on activities completed on a quarterly basis, as per an executed contract. Annually, PDE completes an end-of-fiscal-year summary of activities completed and initiatives undertaken by IU-13 and PDE. This summary is then integrated into the Organ Donation Advisory Committee annual report to the General Assembly.

illustrates each of the content domains and corresponding topic indicators contained in the OTDA Classroom Toolkit.

Project materials define a Curriculum Framework as:

A group of related domains, each seen as an integral subsection of an overarching topic or area of study. As opposed to a curriculum, which is a group of courses for study, a framework is more easily understood as a rubric of skills and topics that can be taught in a variety of ways. Therefore, a curriculum framework is inherently more flexible and adaptable than a specific curriculum. (See Exhibit 8.)

Exhibit 8

IU-13 “Assumptions and Beliefs” Regarding the OTDA Curriculum Framework

- The curriculum framework has been designed to organize the knowledge and skills secondary students will need to make an informed decision related to organ and tissue donation. It does not presuppose a "correct" decision, but rather, focuses on helping learners understand the facts of organ and tissue donation, explore the complexity of the issue, and acquire the decision-making skills they will need for this critical life decision.
- The curriculum framework is learner-centered and based on current research. Information gleaned from student focus groups and teacher surveys has been instrumental in determining the structure and key components of this framework.
- The curriculum framework is a living document that will evolve with the research base and expand dramatically as more and more secondary teachers begin to work with this material.
- The curriculum framework is multidisciplinary in nature. While some academic disciplines may have a more obvious connection with the framework than others, it is our belief that the richness of this material lends itself to implementation across multiple academic disciplines.
- Alignment of the curriculum framework with Pennsylvania's K-12 Academic Standards will have significant impact on the implementation of this curriculum framework in Pennsylvania's secondary schools.

Source: IU-13.

The Classroom Toolkit. The Organ and Tissue Donation Awareness (OTDA) Classroom Toolkit is a 157-page⁵ educational resource for Pennsylvania's secondary teachers who want to implement the OTDA Curriculum Framework in their classroom. The Toolkit, which was initially approved by PDE and began to be distributed to Pennsylvania school districts in FY 2004-05,⁶ is available in hard copy, on a CD-ROM, and in an OTDA section of the IU-13 website that is down loadable. Additionally, accompanying documents promoting and describing the Toolkit include

⁵The 2007 updated version of the Toolkit totals 178 pages.

⁶Prior to completion of the Toolkit, OTDA Education Project update publications were issued in 2000 and 2002.

folders, note cards, envelopes, a brochure, and a student wall calendar published in the 2005-2006 school year.⁷

The Toolkit is organized into five “content domains.” Each domain is defined as “knowledge and skill clusters that contain multiple topics related to OTDA.” They include: Human Experience and Discovery; Biomedical Information; Issues and Considerations; Working With Community Resources; and Critical Thinking and Decision-Making. Each content domain includes several topic indicators, which provide teachers with sub-content within the larger domain.

Domains include real-life stories, general introductions to the domain, lesson plans, sample worksheets and quizzes that may be administered to students, and related articles and current research that may form the basis for classroom instruction. Lesson plans, a crosswalk to Pennsylvania academic standards, a glossary of terms, and relevant resources were developed with input and suggestions from the statewide pilot sites.

For each of the content domains, IU-13’s website provides the corresponding goal, topic indicators, and lesson plans and activities both contained in the Toolkit and added to the website as supplements. According to IU-13, the content and supplementary materials for the framework will continue to evolve as additional schools become involved with the project.

The Toolkit also provides a “General Resources” section which contains a general subject glossary, recommended reading list, video resources, related websites, sample letters that may be sent to parents or guardians both before and after classroom instruction using the Toolkit, and a letter that allows students to express their feelings and desires regarding organ and tissue donation to parents or guardians. Also included with the Toolkit is a “Curriculum Framework Wheel” wall poster that lists each of the content domains and corresponding topic indicators.

An updated version of the Toolkit was released in early 2007. Now totaling 178 pages, the new version of the Toolkit includes a “Quick Start Guide” to the Toolkit, additional “real life stories” of organ and tissue donation, additional examples of school implementation of the Toolkit (including mini-grant implementation sites), updates related to aligning the Toolkit with Pennsylvania’s academic standards, extended sections on living donation and minority donation, an update to the explanation on the operation of the organ transplant waiting list, updated information on GLDP and CORE, statistics from UNOS, and several updates to Toolkit content domains (including a technology lesson plan).

⁷In FY 2005-06, OTDA student wall calendars were distributed to approximately 50 PennDOT driver licensing centers in OPO-targeted regions. Each center was provided with limited supplies of calendars to offer to students 18 years of age and under who became licensed, regardless of organ donor designation status at the time of licensing.

Dissemination of OTDA Materials. According to IU-13, the Toolkit has been distributed to each of Pennsylvania's 501 school districts and to all charter schools, cyber schools, career and technical centers (CTCs), and area vocational-technical schools (AVTS) in Pennsylvania.⁸ Toolkits have not, however, been sent to parochial schools in Pennsylvania. IU-13 also has distributed the Toolkit to the federal Department of Health and Human Services and to 15 other national and international organizations with an involvement in organ and tissue donation, transplantation, and awareness.

According to IU-13, the production cost per Toolkit of the original Toolkit was \$28.92; consisting of the production costs of one hard copy of the Toolkit, a companion CD-ROM of the entire Toolkit for electronic use, and a classroom-size multicolor OTDA curriculum framework poster. Approximately 1,500 hard copies of the Toolkit were produced at this cost, totaling \$43,380. In addition, approximately 250 extra CD-ROM versions of the original Toolkit were produced for distribution upon request.

IU-13 indicated that it is difficult to calculate a distribution cost per Toolkit. IU-13 initiated several actions to minimize the distribution costs of the Toolkit, including mailing large numbers of the Toolkit to other IUs for ultimate delivery to school districts, limiting direct mailing of the Toolkit to individual schools or districts, distributing the Toolkit at conferences and seminars, and making an electronic version of the Toolkit available for download from the IU-13 OTDA Education Project website or via e-mail. The OTDA Education Project Listserv was used to announce the availability of the electronic version of the Toolkit.

The 2007 updated version of the Toolkit was produced at a cost of \$3.13 per Toolkit, which includes a CD-ROM with the entire expanded content and a "Quick Start Guide" to the Toolkit that is included as a 3.5-inch sticker with the CD-ROM. The Quick Start Guide provides general guidance on the content of the Toolkit, strategies for use of part or all of the Toolkit, advice on how to begin use of the Toolkit, an announcement of the OTDA Institute for Educators conference, and contact information for the IU-13 OTDA Education Project Coordinator.

The total cost of the development of the Quick Start Guide stickers, design and layout updates to the Toolkit, and reproduction of 1,000 CD-ROMs of the Toolkit was \$3,116.75. All updates were completed in FY 2006-07. The updated Toolkit is also available for download from the IU-13 OTDA Education Project website. The updated Toolkit is not currently available for distribution in hard copy.

At the secondary school level, the primary method of dissemination of the Toolkit has been through school district curriculum coordinators. Upon receipt

⁸FY 2006-07 is described as an "intensive outreach year" to the Pennsylvania's area vocational-technical schools. In this effort, the IU-13 project coordinator has worked with the PDE AVTS coordinator.

of the Toolkit by the curriculum coordinators, the IU-13 project coordinator and PDE project staff conduct follow-up communication, strongly encouraging curriculum coordinators to place the subject of the Toolkit on the agenda of upcoming school district curriculum committee meetings. For additional outreach and advocacy, the IU-13 project coordinator also works with the Pennsylvania PTA. As of March 2007, IU-13 project staff has attended 20 curriculum coordinator meetings conducted by intermediate units, covering 18 of Pennsylvania's 29 intermediate units as well as a presentation for the Pennsylvania Association of Intermediate Units (PAIU).

The state's intermediate units also maintain an OTDA Curriculum Advisory Committee, independent from the state Organ Donation Advisory Committee and school district curriculum committees, to coordinate the curriculum outreach goals of the state's intermediate units. The Committee consists of 15 members, including OPO representatives, administrative and support education employees, public health educators, education administrators, tissue bank representatives, teachers, and donor family members. According to IU-13 project staff, this Committee serves as the "boots on the ground" in promoting OTDA. Examples of activity include outreach at health fairs, presenting exhibits at conferences, and establishing contacts with students in which the Committee engages in follow-up communication.

While IU-13 does not track actual usage of the Toolkit in the state's secondary schools, a list is maintained of school districts and schools that "have had significant interactions" with IU-13 project staff, including those that have been pilot schools, have had representatives attend one or more OTDA Institute for Educators conferences, or have, in some way, indicated to IU-13 that they are implementing or intend to implement OTDA materials in some manner.

Exhibit 9 provides a list of school districts that met at least one of these criteria as of March 2007. As shown, 82 school districts met the criteria, exhibiting some degree of involvement in the OTDA Education Project, equaling approximately 16 percent of Pennsylvania's 501 school districts. In both the Philadelphia School District and the Pittsburgh City School District, more than one high school within each district provided evidence of some involvement in the OTDA Education Project.

Secondary School Use of OTDA Materials: An Option or Mandate. Although Act 102 provides for secondary education awareness, state law does not mandate the inclusion of organ donation education in the school curriculum.⁹ PDE officials acknowledge that the lack of mandatory implementation is a barrier to achieving greater awareness about organ and tissue donation in Pennsylvania

⁹Organ donation awareness and education is mandated in some states.

Exhibit 9

**Pennsylvania School Districts With
Some Involvement in the OTDA Education Project**

School Districts^a

Ambridge Area	Greenville Area	Pine Grove
Apollo-Ridge	Hampton Township	Pittsburgh City ^b
Athens Area	Harrisburg	Pleasant Valley
Bellwood Antis	Hatboro-Horsham	Pocono Mountain
Bethel Park	Hempfield	Quaker Valley
Butler Area	Indiana Area	Reading
Cambria Heights	Jamestown	Ridley
Canton Public Schools	Keystone	Riverview
Carlynton	Kiski Area	Sayre Area
Central Cambria	Lakeview	School District of Lancaster
Central Fulton	Lampeter Strasburg	Schuylkill Haven
Chartiers Valley	Lebanon	Shenandoah Valley
Claysburg-Kimmel	Leechburg Area	South Side Area
Columbia	Ligonier Valley	Springfield
Conrad Weiser	Loyalsock	State College
Cornell	Marple Newton	Susquehanna Township
Deer Lakes	Mechanicsburg	Tri-Valley
Derry Area	Mercer Area	Troy Area
Derry Township	Mid Valley	Twin Valley
Dunmore	Minersville Area	Tyrone Area
East Lycoming	Moshannon Valley	Wallingford-Swarthmore
Eastern Lancaster County	North Allegheny	Warwick
Eastern Lycoming	Northeastern York	Westmont Hilltop
Erie City	Northwestern	Williamsport Area
Fort LeBoeuf	Parkland	Woodland Hills
Garnet Valley	Penn Cambria	William Penn
Greater Johnstown	Peters Township	
Greensburg-Salem	Philadelphia ^c	

^aIU-13 does not have records on the actual number of secondary schools in which the Toolkit is being used. Rather, the school districts listed are those that IU-13 reports “have had significant interactions” with IU-13 project staff, including those that have been pilot schools, have had representatives attend one or more OTDA Institute for Educators conferences, or have, in some way, indicated to IU-13 that they are implementing or intend to implement OTDA materials in some manner.

^bIn the Pittsburgh City School District, three high schools showed evidence of some involvement in the OTDA Education Project (Alderdice High School, Peabody High School, and Schenley High School).

^cIn the Philadelphia School District, five high schools showed evidence of some involvement in the OTDA Education Project (Philadelphia High School for Creative and Performing Arts, Furness High School, Overbrook High School, Edison High School for Science and Engineering, and Carver High School).

Source: Developed by LB&FC staff using information obtained from the Lancaster-Lebanon Intermediate Unit (IU-13).

schools. The Department, however, takes a position of neutrality regarding potential statutory changes that would mandate implementation, mainly due to the Toolkit's usage as a curriculum framework, as opposed to a prescribed curriculum that is narrowly-tailored for direct implementation in a specific academic content area or areas.

Use of the Toolkit as a curriculum framework, according to PDE officials, provides school districts with the option of integrating OTDA education into existing courses and curricula as needed, and may, therefore, promote the interdisciplinary use of the Toolkit. PDE project staff indicated that the Department's main responsibility under Act 1994-102 is to "lay the facts on the table" regarding the nature of organ and tissue donation in the United States in general and the means and methods of organ and tissue donation in Pennsylvania specifically. PDE staff state that a "value neutral" approach is used in which awareness, not advocacy, is the objective.

According to both PDE and IU-13 project staff, many secondary schools have implemented the OTDA Toolkit in a multi-disciplinary manner. Classes which commonly utilize the curriculum framework contained in the Toolkit include driver's education, health and physical education, science (chemistry, biology), bioethics, philosophy, business, and language courses (including journalism and broadcasting).

While IU-13 Education Project staff informed the LB&FC that they "defer to the Pennsylvania Department of Education on whether the education component of Act 102 should be mandated for implementation in Pennsylvania's secondary schools," they also provided the following comment regarding the merits of mandatory implementation versus the current use of the Toolkit and Curriculum framework as an optional, multidisciplinary tool:

There are certainly pros and cons to both approaches. While a mandate might ensure that all students would have exposure to this material at some point in their secondary career, it would not necessarily offer the same depth and breadth of exposure as a multidisciplinary approach.

OTDA Mini-Grants

Purpose and the Application/Award Process. To help encourage implementation of the OTDA Curriculum Framework and Classroom Toolkit, IU-13 developed a mini-grant funding program beginning in the 2000-01 school year. This program was established to provide seed monies to Pennsylvania school districts willing to implement the OTDA curriculum framework in one or more 10th, 11th, and/or 12th grade classrooms. Eligibility is open to all schools in the state's 501 districts.

The PDE project director oversees the award of mini-grants ranging in amounts from \$1,500 to \$5,000 per school, subject to availability of funds. To apply for a mini-grant, a school must submit an application to IU-13. Applications must include both a project narrative and budget sheet.

The Project Narrative is to consist of the following:

- A description of the applicant’s willingness to participate fully in all project activities and the commitment of key staff.
- A complete description of how the OTDA Curriculum Framework will be implemented locally; including which school(s) will be involved in implementation, which classroom(s) will pilot the OTDA Curriculum Framework, and the responsibilities of key staff during implementation.
- A description of how the OTDA Curriculum Framework will be integrated into existing academic content and used to support the PA Academic Standards.
- A statement of plans for sustainability; including how the school district plans to work to ensure that the curriculum framework continues to be implemented beyond the project year.
- A statement of how many students will be directly involved in classroom activities and school-based events related to the OTDA Education Project.

The budget sheet includes an itemization of funds requested by cost type including personnel, travel, supplies, communications, equipment, contracted services, and other costs. For each cost item, applicants may specify an in-kind matching dollar amount. IU-13 does not reimburse schools for the cost of substitute teachers, nor may attendees receive mileage reimbursement from IU-13 for attendance at an OTDA Institute for Educators conference (a condition of receipt of mini-grant awards). However, applicant schools are permitted to include substitute and mileage expenses in proposed budgets. Applications in which the total grant funds requested exceed \$5,000 or in which the total equipment budget exceeds \$1,500 or 40 percent of the total budget (whichever is less) are judged ineligible.

The projects are funded for one fiscal year, but are designed to maximize long-term sustainability (a prime factor sought during evaluation of the merits of applicants) over more than one project year, and it is hoped that the teachers possibly develop new curricula based on Toolkit implementation. As such, non-direct purchases (such as some proposed technology upgrades) are now receiving a lower priority among the evaluators.

To be eligible for selection as a mini-grant recipient, an applicant must participate in an on-site visit by project staff, submit project implementation progress

reports and a final evaluation report, participate in the two-day Institute for Educators, and subscribe to the OTDA Listserv.

A “Scoring Rubric” is used to rate mini-grant applications and determine award recipients. Raters for FY 2005-06 included representatives from PDE, IU-13, the Gift of Life Donor Program, and CORE. The PDE OTDA Education Project director and coordinator make the final award decisions based on the ratings. In the FY 2006-07 program year, six selection criteria were used, with a corresponding maximum number of points (of a total of 100 possible points) that may be awarded during the evaluation of each applicant.

School districts may reapply for mini-grant monies in consecutive years. According to PDE and IU-13, while priority has been given to first-time applicants, “new or significantly expanded applications from previously funded programs” are also considered.

Examples of use of mini-grant monies are t-shirts with the OTDA logo, school orientation gifts, trivia games with prizes, OTDA awareness videos and skits, hosting guest speakers, conducting field trips, and production of a school TV show on OTDA. Occasionally, schools utilize the services of the state’s OPOs for information, resources, and guest speakers, as well as conducting field trip visits to the OPOs’ facilities. Mini-grant pilot schools also often post questions and answers and share project activities with other schools through the OTDA Education Project Listserv. The IU-13 project director indicated that a potential future initiative is to focus the mini-grants to a specific-subject area of need.

Some schools have chosen to implement the OTDA curriculum into multiple academic disciplines, while others have chosen single content areas. Such integration, according to some teachers from school districts who implemented portions of the OTDA Classroom Toolkit into their curriculum, will continue in academic years following receipt of mini-grant funds. According to one teacher quoted in the Toolkit, the OTDA education framework “became a living document and allowed multiple methods of application into the curriculum.” As a result, according to the teacher, “This will help ensure the continuation of the framework in future years as compared to an ‘add on,’ which is done at the expense of the required curriculum and usually only lasts one time.”

Another teacher commented that, through integrating the OTDA curriculum framework into the existing curriculum, “it eliminates the question, ‘When will I ever use this?’ and makes learning easier for the students because it is directly applicable to something they feel is meaningful.”

Table 7 provides amounts received by OTDA Education Project mini-grant award recipients for fiscal years 2005-06 and 2006-07. Award recipients in

FY 2005-06 were funded entirely through IU-13 contract monies. In FY 2006-07, the Gift of Life Donor Program (GLDP) and the Center for Organ Recovery and Education (CORE) each contributed \$2,500 (a combined total of \$5,000 in additional funding) for the purpose of funding additional mini-grant implementation sites and supplementing awards to sites also receiving an award from IU-13.

Table 7

OTDA Mini-Grant Recipient Schools

FY 2005-06 Program Year:

<u>School/School District</u>	<u>Amount Awarded</u>
Dunmore HS/Dunmore SD	\$ 5,000
Edison/Fareira HS/Philadelphia SD	5,000
Hampton HS/Hampton Township SD	4,027
Ridley HS/Ridley SD	3,825
Shenandoah Valley HS/Shenandoah Valley SD	3,432
Cambria Heights HS/Cambria Heights SD	<u>3,060</u>
Total	\$24,344

FY 2006-07 Program Year:

<u>School/School District</u>	<u>Amount Awarded</u>
Carlynton HS/Carlynton SD	\$ 4,862
Furness HS/Philadelphia SD	3,769
Tri-Valley HS/Tri-Valley SD	2,738
Pleasant Valley HS/Pleasant Valley SD	2,000 ^a
Ambridge Area HS/Ambridge Area SD.....	1,875 ^a
Crawford County AVTS	<u>1,758^b</u>
Total	\$17,002 ^{c, d}

^aMini-grant implementation sites funded entirely by monies from Pennsylvania's organ procurement organizations, the Gift of Life Donor Program (GLDP) and the Center for Organ Recovery and Education (CORE).

^bMini-grant funding awarded to the Crawford County Area Vocational-Technical School (AVTS) was comprised of \$631 in funding through the OTDA Education Project mini-grant program and \$1,127 in funding from the state's OPOs.

^cTotal funding is comprised of \$12,002 in funding from PDE/IU-13 and \$5,000 in funding from the state's OPOs.

^dCentral Cambria High School was awarded a mini-grant in the amount of \$5,000 for FY 2006-07, but subsequently withdrew their application due to staffing changes.

Source: Lancaster-Lebanon IU-13.

In the FY 2005-06 program year, PDE and IU-13 awarded six mini-grants to Pennsylvania high schools, totaling \$24,344. In the FY 2006-07 Program Year, six mini-grants were awarded, totaling \$17,002. Through FY 2006-07, 26 Pennsylvania

high schools and one Area Vocational-Technical School (AVTS) have served as OTDA Education Project pilot school implementation sites.

OTDA Institute for Educators

The first “OTDA Institute for Educators” was held in the fall of 2004. At that time, the institutes were convened twice annually. Because attendance did not meet expectations, IU-13 and PDE now jointly coordinate a single two-day conference.

The Institute is a professional development, networking, and educational conference in which knowledge and best practices related to organ and tissue donation awareness education are shared. Attendees also receive materials that may further aid their OTDA instruction.

Attendees include mini-grant recipient school districts, educators from school districts both who have implemented some aspect of the Toolkit and those with an interest in receiving mini-grant funds for OTDA implementation, high school and college students presenting OTDA projects or with an interest in OTDA awareness and/or education, representatives from the state’s OPOs, and other key figures in organ and tissue donation awareness and transplantation. Institute attendance is mandatory for mini-grant recipient sites.

“Datesavers” and Institute applications are sent to all Pennsylvania school districts, and participants are selected based on their involvement with the OTDA Toolkit and Curriculum Framework. Meals provided at the conference and lodging expenses have been provided to attendees at each Institute for Educators. As indicated previously, while IU-13 does not reimburse schools for the cost of substitute teachers or mileage, applicant schools are permitted to include these expenses in proposed budgets submitted with their mini-grant implementation site application.

In 2006-07, IU-13 budgeted \$15,500 in support of the OTDA Spring Institute for Educators.

Project Contracts and Costs

PDE awarded IU-13 one-year contracts in fiscal years 1997-98 through 2001-02. No contract was awarded to IU-13 in FY 2002-03. To promote project continuity, PDE awarded IU-13 a three-year contract for fiscal years 2003-04, 2004-05, and 2005-06. While a one-year contract was executed with IU-13 for FY 2006-07, a multi-year contract is again planned for fiscal years 2007-08, 2008-09, and 2009-10. PDE’s Bureau of Teaching and Learning Support provides supportive activities and contract monitoring.

Table 8 provides amounts authorized for expenditure on the OTDA Education Project from FY 1998-99 through FY 2005-06.

Table 8

**OTDA Education Project Amounts Authorized for Expenditure
From the Donation Awareness Trust Fund**

<u>Fiscal Year</u>	<u>Amount Authorized</u>
1997-98	\$ 20,792
1998-99	150,000
1999-00	114,198
2000-01	102,000
2001-02	117,000
2002-03	0
2003-04	150,000
2004-05	150,000
2005-06	<u>150,000</u>
Total.....	\$943,990

Source: Developed by LB&FC staff using information obtained from the PA Department of Health.

Table 9 shows dates of contract execution with IU-13, amounts budgeted, total expenditures, and unexpended monies for each contract year to date. Due to contracts with PDE not being executed prior to or near the beginning of a fiscal year, IU-13 was unable to expend the entire authorized contract funding during the first four contract periods. Cumulatively, this equaled \$108,302 in unexpended contract monies since FY 1998-99.

In FY 2005-06 (the final year of a three-year contract), IU-13's project expenditures exceeded the funding provided in the contract, resulting in IU-13 contributing staff time to OTDA Project duties at a cost of approximately \$19,969 in salaries and benefits.

In FY 2002-03, IU-13 received no funding for implementation of the OTDA Education Project. In the opinion of the IU-13 project director, the program lost at least some credibility with the schools who had hoped to secure mini-grant monies during that year. Subsequently, a three-year contract was executed for fiscal years 2003-04, 2004-05, and 2005-06.

Table 9

IU-13 Contract Information Since Program Inception

<u>Contract Period</u> ^a	<u>Date of Contract Execution</u>	<u>Contract Budgeted Amount</u>	<u>Actual Expenditures</u>	<u>Unexpended Contract Monies</u>
1998-99.....	April 14, 1999	\$150,000	\$111,802	\$38,198
1999-00.....	October 1999	114,000	93,812	20,118
2000-01.....	October 5, 2000	102,000	71,161	30,839
2001-02.....	July 30, 2001	117,000	97,853	19,147
2002-03.....		No Contract Executed		
2003-06 ^b	September 30, 2003	450,000	450,000	0
2006-07.....	October 18, 2006	150,000	--	--

^aRecords provided by PDE indicate \$20,792 was authorized for expenditure through contract with IU-13 in FY 1997-98.

^bRepresents a three-year contract.

Source: Developed by LB&FC staff using information obtained from the Lancaster-Lebanon Intermediate Unit (IU-13).

As shown in Table 9, many of the contracts between PDE and IU-13 were not executed at or near the beginning of the fiscal year. For example, in FY 1998-99, the contract with IU-13 was not executed until April 1999, resulting in \$38,198 in unexpended contract monies. The date closest to the beginning of a fiscal year in which a contract was executed was FY 2001-02, in which the contract was executed on July 30 of the fiscal year.

In 2003, both PDE and IU-13 agreed that the greatest deficiency in the program was the lack of timeliness in executing the actual contract on a yearly basis. To that point, no contract had been executed prior to the beginning of the new fiscal year, resulting in a need to complete 12 months of work into a much shorter time period. Upon identifying this deficiency, PDE and IU-13 made the decision to move from a single-year contract to a multi-year contract. PDE and IU-13 then began working on a multi-year contract and a multi-year work plan in order to develop a strong foundation for the program.¹⁰

For FY 2006-07, which is a single year contract, IU-13 received an expenditure authorization of \$150,000.¹¹ Table 10 provides a breakdown of estimated project costs from the FY 2006-07 intergovernmental agreement between PDE and IU-13. Neither PDE nor IU-13 has received any direct General Fund monies for activities related to the OTDA Education Project.

¹⁰According to IU-13 project staff, during periods in which IU-13 was waiting for execution of their contract, project staff were reassigned within IU-13 in an effort to provide continuous employment. Prior to the execution of multi-year contracts, no IU-13 staff member worked full-time on the OTDA Education Project.

¹¹For FY 2007-08, PDE has requested an executive authorization of \$225,000 for the OTDA Education Project. As of March 2007, the Organ Donation Advisory Committee has recommended \$200,000 for the OTDA Education Project for FYs 2008-09 and 2009-10.

Table 10

IU-13 Contract Estimated Project Costs
(FY 2006-07)

<u>Expenditure Purpose</u>	<u>Est. Amount</u>	<u>% of Total</u>
Goal 1: Awareness (Travel, Printing, Conference Materials).....	\$ 8,737	6%
Goal 2: Research-Based Classroom Tools (Materials Update).....	1,900	1
Goal 3: Professional Development Activities (Institutes, Technical Assistance, Discussion Forum)	20,000	13
Goal 4: Implementation Site Grants and Associated Costs.....	11,730	8
Goal 5: OTDA Curriculum Advisory Committee Support	3,000	2
Project Staff and Overhead		
OTDA Project Coordination (Salary and Benefits).....	71,678	--
• Project Director		
• Project Coordinator		
• Professional Staff		
Support Staff (Salary and Benefits)	16,285	--
• Program Assistant		
• Secretary		
Technology.....	2,163	--
Space Rental.....	4,999	--
Telephone	1,017	--
Administrative Costs	<u>8,491</u>	--
Estimated Staff and Overhead Total.....	<u>\$104,633</u>	<u>70</u>
Total Costs	\$150,000	100%

Source: FY 2006-07 Intergovernmental Agreement Between PDE and IU-13.

Project Evaluation

The “By The Numbers” Evaluation

In FY 2005-06, PDE instructed IU-13 to undertake a substantive, independent evaluation of the OTDA Education Project. IU-13 subcontracted with By The Numbers to complete an evaluation of the secondary education component of the Organ and Tissue Donation Awareness Program (OTDAP) during the period 2003 through 2006. The report, released in July 2006, is entitled *Organ and Tissue Donation Awareness Education Project: 2003-2006*. The total cost of the report was \$25,910, and was funded by dedicating a portion of Trust Fund monies received through contract by IU-13 for the OTDA Education Project in each FY 2003-04, 2004-05, and 2005-06.

Achievement of Project Objectives. In conducting this evaluation, the contractor surveyed curriculum coordinators, principals, and other relevant school district personnel and interviewed members of the Organ Donation Advisory Committee. In addition, a “Classroom Toolkit Survey” was mailed to individuals on the distribution list or who attended one of the OTDA Institute for Educators conferences and three school district case studies were conducted. Focus groups were also held with teachers who attended the 2005 OTDA Institute for Educators.

The By the Numbers group identified three key objectives of the OTDA Education Project and structured its evaluation around these objectives:

- develop educational tools needed by secondary school teachers to implement Organ and Tissue Donation Awareness Education in their classrooms;
- hold bi-annual OTDA Institutes for Educators as a forum for knowledge building and networking among Pennsylvania secondary school teachers; and
- make Pennsylvania secondary schools aware of the existence and activities of the project.

In assessing the Project’s accomplishment of these objectives, the report concluded as follows:

Results from this evaluation indicate that the first of these objectives has been met in its entirety. The second objective has largely been met—a series of well-developed and well-received OTDA Institutes have been held, but attendance has been relatively low. The third objective has been partially met—many Pennsylvania school districts have been exposed to the project, and many of these are using project materials, but gaps in knowledge about the project remain.

The report also states that, “The principal educational tools developed as part of this project, the OTDA Classroom Toolkit and Curriculum Framework, have by all accounts been a major success.” This is evidenced, the report concludes, through the positive comments regarding the Toolkit made by teacher focus group participants and case study interviewees, including compliments regarding the Toolkit’s design and the quality of the content domains.

It is evident from the evaluation that the products developed by IU-13 (i.e., the OTDA Classroom Toolkit and Curriculum Framework) are very well done and comprehensive materials. Teacher focus groups and case study participants interviewed during the By the Numbers evaluation describe the Toolkit as “incredibly well structured,” “very valuable,” “a bounty of information,” and “very user

friendly.” In a survey conducted of curriculum coordinators in the study, all respondents had a positive opinion of the Toolkit and Curriculum Framework.

Further evidence of the quality of project materials is the demand that IU-13 has seen from outside agencies for the materials and the recognition and awards they have received. The Toolkit has received several awards, including an Award of Excellence from the Pennsylvania School Public Relations Association and an Award of Excellence from the Pennsylvania School Boards Association (PSBA). In addition, the OTDA Education Project Calendar has received both an Award of Excellence and an Award of Honor from the PSBA, and IU-13 granted a Teamwork Award to the OTDA Education Project staff. IU-13 project staff has also presented the Toolkit at two national conferences.

Extent of Project Penetration in the State’s Secondary Schools. Despite the quality of the Toolkit and Curriculum Framework, the organ donation awareness materials they contain have not yet received widespread use in the state’s secondary schools. The By the Numbers report states that approximately 68 school districts, or about 13.6 percent of all districts, are currently using OTDA Education Project materials in the classroom (as of the end of 2006).

In the By the Numbers report, each of Pennsylvania’s counties was classified according to their level of OTDA Project activities, ranging from counties with no participation in the OTDA Project to counties containing one or more affiliated sites using OTDA Project materials. As shown on Table 11, only eight counties contain one or more affiliated sites using OTDA Project materials.

Table 11

Implementation Status of the OTDA Education Project in Pennsylvania Counties	
<u>Degree of Participation of Schools in the County</u>	<u>Number of Counties</u>
No participation in the OTDA Project.....	20
County or most of county lies in an IU that has hosted OTDA project at a curriculum coordinators meeting.....	26
County has schools that have expressed interest in OTDA project and/or applied for a mini-grant.....	13
County contains one or more affiliated sites using OTDA project materials	8

Source: By The Numbers, *Organ and Tissue Donation Awareness Education Project: 2003-2006 Evaluation Report*.

Of the remaining counties, 26 include schools that have hosted a curriculum coordinators meeting at which the OTDA Education Project was presented and explained, 13 counties have schools that have expressed an interest in the OTDA

Project and/or applied for a mini-grant, and 20 counties have had no participation in the Project.

Responses to the Classroom Toolkit survey conducted as a component of the By The Numbers report, administered to school district officials on the distribution list for the Toolkit or who attended one of the OTDA Institutes for Educators, yielded that only 74 percent of respondents acknowledged receiving the Toolkit. This result, according to the report, was “surprisingly low” given the sample set of respondents. Of the respondents who received the Toolkit, 70 percent reported presenting Toolkit material to their students in the previous school year.

Among respondents who used the OTDA Classroom Toolkit in their school, 85 percent indicated that they shared information in the Toolkit with other teachers, principals, assistant principals, or other administrators. Of those who shared elements of the Toolkit, 74 percent indicated that either an “overwhelmingly positive” or “generally positive” reaction occurred. Among respondents who did not share the Toolkit with others, three of six respondents indicated that “either time in the teacher’s curriculum or of not having enough time together with other teachers” was a factor. Further, 90 percent of respondents who used the Toolkit in the classroom reported that no negative response was received regarding the presentation of information about organ and tissue donation to students.

The Classroom Toolkit Survey also found that 98 percent of respondents “indicated that they will continue to present material from the Toolkit to students.” While By The Numbers found that attendees at the Institutes for Educators praised the quality of the conference, low attendance was cited as the “principal limitation.” Finally, the report found, “greater support for the OTDA Project among principals and teachers than among curriculum coordinators.”

Recommendations for the OTDA Education Project. Given the quality of the OTDA Curriculum Framework and Classroom Toolkit, but in light of the relatively low utilization of the Toolkit in Pennsylvania’s secondary schools, the contractor’s evaluation report contains five primary recommendations to enhance and strengthen the OTDA Education Project. These are summarized on Exhibit 10.

**A Summary of Recommendations Made to Enhance
and Strengthen the OTDA Education Project**
(By the Numbers Report – 2006)

1. *Market the Classroom Toolkit and Curriculum Framework Directly to Teachers and Principals*

Secure whatever permissions are necessary from other IUs and/or the Pennsylvania Department of Education in order to engage in a direct marketing campaign (e.g., to teachers, principals, and school district-level administrators). To facilitate this, develop a database of secondary school teachers in key disciplines (such as biology, anatomy/physiology, health, ethics/bioethics, physical education, and driver's education) and a database of building principals on basis of information provided by the IUs and/or the Pennsylvania Department of Education.

2. *Prepare a Quick Start Guide for the Toolkit^a*

The Toolkit is an excellent resource but its size may be imposing to someone who is unsure about incorporating organ and tissue donation awareness into the curriculum and may not have even given any real thought to the topic prior to receiving the Toolkit. A brief "two-page quick start guide" would provide time-pressed teachers and administrators with an entrée into the Toolkit.

3. *Subject to Available Funding, Cover the Cost of Substitutes for Teachers Attending OTDA Institutes*

OTDA Institutes for Educators have been very well-received but attendance has been relatively low. Reimbursing school districts for the cost of a substitute could significantly increase Institute attendance.

4. *More Effectively Demonstrate How OTDA Curricular Materials Are Consistent with PSSA Standards*

Demonstrating how the curricular materials are consistent with PSSA standards should be a central component of all marketing efforts for the OTDA Project. This could be highlighted in the quick start guide.

5. *Subject to Available Funding, Periodically Release Toolkit Updates*

To reduce printing costs while ensuring that material stays current, updates could be released at varying time intervals by type of media: a new printed version of the Toolkit every few years or so; annual updates on DVD; and updates as often as necessary online.

^aA Quick Start Guide was created as part of the 2007 updated version of the Classroom Toolkit.

Source: Summarized by LB&FC staff from a report entitled *Organ and Tissue Donation Awareness Education Project: 2003-2006*, By the Numbers, 2006. The complete text of the report recommendations can be found in that publication.

D. Donor Designation and the Development and Maintenance of a Statewide Donor Registry

Findings

- D-1. *Pennsylvania has made substantial gains in promoting organ and tissue donor awareness and designation. Since OTDAP was initiated in 1995, the Commonwealth has built an organ and tissue donor registry that, as of March 1, 2007, included 4,006,425 Pennsylvanians, or 43.2 percent of the state's total population of licensed drivers and state I.D. card holders. Prior to the passage of Act 1994-102, Pennsylvania did not have a statewide database of organ and tissue donors.*
- D-2. *Among the 67 counties, donor designation rates range from a low of 29.3 percent of licensed drivers/state I.D. card holders to a high of 53.8 percent of licensed drivers/state I.D. card holders. As shown below, four counties, Centre, Chester, Warren, and Cumberland, have registration rates in excess of 50 percent. On the low end, Philadelphia, Fayette, Greene, and Fulton counties are in the 29 to 36 percent donor designation range.*

<u>Ten Highest Donor Designations Counties</u>	<u>Ten Lowest Donor Designations Counties</u>
Centre53.8%	Philadelphia29.3%
Chester.....52.7	Fayette32.5
Warren51.2	Greene33.9
Cumberland50.3	Fulton35.7
Erie.....49.9	Bedford.....37.4
York.....49.2	Clarion.....38.7
Montgomery48.5	Luzerne38.8
Bucks48.1	Armstrong.....39.0
Susquehanna.....47.8	Indiana39.2
Bradford47.6	Lawrence.....39.2

Of the 4,006,425 Pennsylvanians who are designated as organ and tissue donors, 54.4 percent are female and 45.6 percent are male. The largest cohort, numbering 1.7 million, is in the 41 to 60 age group.

- D-3. *Donor registries are a database of those individuals in a given state who officially record their desire to be an organ and tissue donor and, thereby, have given consent to make an anatomical gift. Although the development of one has been considered, a national registry does not yet exist. Likewise, no agency currently maintains comprehensive statistics on the size of state donor registries or the percentage of licensed drivers who are donors. Through contacts with state departments of transportation and motor vehicles, OPOs, and the Donate Life America organization, we were able to obtain information on*

the number and percentage of drivers reportedly designated as organ and tissue donors in a sample of 27 other states. Among the states for which comparable information is available, Pennsylvania ranks 17th in the percentage of the state's driver population that has registered as an organ and tissue donor. There is, however, considerable potential for further expansion of the size of Pennsylvania's donor registry.

- D-4. *As demonstrated by reported donor percentages in the range of 60 to 70 percent in a number of other states, it would appear that there is room for upward expansion of Pennsylvania's statewide donor designation rate. This assumption is supported by a 2005 Gallup telephone survey that found that nearly two-thirds of Pennsylvanians not yet registered for organ and tissue donation support donation for themselves.*

As of March 1, 2007, 5.3 million of Pennsylvania's 9.3 million licensed drivers were not registered as organ and tissue donors. Applying the two-thirds estimate from the 2005 Gallup survey of Pennsylvanians who have not yet registered but who support organ donation for themselves would indicate a potential pool of approximately 3.4 million new drivers that the OTDAP can conceivably reach and bring onto the donor rolls.

PennDOT Actions

By virtue of several requirements set forth in Act 1994-102, PennDOT is assigned a key role in organ donor enlistment efforts in the Commonwealth. This section discusses the specific duties and responsibilities assigned to PennDOT and the Department's implementation actions and participation in the OTDAP to date.

Redesign of the PA Driver's License and I.D. Card System

Act 102 required PennDOT to redesign the Commonwealth's driver's license and identification card application system to enable Pennsylvanians to sign-up as organ donors. The act states as follows:

Beginning as soon as practicable, but no later than January 1, 1995, or one year following the effective date of this section, whichever is later, the Department of Transportation shall redesign the driver's license and identification card application system to process requests for information regarding consent of the individual to organ or tissue donation. The following question shall be asked:

Do you wish to have the organ donor designation printed on your driver's license?

Only an affirmative response of an individual shall be noted on the front of the driver's license or identification card and shall clearly indicate the individual's intent to donate his organs or tissue. A notation on an individual's driver's license or identification card that he/she intends to donate his organs or tissue is deemed sufficient to satisfy all requirements for consent to organ or tissue donation.

According to the Bureau of Driver Licensing, this provision was actually implemented ahead of schedule on December 6, 1994.

Voluntary Monetary Donations to the Organ Donation Awareness Trust Fund

Additionally, by January 1, 1995, PennDOT was required to provide driver license applicants (for both original license/ID and renewal) the opportunity to contribute \$1 to the Organ Donation Awareness Trust Fund. This provision was implemented in March 1995. Act 1998-74 added the provision for a voluntary \$1 donation at the time of a vehicle registration renewal. This provision took effect in July 1999. Whether the donation is made in connection with the driver's license or the vehicle registration procedure, PennDOT makes it clear to the applicant that the \$1 donation is optional and is to be added to the regular fee for each issuance or renewal of a license, identification card, or vehicle registration.

Development and Maintenance of a Statewide Donor Registry

System Description. Rapid and secure access to an individual's decision regarding organ donation is important for the OPO and hospital personnel involved in organ donation. Although "donor registry" has various definitions, the Institute of Medicine defines this term to mean "an online systematic source of accessing donor consent information 24 hours a day, 7 days a week."

Since Illinois launched the first statewide donor registry in 1993, donor registries have been developed in many states as a means by which an individual's consent to be a donor is recorded, stored, and readily retrievable by authorized parties. Pennsylvania's donor registry is maintained by the Department of Transportation's Bureau of Driver Licensing as a feature of the driver licensing database.¹ When an individual applies for or renews a driver license or photo identification card, the decision to become an organ donor is recorded in the database as either a Yes "Y" or No "N."

¹Officially, PennDOT contends that it does not maintain a "donor registry" but rather a database of individuals who hold a driver's license or identification card on which they have registered their decision to be an organ and tissue donor.

Prior to on-line designation,² most Pennsylvanians typically had to wait for the four-year renewal cycle, especially if they had not designated themselves as an organ donor when they applied for their initial license. The operational guidance to the photo license technician at PennDOT Photo License Centers provides a description of how the organ donor designation process actually is to occur.

After the technician has verified the customer's identity, the technician is to point to the customer monitor and say "Please step up to the monitor and answer questions on the screen using the small keypad to make your selections. If you need help, I can assist you." The customer views the screen which asks the question "Do you wish to have the ORGAN DONOR designation printed on your driver's license?" If the Organ Donor box is checked when the customer has finished answering the question, the technician is to verify the customer's decision by asking "I see you have selected the Organ Donor designation. Is this correct?" If the customer responds that it is incorrect, the technician removes the check mark from the box.

While the process seems simple enough, a customer's reaction could potentially be emotionally intense and negative, especially if no prior thought has been given to their decision to become an organ donor. In its driver's license and renewal application forms, brief information is provided to indicate that the applicant has or will have the opportunity to request Organ Donor designation at the Photo Center at the time they have their photo taken.

The Pennsylvania Driver's Manual, for example, states as follows:

Each time you renew your Pennsylvania driver's license, you will be asked if you want the "ORGAN DONOR" designation on your license. You should give thought to this decision before going to the Photo License Center to have your photo taken. The words "ORGAN DONOR" will appear on your driver's license when you say "YES" to being designated as an organ donor at the Photo Center.

The Manual also provides for applicants under age 18 to become organ donors:

Applicants under 18 years of age may request and obtain the organ donor designation on their driver's license; however, they must have written consent from a parent, guardian, or a person in loco parentis or spouse. The parent or guardian may give consent by checking the appropriate block on the Parent or Guardian Consent Form (DL-180TD). For information on Organ and Tissue Donation, contact 1-877-DONOR-PA.

²As discussed later in this section, on-line designation became available in Pennsylvania in July 2006.

Information printed on the various PennDOT driver license application forms and in the PA Driver's Manual prompts the applicant of the need to make a decision related to organ donation.

Participation in Awareness Activities. The online option for designating oneself as an organ donor has the potential to encourage more individuals to designate themselves as organ donors. Although this feature has been in place for less than one year, it has been used by nearly 500 PennDOT customers as the method to register their decision to become an organ donor.

However, citizens vary greatly in terms of their facility and access to internet services. For the near future, the traditional mailings and follow-up processing at the photo license centers will continue to be the means that most Pennsylvanians use to obtain their driver's license or photo ID. In many cases, customers will not have given serious thought to organ donation prior to their visit to the Photo License Center.

To address this, one aspect of the recent and continuing statewide public awareness campaign entitled "Ordinary People, Extraordinary Power" was the development of informational materials for display at the Driver License/Photo License Centers. These materials consist of a poster and poster frame, brochures in Spanish as well as English, and computer toppers. These items were sent to all Driver License Center supervisors by the consultant to the OPOs on the public awareness campaign with the following instructions:

Thank you for your support of the Organ and Tissue Donor Awareness effort sponsored by the Pennsylvania Department of Health, Pennsylvania Department of Transportation, the Center for Organ Recovery and Education and Gift of Life Donor Program. Your assistance in properly displaying the poster, computer topper and brochure (and keeping a supply of brochures in the display racks) will be a tremendous help in raising awareness and encouraging your customers to say "yes" to organ and tissue donation.

Additionally, the centers were given a visual depiction of how the materials were to be displayed and were also provided contacts for reordering the materials. Please refer to part B of this Section for the results of our field visits to a sample of 16 centers to determine the visibility and availability of these awareness materials.

OPO Access to Driver Licensing Database. Act 2006-48 permitted licensed OPOs operating in Pennsylvania 24-hour electronic access to information necessary to confirm an individual's organ donor status through PennDOT's driver licensing database. Necessary information (to be provided by the OPOs) includes an individual's name, date of birth, driver's license number, and organ donor status.

OPOs are prevented from using the information for any purpose other than to confirm an individual's organ donor status (as provided on identification available from the individual at or near the time of death). OPOs are not assessed a fee for access to this information. Prior to Act 2006-48, OPOs were required to contact the Pennsylvania State Police to confirm an individual's organ donor status.

As of January 2007, the OPOs were in the process of finalizing agreements with service providers that will provide the electronic connection from the OPO representatives to the PennDOT driver licensing database. Once finalized, the OPOs will have 24-hour access to the driver licensing database for the purpose of determining and/or confirming an individual's organ donor designation status. While PennDOT does not charge an annual fee to the OPOs for use of the database, the OPOs are responsible for service provider costs.

According to PennDOT, a further computer systems upgrade is planned that will enable OPOs to have secure access to the driver licensing database via the Internet, thereby reducing communication costs for the OPOs. This change is scheduled to commence in 2009.

On-Line Donor Registration. A growing number of states in which the registry is housed and operated by the DMV also have other means for residents to join the registry, most notably through the Internet. Pennsylvania joined this group in July 2006.

At that time, PennDOT modified the "Driver and Vehicle Services" section of its website to permit persons holding state driver's licenses and state photo identification cards to add the "Organ Donor" designation to their official record at anytime on-line at no charge to the individual. At the end of the transaction, individuals may print a document to keep with their driver's license or identification card indicating their new organ donor designation. The customer may also submit a form and appropriate fee to obtain a new license or ID card with the "Organ Donation" designation affixed rather than waiting for their four-year renewal period to occur.

A link is provided on the "Donate Life PA" website (<http://www.donatelife-pa.org>)³ to the secure PennDOT website for this purpose. In addition to a press release announcing this new capability issued on August 3, 2006, for several months following the launch of this capability, PennDOT publicized the option in the "What's Hot at the DOT" section of the Driver and Vehicle Services section of the website.

³When going to the PennDOT website, an individual interested in becoming an organ donor is able to go to "Driver and Vehicle Services" and click on "Online Services Center" then click on "Add Organ Donor Designation." A screen entitled "Online Organ Donor Designation Login" appears that presents the process in two steps: Read Instructions; and, Online Organ Donor Designation Login."

PennDOT reports that as of March 2007, 470 individuals had completed an organ donor designation using the online service. Over 700 additional individuals attempted to use the service who were already listed with an organ donor designation.

Liaison and Statistical Reporting Functions. Although PennDOT does not have a membership position on the Organ Donation Advisory Committee, the Department has designated a staff member from the Bureau of Driver Licensing as a liaison to the Committee. A PennDOT staff person attends each Advisory Committee meeting to update the Committee on developments related to the statewide registry. This individual works with the Advisory Committee and the Department of Health to promote communication with Department of Transportation officials and facilitate enhancements to the statewide registry (e.g., OPO access to the registry and implementation of on-line donor registration).

The Department's Bureau of Driver Licensing also compiles statistical data on organ donor designation through the state registry and reports this information to the Organ Donation Advisory Committee on a regular basis. Organ donor statistical reports provided by PennDOT include donor breakdowns by county, gender, and age. To facilitate the targeting of public awareness and marketing initiatives, the Department has also begun to compile data on organ donor designation activity at individual driver license photo-centers.

Size and Composition of the State Registry

Table 12 shows that as of March 1, 2007, a total of 4,006,425 Pennsylvanians had chosen to place their names on the state's Organ Donor Registry. This number includes organ designation made on driver licenses, photo identification cards, and learner permits. The number of persons who have registered as donors constitutes 43.2 percent of the state's total licensed driver population.

In four counties, Centre, Chester, Warren, and Cumberland, the number of registrants exceeds 50 percent of the licensed drivers in the county. Centre County leads the state at 53.8 percent while Philadelphia County has the lowest percentage at 29.3 percent of the county's licensed drivers registered as donors.

Of the 4,006,425 Pennsylvanians who are organ and tissue donors, 54.4 percent are female and 45.6 are male. The age composition of the donor registry is shown on Table 13.

While most states have a donor registry linked in some way to the state's department of motor vehicles, there is no central source of information on the comparative donor designation rates among the various states. We surveyed a number of states and also obtained comparable information for various state registries that was compiled by the Donate Life America Donor Designation Collaborative.

Table 12

**The Number of Drivers Designated as Organ and Tissue
Donors on the Pennsylvania Registry, by County**
(As of March 1, 2007)

<u>County Ranking</u>	<u>County</u>	<u>Total Drivers</u>	<u>Organ Designation</u>	<u>Percent of Total</u>
1	Centre	87,302	46,927	53.8%
2	Chester	339,581	178,914	52.7
3	Warren	30,968	15,851	51.2
4	Cumberland	181,747	91,453	50.3
5	Erie.....	201,288	100,466	49.9
6	York	321,922	158,523	49.2
7	Montgomery.....	615,179	298,387	48.5
8	Bucks	484,359	233,066	48.1
9	Susquehanna.....	31,655	15,128	47.8
10	Bradford	46,776	22,245	47.6
11	McKean.....	32,185	15,278	47.5
12	Butler	141,834	67,166	47.4
13	Adams.....	72,439	34,013	47.0
14	Lancaster	366,809	170,519	46.5
15	Montour.....	13,778	6,376	46.3
16	Crawford	66,554	30,742	46.2
17	Tioga.....	30,660	14,151	46.2
18	Elk.....	26,383	12,158	46.1
19	Cameron	4,219	1,937	45.9
20	Wyoming.....	24,321	11,155	45.9
21	Wayne.....	46,734	21,389	45.8
22	Dauphin	198,275	90,365	45.6
23	Blair.....	97,906	44,484	45.4
24	Lycoming	87,753	39,858	45.4
25	Venango	41,177	18,587	45.1
26	Lehigh	241,555	108,446	44.9
27	Clearfield.....	59,379	26,462	44.6
28	Delaware.....	413,435	183,543	44.4
29	Union	27,064	11,994	44.3
30	Northampton	240,431	105,949	44.1
31	Sullivan	5,067	2,228	44.0
32	Pike.....	40,822	17,885	43.8
33	Clinton.....	25,769	11,282	43.8
34	Perry	35,869	15,632	43.6
35	Allegheny	918,294	399,183	43.5
36	Potter	13,716	5,950	43.4
37	Lackawanna.....	156,017	67,622	43.3
38	Mifflin	30,910	13,352	43.2
39	Lebanon.....	99,997	43,178	43.2
40	Franklin	103,302	44,556	43.1
41	Forest.....	4,554	1,956	43.0
42	Huntingdon	32,810	14,036	42.8
43	Cambria	111,452	47,383	42.5
44	Berks.....	298,060	126,608	42.5
45	Columbia.....	48,940	20,467	41.8
46	Jefferson	35,599	14,828	41.7
47	Somerset	59,963	24,770	41.3

Table 12 (Continued)

<u>County Ranking</u>	<u>County</u>	<u>Total Drivers</u>	<u>Organ Designation</u>	<u>Percent of Total</u>
48	Monroe.....	125,134	51,359	41.0%
49	Mercer.....	87,665	35,962	41.0
50	Westmoreland.....	278,869	114,363	41.0
51	Snyder	27,179	11,128	40.9
52	Beaver	130,238	53,238	40.9
53	Carbon	50,501	20,459	40.5
54	Washington.....	162,219	65,448	40.4
55	Schuylkill.....	110,478	43,757	39.6
56	Juniata	16,210	6,382	39.4
57	Northumberland.....	68,465	26,952	39.4
58	Lawrence	74,448	29,196	39.2
59	Indiana	61,967	24,281	39.2
60	Armstrong	59,908	23,367	39.0
61	Luzerne.....	248,934	96,484	38.8
62	Clarion	28,320	10,970	38.7
63	Bedford	38,389	14,359	37.4
64	Fulton.....	11,436	4,086	35.7
65	Greene.....	28,268	9,572	33.9
66	Fayette.....	113,344	36,785	32.5
67	Philadelphia.....	<u>960,930</u>	<u>281,829</u>	29.3
	Totals.....	9,277,711	4,006,425	43.2%

Source: Pennsylvania Department of Transportation, March 1, 2007.

Table 13

**The Composition of the Pennsylvania Organ and Tissue
Donor Registry, by Age and Gender**
(As of March 1, 2007)

Male:

<u>Age</u>	<u>Drivers Male</u>	<u>Organ Designation Male</u>	<u>Percentages</u>
16-17	99,335	46,392	46.7%
18-20	229,883	104,632	45.5
21-30	750,593	320,732	42.7
31-40	763,070	330,232	43.3
41-60	1,737,570	749,655	43.1
61-75	654,100	211,795	32.4
>75	<u>294,955</u>	<u>64,727</u>	21.9
Total	4,529,506	1,828,165	40.4%

Female:

<u>Age</u>	<u>Drivers Female</u>	<u>Organ Designation Female</u>	<u>Percentages</u>
16-17	95,296	49,105	51.5%
18-20	223,753	113,976	50.9
21-30	746,849	379,798	50.9
31-40	769,314	406,726	52.9
41-60	1,795,651	902,200	50.2
61-75	731,789	249,612	34.1
>75	<u>385,553</u>	<u>76,843</u>	19.9
Total	4,748,205	2,178,260	45.9%

Total:

<u>Age</u>	<u>Drivers Total</u>	<u>Organ Designation Total</u>	<u>Percentages</u>
16-17	194,631	95,497	49.1%
18-20	453,636	218,608	48.2
21-30	1,497,442	700,530	46.8
31-40	1,532,384	736,958	48.1
41-60	3,533,221	1,651,855	46.8
61-75	1,385,889	461,407	33.3
>75	<u>680,508</u>	<u>141,570</u>	20.8
Total	9,277,711	4,006,425	43.2%

Source: Pennsylvania Department of Transportation, March 1, 2007.

As Table 14 shows, led by Utah at 70 percent, 12 of the 27 states report that over 50 percent of their licensed drivers are registered organ and tissue donors. Pennsylvania ranks 17th in this listing.

Table 14

The Number and Percentage of Drivers Designated as Organ and Tissue Donors on the Registries of Selected States

<u>State</u>	<u>Licensed Drivers</u>	<u>Actionable Donor Designations (ADD)^a</u>	<u>ADD Share^b</u>
Utah.....	1,582,599	1,111,507	70%
New Mexico	1,271,365	842,625	66
Virginia	5,112,523	3,258,963	64
Indiana	4,521,329	2,824,825	62
Oklahoma.....	2,369,621	1,469,595	62
Idaho	942,983	581,389	62
Minnesota.....	3,083,007	1,895,656	61
Alaska	482,532	295,000	61
Washington	4,504,581	2,736,344	61
Colorado.....	3,205,054	1,923,032	60
Wisconsin.....	3,910,188	2,165,913	55
Missouri.....	4,047,652	2,226,606	55
Ohio.....	9,299,602	4,593,066	49
Nebraska.....	1,315,819	630,478	48
Louisiana.....	3,169,627	1,493,517	47
North Carolina.....	7,111,048	3,216,783	45
Pennsylvania	9,277,711^c	4,006,425	43
Delaware.....	902,750 ^d	352,074	39
Hawaii	843,876	325,550	39
Florida	13,146,357	5,000,000	38
Massachusetts	4,645,857	1,685,457	36
West Virginia.....	1,292,036	467,895	36
Rhode Island.....	741,841	265,636	36
Connecticut.....	2,694,574	875,056	32
District of Columbia...	352,476	104,557	30
Arizona.....	3,783,927	1,007,050	27
New Jersey	5,799,532	1,260,673	22
Illinois.....	8,057,683	1,578,814	20

^aIn many cases, the numbers of designated donors are self-reported and compiled by the Donor Designation Collaborative faculty. In other cases, data was obtained through telephone contacts made by LB&FC staff.

^bADD Share is the percentage of licensed drivers who are designated donors. Percentages are rounded.

^cIncludes state identification card holders.

^dEstimated.

Source: Donate Life America Donor Designation Collaborative Faculty, March 2007, and contacts to other states made by LB&FC staff.

E. Payments to Donors or Donors' Families for Hospital, Medical, Funeral, and Incidental Expenses

Findings

- E-1. Act 102 directs the Organ Donation Advisory Committee to develop procedures, including the development of a pilot program, necessary to implement the donor benefits component of OTDAP. To date, implementation of the Act 102 provision that provides for reimbursement of certain expenses incurred by organ donors or their family members has centered on (1) consideration and rejection by the Department of Health of a funeral expense benefit pilot program proposed twice by the Organ Donation Advisory Committee; (2) the administration instead of a food and lodging expenses pilot program jointly developed by the Advisory Committee and the Department of Health; and (3) planning for a grief counseling benefit recently proposed by the Advisory Committee.*
- E-2. Tissue Donor Exclusion. Currently, tissue donors and their families are excluded from eligibility for donor and donor family benefits. Although the program is designated as the “Organ and Tissue Donor Awareness Program,” language in Act 1994-102 extends eligibility for expense benefits only to persons who make a “vital organ” donation. This has been a point of discussion at meetings of the Advisory Committee and remains an unresolved issue. While Committee members recognize the inequity of the exclusion, they also recognize the statutory and financial restrictions involved. Given their relatively larger numbers (approximately 1,200 in 2006), providing unlimited eligibility for tissue donors could quickly draw down the Trust Fund balance.*
- E-3. A Proposed Funeral Expense Benefit Pilot Program. Although Act 102 authorizes the Organ Donation Advisory Committee to establish a pilot program to reimburse a portion of organ donors’ funeral expenses, the Committee’s proposals to proceed have not been approved by the Secretary of Health. The Secretary’s denials stem from concerns that such payments would violate federal law that prohibits transfers of human organs for “valuable consideration.” No state has such a program and, since 1999, word of the possibility of such a plan in Pennsylvania has drawn national attention from the media and the transplant community.*

While no test cases are available, a recent Department of Justice opinion in the area of kidney exchanges may provide some guidance. This opinion concluded that the two types of kidney exchanges at issue did not “clearly and definitely” fall within NOTA’s prohibition as transfers for “valuable consideration.” In reaching this conclusion, the Department acknowledged that NOTA Section 301 does not define “valuable consideration” but simply provides guidance as to what is not valuable consideration. The opinion went on to state that

“valuable consideration” as applied to organ donations, involved “some sort of buying and selling, or otherwise commercial transfer, of organs.” Moreover, the Department of Justice declared that the prohibition in NOTA must be read narrowly, or less harshly, because NOTA lacked complete clarity on the issue of what constitutes “valuable consideration” and because as a criminal statute, the rule of lenity required a narrow reading of the prohibition.

Within the transplant community, positions vary. There are indications, however, of a fairly recent shift in attitudes toward support of the idea that, at a minimum, pilot projects should be undertaken to help gather data as to the feasibility and effectiveness of financial incentives, such as the payment of a portion of funeral expenses, in increasing organ donation rates.

- E-4. The Organ Donation Expense Benefit Pilot Program. Following disapproval of the funeral expense benefit pilot program, the Advisory Committee instead developed a plan to help organ donors and their families defray lodging and meal expenses under the “incidental expenses” language in Act 102. The “Organ Donation Expense Benefit Pilot Program” began in 2002 as a three-year pilot in recognition and appreciation of the “gift of life.” From its inception through June 30, 2006, 473 donors or their families received expense benefits for lodging and meal expenses associated with making a vital organ donation. These payments, which are paid directly to transplant hospitals or referral hotels, have totaled \$93,781 over five fiscal years and have, with one exception, exclusively benefited living donors. The average benefit payment made per donor/donors family has been about \$198. As of early 2007, it continued to operate as a “pilot program.”*
- E-5. A Planned Grief Counseling Benefit Program. In an effort to provide a Trust Fund benefit to the families of deceased donors, the Organ Donation Advisory Committee is planning to implement a Trust Fund-supported family grief counseling and bereavement support benefit through community-based service providers. The timeline originally established for the program called for services to begin in July 2007, but the pilot is currently behind schedule. Initial start-up costs are budgeted at \$30,000 with annual costs thereafter estimated at approximately \$165,000.¹*

Through this effort, the Advisory Committee, along with the Department of Health and the two OPOs, are seeking to develop an aftercare program to provide readily accessible, no cost, short-term grief counseling to donor families throughout the state. While such services are currently available to some degree through the OPOs, availability is limited due to geographic location of families and counselors and financial issues.

¹See pages 135 and 136 for cost estimates calculated by LB&FC staff, including an estimate of the costs of expanding eligibility to tissue donors.

Hospital, Medical, and Funeral Expenses

Act 102 directs the Organ Donation Advisory Committee to develop procedures, including the development of a pilot program, necessary to implement the donor benefits component of OTDAP. Act 102, at Section 8622(b), provides that following the payment of program implementation costs, including Advisory Committee costs, funds remaining in the Governor Robert P. Casey Memorial Organ and Tissue Donation Awareness Trust Fund may be expended to help cover various specified expenses incurred by a donor or donor's family in connection with making a vital organ donation. Section 8622(b) states, in part, as follows:

Any remaining funds are appropriated subject to the approval of the Governor for the following purposes: 10 percent of the total fund may be expended annually by the Department of Health for (1) reasonable hospital and other medical expenses, (2) funeral expenses and (3) incidental expenses incurred by the donor or donor's family in connection with making a vital organ donation.²

This subparagraph goes on to state "Such expenditures shall not exceed \$3,000 per donor and shall only be made directly to the funeral home, hospital or other service provider related to the donation. No part of the fund is to be transferred directly to the donor's family, next of kin or estate."

To date, the Department of Health has not expended any Trust Fund monies for hospital, medical, or funeral expenses. While the Department and the Advisory Committee have given extensive consideration to the funeral expense question, it does not appear from Committee records and meeting minutes that discussion has occurred relative to the payment of medical or hospital expenses.

Proposals for a Funeral Expense Pilot Program

The Initial Proposal. According to officials of the Department of Health, as early as May 1997,³ the Bureau of Family Health and the Organ Donation Advisory Committee began to plan for the reimbursement of a portion of an organ donor's funeral expenses under the Act 102 provisions. A subcommittee was developed to evaluate and provide recommendations for a voluntary benefit program according to Act 102. By 1999, these discussions had reached the proposal stage. As proposed, the plan would have provided a \$300 stipend to help families of organ donors cover their funeral expenses. The payment was to be made directly to funeral homes and not to family members.

²Act 102 defines a "vital organ" as a heart, lung, liver, kidney, pancreas, small bowel, large bowel, or stomach for the purpose of transplantation.

³Funding had been insufficient in 1995 and 1996 to implement the reimbursement program.

Based on media reports at that time, the inclusion of this provision in the law and the subsequent planning for the payment of funeral expenses originated, at least partially, from the heart-liver transplant Governor Robert Casey received in June 1993. In that case, the donor's parents had difficulty raising funds for their son's funeral. The prime sponsor of Act 1994-102, said at the time that the funeral benefits provision enacted in 1994 was intended to help other families avoid what the donor family faced after their donation for the Governor Casey transplant.

In 1984, the National Organ Transplant Act (NOTA) had made it a federal crime to "knowingly acquire, receive, or otherwise transfer any human organ for valuable consideration for use in human transplantation if the transfer affects interstate commerce." (The relevant provisions of NOTA are cited in Exhibit 11. In the years following NOTA's passage, many state legislatures, including Pennsylvania, followed the federal government in outlawing monetary transactions related to the acquisition of organs for transplantation. By 1989, 20 other countries, the World Health Organization, and an array of international medical associations related to transplantation had passed similar regulations and declarations.

Exhibit 11

The "Valuable Consideration" Provisions of the National Organ Transplant Act of 1984

To address the nation's organ donation shortage and improve the organ matching and placement process, the U.S. Congress passed the National Organ Transplant Act (NOTA) in 1984.

Section 301 of NOTA places certain restrictions on how human organs may be transferred, stating as follows:

(a) Prohibition

It shall be unlawful for any person to knowingly acquire, receive, or otherwise transfer any human organ for *valuable consideration* for use in human transplantation if the transfer affects interstate commerce.

Violations of this prohibition are subject to criminal penalties of a possible \$50,000 fine, five years imprisonment, or both. The term "valuable consideration" is not specifically defined by NOTA or by any implementing regulation. Section 301(c)(2) lists practices, however, that are specifically excluded from being considered "valuable consideration." "Valuable consideration" does not include the following:

- the reasonable payments associated with the removal, transportation, implantation, processing, preservation, quality control, and storage of a human organ; or
- the expenses of travel, housing, and lost wages incurred by the donor in connection with the donation of an organ.

Source: Section 301 of NOTA, codified at 42 U.S.C. §274e.

No other state had such a funeral benefit program as proposed by act 102 and news of Pennsylvania's plan triggered fairly widespread national media reaction. Word of the plan actually became known in early May 1999, about one month prior to its formal announcement. Almost immediately, an article appeared in the *New York Times* stating that "Pennsylvania is planning to become the first state in the nation to break a long-held taboo against providing a financial reward for organ donation."

A member of Pennsylvania's Organ Donation Advisory Committee and an advocate of the plan stated that the pilot program "is absolutely not about buying and selling organs." Rather, he described it as a voluntary death benefit for a family that gave a gift and that the intent of the pilot is to test it and see if it makes a difference to families.

However, the Pennsylvania plan generated intense discussion among transplant surgeons, organ recipients, donor families, and others in the organ donation field. Critics posed the following questions:

- Will the promise of a stipend, however small, induce families to lie about the medical histories of their loved ones, withholding information that could affect the health of the transplant recipient?
- Will the money prompt a disproportionate increase in donation among the poor, injecting further economic imbalance into a system that is already skewed in favor of the wealthy?
- Will the plan backfire, hindering organ donation by offending families who believe their gift is tainted by payments?
- In an era when surgeons are routinely transplanting kidneys from living donors who are not related to the recipients, could the stipends mark the first step on the road toward outright sale of organs?

The *New York Times* article concluded by stating that transplant surgeons and organ procurement organizations across the country "were watching Pennsylvania's experiment closely," and some were already making plans to follow it if it proves successful in increasing donations.

Another article on the Pennsylvania plan published by the center for Bioethics at the University of Minnesota in May 1999 questioned whether incentives such as funeral credits would violate at least the spirit of the ban on organ sales. The article also asked whether the plan would provide reasonable incentives to motivate families who need an enticement, or exploit the families of patients who wouldn't donate organs except that they need the money.

On June 9, 1999, the Organ Donation Advisory Committee officially delivered its plan to the Pennsylvania Secretary of Health for review and approval. The Secretary of Health received the plan and stated that the Department would conduct a thorough review of the proposed funeral reimbursement pilot program, including exploration of both its ethical and legal implications.

At that time, the Secretary directed the state Physician General to review ethical issues raised by the funeral benefits program. In conducting this review, the Physician General met with four bioethicists who concluded that a proposed \$300 funeral donation did not violate any ethical or bioethical principles but that if the amount were to be increased, it could cause a crossover into an unethical situation. Also at that time, however, DOH legal counsel advised the Secretary that the use of Trust Fund monies for funeral expenses would violate NOTA's prohibition on the transfer of organs for "valuable consideration."

There are conflicting reports on whether the Department of Health sought an opinion from the federal government on the proposed funeral benefit. Representatives of the state's two OPOs stated that the Department of Health attorneys did not seek a ruling from the federal government on the legality of the funeral benefit but instead relied on their own judgment. Current Counsel to the Advisory Committee told us, however, that DOH legal staff at the time did request federal guidance through a telephone discussion.

As an alternative to the funeral expense benefit, the Secretary of Health reportedly requested that the Organ Donation Advisory Committee instead pursue the development of a pilot program that would reimburse donor families for lodging and meal expenses. Such payments are expressly allowable under the National Organ Transplant Act.

Neither the legislative sponsor of the provision nor officials of Pennsylvania's OPOs agreed with this decision to proceed without a funeral benefit. The sponsor reportedly indicated that the meal-lodging benefit was "so far afield from what I was originally trying to do that it's insulting to the families who really need help." The OPO executives added that the lodging and meal expenses benefit plan would very likely be helpful only for living donors.

In March 2000, counsel for one of Pennsylvania's organ procurement organizations sent correspondence to the Department of Health's Chief Counsel to make the case for implementing the funeral expense pilot program. The Department remained firm in its belief that the proposed pilot would violate federal law and that it would not seek guidance from the federal government as to the legality of the funeral benefit under federal law. The Advisory Committee proceeded to instead develop the lodging and meals expense pilot. This pilot benefit program began in July

2002. (See pages 129 to 131 for a discussion and analysis of the lodging and meal expenses pilot program.)

Consideration of the Funeral Expense Pilot Program Since 2000. Relatively little formal activity on the funeral expense pilot has transpired since the initial proposal was turned down. An Assistant Counsel in the Department of Health with whom we spoke expressed the opinion that the funeral expense benefit pilot cannot proceed while NOTA remains good law and that the decision by the Secretary of Health in 2000 effectively ended the issue of exploring the permissibility of implementing it.

Nevertheless, a review of the minutes of the meetings of the Organ Donation Advisory Committee since 2001 shows that Committee members have raised the subject of the funeral expense pilot on a number of occasions. For example, based on meeting minutes, the topic was raised at an Advisory Committee meeting held in June 2003 and again at the Committee's meeting in December 2004. In 2004, the co-chairperson of the Advisory Committee stated that the Committee members needed to look again at the funeral benefits question and the following March indicated that an evaluation of the funeral benefits pilot is upcoming.

By March 2006, the Advisory Committee had developed another proposal that it presented at a meeting with the Secretary of Health. The outcome of that meeting was that the Secretary concluded that the OPOs should work with the Advisory Committee to develop a proposal for another pilot project that would provide expense reimbursement, but not for funeral expenses. It appears that the grief counseling benefit pilot that was announced shortly thereafter resulted from the March 2006 meeting. (See pages 131 to 136 for a discussion and analysis of the grief counseling benefit proposal.)

Results of a Survey of Pennsylvania Residents About Providing Funeral Expense and Other Benefits to Families of Organ Donors

Between March and August 2001, a group of researchers⁴ administered a telephone survey to a random sample of Pennsylvania households about issues related to organ donation incentives and benefits.⁵ The researchers expected many households to be knowledgeable about donor benefits because of the media coverage that Pennsylvania's proposed funeral expense benefits pilot program had recently received.

⁴Including researchers from the Department of Medicine and the Center for Research on Health Care, University of Pittsburgh; Case Western Reserve University School of Medicine; Ann Arbor Veterans Administration Medical Center; University of Michigan School of Medicine; the Gift of Life Donor Program (Philadelphia, PA), and the University of Pennsylvania.

⁵"Do Incentives Matter? Providing Benefits to Families of Organ Donors," C.L. Bryce, L.A. Siminoff, P. A. Ubel, H. Nathan, A. Caplan, and R. M. Arnold, *American Journal of Transplantation*, 2005. Please note that the discussion in this section does not represent a complete description of the survey methodology and results.

The survey explored whether respondents supported donor benefits as a matter of policy and whether they thought that benefits would affect donation rates. The survey first asked about “incentives” generally and then inquired about specific types of benefits.

The focus of the survey was to describe several types of donor benefits and ask respondents about providing such benefits to relatives of organ donors through a state-run program. The survey first asked respondents whether they agreed or disagreed with the following general statement. “The state should offer incentives or benefits that encourage eligible families to donate a loved one’s organ.” Answers were ranked on a five-point scale ranging from strongly agree to strongly disagree (or were recorded as “does not know” or “refuses to answer”).

The survey then described five benefits that could potentially be offered to donor families: funeral benefits for the organ donor; charitable contributions made in the name of the organ donor; reimbursement of travel and lodging expenses incurred by the family in conjunction with the organ donor’s death; direct cash payments, and help with medical expenses incurred by the organ donor. While these are not the only benefits that might be offered, they were chosen because they have been discussed in the literature and have an inherent economic value. The survey randomized the order to which benefits were presented to respondents. For each benefit, the survey asked the following:

- whether the respondent would favor or oppose a state program offering such a benefit to eligible families;
- how the program would affect the respondent’s own willingness to give consent and donate on behalf of a family member;
- how the program would affect the respondent’s own willingness to become (or remain) a registered organ donor; and
- how the respondent expected the program to affect the willingness of other people to consent and donate organs on behalf of a family member.

The survey was completed by 971 respondents, or 69 percent of the eligible households contacted. Of the respondents, 45.6 percent were registered organ donors, and 51.7 percent were non-white.

The survey found moderate support for donor benefits as a general policy, with 59 percent of respondents agreeing that “the state should offer incentives or benefits that encourage eligible families to donate a loved one’s organs.”

As shown in Table 15, the level of support was substantially higher when respondents were asked specifically about funeral benefits, charitable contributions, travel/lodging expenses, and medical expenses (which were supported by 81 percent, 73 percent, 78 percent, and 84 percent of respondents, respectively), and it was

lower when the survey asked specifically about direct payment (which was supported by only 53 percent of respondents).

When asked how specific benefit programs would affect their own willingness to donate organs on behalf of a family member, between 71 percent and 76 percent of respondents (depending on the benefit) said that benefits would have no effect. Among those for whom a benefit would have an impact, most reported that the benefit would make them more willing to donate. Net gains in willingness (defined as the percentage that would be “more willing” minus the percentage that would be “less willing”) were positive for all five benefits but were largest for medical expenses (23 percent) and smallest for direct payment (9 percent).

Table 15

Summary of PA Survey Respondents’ Reactions to Donor Benefits Programs

Type of Benefit	Overall Support For Benefits Programs (%) ^a		Percentage Indicating an Effect on Their Willingness to:					
	Favor	Oppose	Consent/Donate ^b		Register as a Donor		Donate ^c	
			More Likely	Less Likely	More Likely	Less Likely	More Likely	Less Likely
Funeral Benefits	81%	17%	23%	3%	22%	5%	68%	5%
Charitable Contributions....	73	25	21	5	18	8	51	8
Travel/Lodging Expenses..	78	19	22	2	20	4	64	5
Direct Payment.....	53	42	17	8	16	9	59	5
Medical Expenses	84	13	26	3	24	5	70	4

^aPercentage who did not know or refused to answer is not shown (range: 2-5%).

^bPercentage reporting no effect, did not know, or refused to answer is not shown (range: 71-76%).

^cPercentage reporting no effect, did not know, or refused to answer is not shown (range: 26-41%).

Source: “Do Incentives Matter? Providing Benefits to Families of Organ Donors,” C.L. Bryce, L.A. Siminoff, P. A. Ubel, H. Nathan, A. Caplan, and R. M. Arnold, *American Journal of Transplantation*, 2005.

Discussion and Consideration Within the Organ Transplant Community of Funeral Expense Benefits and Other Financial Initiatives

There is considerable discussion within the organ transplant community regarding what is permitted under the NOTA concept of “valuable consideration” and to what extent financial incentives can and should play a role in the structure of how organ donation operates. While positions vary, there are indications of a fairly recent shift in attitudes within professional circles toward support of the idea that, at a minimum, pilot projects should be encouraged and undertaken to help gather data as to the feasibility and effectiveness of financial incentives in increasing organ

donation rates. An article in the *Journal of Medical Ethics* described an “evolution of attitudes” from the early 1980s to the present:⁶

A vehement rejection on ethical grounds of anything but uncompensated donation—once the professional norm—has slowly been replaced by an open debate of plans that offer financial rewards to persons willing to have their organs, or the organs of deceased kin, taken for transplantation.

This section discusses the positions of various organizations in the transplant field on this question and their relationship to the “valuable consideration” provision in federal law. (A summary of the various positions is provided in Exhibit 12

Advisory Committee on Organ Transplantation. The federal Advisory Committee on Organ Transplantation (ACOT) has addressed the scope of NOTA’s prohibition on “valuable consideration” for donation and the question of what should be considered “valuable consideration” under the federal law. ACOT, through a subcommittee, was considering alternatives to the purely altruistic system of organ donation that presently exists. ACOT’s objective was to set the stage for discussion to move forward on “valuable consideration” and to determine whether and what changes or clarifications might be recommended by ACOT to the concept.

ACOT considered fourteen incentive options, one of which was the payment of funeral expenses for deceased donors. While ACOT did not find the funeral benefits option to be unquestionably acceptable under the NOTA prohibition of “valuable consideration,” the subcommittee found that a funeral benefits program would be an “ideal” demonstration project and voted to keep the funeral benefits concept under consideration by the subcommittee.

The ACOT subcommittee concluded that it is desirable to get clarification and greater specificity in regard to what it considered “the broad and somewhat confusing prohibition of valuable consideration in the context of organ donation.” To this end, ACOT approved the following recommendation (with explanation) in November 2004. Specifically, ACOT recommended amending NOTA to allow for the Secretary of Health and Human Services to identify, by regulation, additional practices that could be excluded from the concept of “valuable consideration” under the law:

Recommendation 36: The Advisory Committee on Organ Transplantation (ACOT) recommends that the Secretary of Health and Human Services (HHS) seek authority to identify and exclude certain practices from the definition of “valuable consideration” in section 301(a) of the National Organ Transplant Act, as amended.

⁶Shifting Ethics: Debating the Incentive Question in Organ Transplantation,” Donald Joralemon, *Journal of Medical Ethics*, 2001; 27:30-35.

Exhibit 12

Positions of Key Organizations and Observers Regarding Financial Incentives

Organization	Position
Institute of Medicine of the National Academies	A payment earmarked for the deceased donor's funeral expenses as an incentive to consent to donation and an expression of gratitude for the decision may be conceptually and morally distinguishable from buying an organ because such a payment in no way reflects the actual value of the organ. However, a pilot study should be undertaken <i>only</i> if other, less controversial, strategies of increasing organ donation have been tried and proven unsuccessful.
United Network for Organ Sharing (UNOS)	Feasibility and effect of financial incentives remained questionable without supporting data and should not be pursued until financial incentives are widely accepted as different from the purchasing of organs.
Council on Ethical and Judicial Affairs of the American Medical Association	Supports the implementation of pilot program to study the influence of financial incentives on organ donation rates, subject to certain conditions; incentives should play no role in the allocation of donated organs.
American Society of Transplant Surgeons	While expert panel opposed exchange of money for cadaver donor organs, majority supported reimbursement for funeral expenses or a charitable contribution as an ethically permissible approach (depending on the amount) that conveyed the appreciation of society to the family for donation. Pilot project supported.
International Society for Heart and Lung Transplantation	Seventy percent of members surveyed supported the concept of indirect compensation, such as the payment of funeral expenses or donation to a charity of the family's choice.
American Society of Transplantation	Opposes payment for organs from living and deceased donors, but acknowledged that limited incentives serve as "recognition" and merit broad discussion and careful study. Supports small pilot programs to study effectiveness and impact on altruism.
International Forum for Transplant Ethics	Believes the issue of incentivizing organ donation should be considered, possibly allowing for incentives that are regulated.
Gary Stanley Becker, (Nobel Prize for Economic Sciences Winner 1992)	Compensating persons for allowing their organs to be used after their death, or for kidneys and livers to be used while they are alive, would enormously widen the scope of potential organ market. Arguments against allowing compensation are not compelling when weighed against lives that would be saved by the increased supply.
The Transplantation Society	Guidelines state "No transplant surgeon/team shall be involved directly or indirectly in the buying or selling organs/tissue" and that "organs and tissues should be freely given without commercial consideration or financial profit."
National Kidney Foundation	Stated that "it is impossible to separate the ethical debate of financial incentives for non-living donation from the unethical practice of selling human organs."
World Health Organization	Guiding Principles on Human Organ Transplantation state opposition to any commercialization of the organ transplant process. Giving or receiving payment (including any other compensation or reward) for organs should be prohibited.

Sources: Developed by LB&FC staff based on an examination of pertinent reports, documents, and position statements of the listed organizations.

The Secretary's authority should be limited to legitimate and beneficial practices that are intended to increase the supply of human organs, without creating a commercial market for the purchase or sale of human organs or posing a risk of coercion of a potential donor or donor family. In addition, the Secretary should be required to obtain an appropriate independent ethical evaluation before excluding any practice from the prohibition on valuable consideration.

ACOT has concluded that a process to limit the scope of "valuable consideration" would encourage the development of ethical practices to increase the supply of human organs and provide certainty to the transplant community about the scope of permissible activities. Regulatory authority is both more flexible and more responsive to innovation than an expanded statutory list of practices that are not included in the term "valuable consideration." The notice and comment period will provide an opportunity for public and professional input into any proposed regulation.

Institute of Medicine of the National Academies. The Institute of Medicine of the National Academies (IOM), in its 2006 report *Organ Donation: Opportunities for Action*, points out that the legal ban⁷ on financial incentives for organ donation did not end the discussion regarding incentives.

The IOM report stated as follows:

The discrepancy between organ supply and need remained troubling; and even though the rates of organ donation increased, they remained disappointing, even with the adoption of measures such as required request, which assumed that there was no shortage of givers, only a shortage of askers. Not surprisingly, proposals for the use of financial incentives and new nonfinancial incentives emerged with greater frequency and forcefulness. The most radical of these proposals involved legalizing the purchase and sale of organs in a free market.

The IOM report, however, acknowledged that the issue of financially incentivizing organ donation rests in part on a widely shared supposition that solid organs of deceased individuals should not be bought and sold.

The IOM reported that surveys of public opinion, however, showed mixed findings and suggested the public is largely ambivalent regarding this issue. The IOM reported that the 2005 National Survey of Organ Donation found that 18.8 percent of respondents would be more likely to donate a family member's organs if they were offered a payment, 10.8 percent would be less likely, and the vast

⁷In addition to the ban under NOTA, many states, including Pennsylvania, also have state statutes banning financial incentives for organ donation.

majority—68.2 percent—would be neither more nor less likely to grant consent.⁸ The IOM committee believes that there are powerful reasons to preserve the idea that organs are donated rather than sold and the question remains whether rates of donation would increase even more if current motivation to donate were reinforced by providing something of material worth. The IOM reasoned that

Human behavior is complex, and people often have multiple motivations for engaging in an act. For example, charitable gifts continue to be perceived as donations, even though they are also accompanied by tax incentives. Under the right circumstances, donated organs might continue to be viewed as gifts, despite the presence of financial incentives.

The IOM stated that financial incentives for donation are meant to function within the gift model of donation with proponents for financial incentives arguing that the distinction between an incentive of material value and a payment for organs is sometimes lost in the discussion. The IOM concluded that upholding this distinction is fundamental to whether or not the strengths of the gift model can be preserved if donation is to be rewarded by a financial payment. Thoughts vary, according to the IOM, on whether a financial incentive for organ donation successfully avoids the commodification concern and preserves the strengths of the gift model and the IOM specifically considered the hypothetical proposal to pay funeral benefits expenses as an incentive for organ donation.

The IOM found that survey data consistently indicate that the public would be more receptive to an incentive program involving a funeral payment than a direct cash payment for organs. Moreover, the IOM thought that a \$1,000 payment, for example, earmarked for the deceased donor's funeral expenses as an incentive to consent to donation and an expression of gratitude for the decision may be conceptually and morally distinguishable from buying an organ because such a payment in no way reflects the actual value of the organ, and it would be positioned within a gift model or organ donation, analogous to a tax incentive for charitable giving rather than a purchase.

The IOM concluded that there was substantial uncertainty about the effects of offering financial incentives for donation and that there was a genuine possibility that it could reduce the rates of organ donation. As such, the IOM did not favor making financial payments to benefit families, either directly or indirectly. Moreover, the IOM concluded that a pilot study of the effect of financial incentives should be undertaken only if other, less controversial, strategies of increasing organ donation have been tried and proven unsuccessful and if, as a result, policy makers have become inclined to implement such a strategy.

⁸The percentages from the same question in the 1993 survey showed 12 percent more likely to donate, 5 percent less likely, and 78 percent neither more nor less likely to donate.

The American Society of Transplant Surgeons. In 2002, the American Society of Transplant Surgeons published a report *Financial Incentives for Cadaver Organ Donation: An Ethical Reappraisal*.⁹ For this study, the Society assembled a panel of ethicists, organ procurement organization executives, physicians, and surgeons to determine whether an ethically acceptable pilot trial could be proposed to provide a financial incentive for a family to consent to the donation of organs from a deceased relative.

The panel expressed unanimous opposition to the exchange of money for cadaver donor organs on the basis that either a direct payment or tax incentive would violate the ideal standard of altruism in organ donation and unacceptably commercialize the value of human life by commodifying donated organs. However, a majority of the panel supported reimbursement for funeral expenses or a charitable contribution as an ethically permissible approach.

The panel concluded that the concept of the organ as a gift could be sustained by a funeral reimbursement or charitable contribution that conveyed the appreciation of society to the family for their donation and that depending on the amount of the reimbursement provided for funeral expense, this approach could be ethically distinguished from a direct payment. The panel suggested that a pilot project be conducted to determine whether this kind of financial incentive would be acceptable to the public and successful in increasing organ donation.

Other Organizations.

UNOS. A 1993 white paper by the Payment Subcommittee of UNOS stated that the feasibility and effect of financial incentives for organ donation remained questionable without the availability of supporting data and should not be pursued until financial incentives are widely accepted as different from the purchasing of organs.

The Council on Ethical and Judicial Affairs of the American Medical Association. In 2000, the Council issued a report supporting the implementation of a pilot program to study the influence of financial incentives on organ donation rates, subject to certain conditions. The AMA's position is that only the potential donor may accept the incentive, which should be of moderate value, and should be paid only after the organs have been retrieved and judged medically suitable for transplantation. Moreover, the AMA believes incentives should play no role in the allocation of donated organs.

International Society for Heart and Lung Transplantation. A survey was conducted of the membership of the International Society for Heart and Lung Transplantation, looking for opinions as to how to improve organ donation. Seventy

⁹See, TRANSPLANTATION, Vol. 73, 1361-1367, No. 8, April 27, 2002.

percent of respondents supported the concept of indirect compensation, such as the payment of funeral expenses or donation to a charity of the family's choice (the majority of respondents thought "presumed consent" to be the single best way to significantly improve organ donation.)

American Society of Transplantation. The American Society of Transplantation (AST) policy opposes payment for organs from living and deceased donors but does recognize that more recent proposals for financial incentives deal with a limited incentive such as contributions towards the donor's funeral expenses or a modest lump sum payment to a beneficiary of the donor. The AST acknowledged that these incentives would be given as recognition of the donor's life saving act and concluded that they merit broad discussion and careful study. The AST suggested that small pilot programs might provide needed information that could be used to answer difficult questions about whether limited financial incentives both will increase donation and not compromise altruistic donation.

International Forum for Transplant Ethics. This organization does not advocate for a permanent prohibition on incentivizing organ donations and believes the issue should be considered again, possibly allowing for incentives that are regulated.

Transplantation Society. This is an international organization tasked with providing global leadership in the practice of human transplantation, including promoting ethical standards for clinical care and scientific investigation. The Council of The Transplantation Society first addressed commercialization or brokerage of transplantable organs more than 20 years ago to declare its opposition. TTS guidelines, developed at the time and still in place today, state that "No transplant surgeon/team shall be involved directly or indirectly in the buying or selling organs/tissue" and that "organs and tissues should be freely given without commercial consideration or financial profit."

National Kidney Foundation. The National Kidney Foundation (NKF) also opposes payment for organs and has stated that "it is impossible to separate the ethical debate of financial incentives for non-living donation from the unethical practice of selling human organs." The NKF stated that the consequence of congressional endorsement of a payment for organs through demonstration projects would be profound, possibly propelling other countries to sanction an unethical and unjust standard of immense proportions in which the wealthy readily obtain organs from the poor.

World Health Organization. The World Health Organization's Guiding Principles on Human Organ Transplantation state the organizations opposition to any commercialization of the organ transplant process. They state (in pertinent part) that organs and tissues may be removed from the bodies of deceased and living persons for the purpose of transplantation only in accordance with the following Guiding Principles.

- *Guiding Principle 5:* The human body and its parts cannot be the subject of commercial transactions. Accordingly, giving or receiving payment (including any other compensation or reward) for organs should be prohibited.
- *Guiding Principle 7:* It should be prohibited for physicians and other health professionals to engage in organ transplantation procedures if they have reason to believe that the organs concerned have been the subject of commercial transactions.

Alternative Views of Whether “Valuable Consideration” Provisions in Federal Law Prohibit Implementation of a Pennsylvania-Type Funeral Expense Benefit Pilot Program

As discussed previously, no other state has attempted to implement an organ donor funeral expense benefit and there is no test case upon which state policymakers can rely. While there is some movement to evaluate integrating financial incentives into the organ donation process, the question remains as to what extent financial incentives can legally be used under the provisions of the National Organ Transplant Act (NOTA). Counsel to the federal Advisory Committee on Organ Transplantation (ACOT) indicated there has been no active response to ACOT’s recommendation to amend NOTA to give HHS discretion in clarifying “valuable consideration.” Moreover, no court case has addressed the statutory interpretation of this section of NOTA.

Since the Advisory Committee first proposed the funeral expense pilot in 1999, the Department of Health has consistently held that a program that reimburses an organ donor’s funeral expenses necessarily violates NOTA Section 301. The state’s OPOs, however, have disagreed.

General counsel to one of Pennsylvania’s two OPOs argued the point in a March 28, 2000, letter to DOH, concluding that the NOTA prohibition is limited only to the *selling* of organs for profit and that “it is inconsistent with the express language of [NOTA], as well as the legislative history, to broaden the prohibition well beyond its express words to somehow prohibit the *reimbursement* of a portion of the funeral expenses of an organ donor.”(emphasis added). Moreover, OPO counsel concluded that, as a criminal statute, NOTA Section 301 should be strictly construed and strictly limited to pure commercial transactions in human organs. To do otherwise, “would violate the basic tenets of statutory construction and criminalize conduct that [was] never expressly addressed.”

A recent Department of Justice (DOJ) opinion on the subject of kidney exchanges may impact the discussion concerning the relationship between financial incentives for organ donation and NOTA’s prohibition on organ transfers for “valuable consideration.” On March 28, 2007, the U.S. Department of Justice, through

its Deputy Assistant Attorney General for the Office of Legal Counsel, issued a memorandum opinion to the Department of Health and Human Services regarding the legality of kidney exchange practices in light of “valuable consideration.”

The DOJ addressed two forms of kidney exchange. First was the Living Donor/Deceased Donor Exchange, where a living donor donates a kidney to an unknown, compatible recipient on the list for a deceased donor in exchange for the living donor’s intended (but incompatible) recipient receiving some priority on the deceased-donor waiting list, thereby shortening his waiting time. Second was the Paired Exchange, where an OPO matches two or more incompatible donor/recipient pairs where each living donor is compatible with another living donor’s intended recipient.

Because each procedure involves a transfer of a human organ in exchange for a benefit to the living donor’s intended recipient as a third party, it, therefore, calls into question the legality of the kidney exchange under NOTA Section 301 as a possible transfer for “valuable consideration.” In issuing its opinion, the DOJ concluded that since the kidney exchanges do not involve exchanges of things of pecuniary, readily convertible into monetary value, they do not “clearly and definitely” fall within the prohibition of NOTA Section 301.

Though the DOJ opinion did not directly address *financial* incentives for organ donation, the DOJ’s analysis provides helpful insights relating to the financial incentives discussion and arguably opens the door for further development of financial incentives programs. DOJ concluded that NOTA Section 301 does not define “valuable consideration” but simply provides guidance as to what is not valuable consideration. By doing this, DOJ clarified the role of this language in NOTA and allowed that simply because an activity is not specifically excluded from “valuable consideration” under the language of NOTA Section 301, it could still be excluded and thereby permissible.

Therefore, since NOTA does not define “valuable consideration,” DOJ had to undertake a process of legal analysis and statutory interpretation to determine its meaning. In doing this, the DOJ concluded that “valuable consideration” as applied to organ donations, involved “some sort of buying and selling, or otherwise commercial transfer, of organs.” Consideration, to be “valuable,” should be “pecuniary, readily convertible into monetary value.”

The DOJ opinion focused on the involvement of *monetary* value in the transfer of human organs, specifically to address the question of whether something not of monetary value could be “valuable consideration.” DOJ concluded that for consideration to be “valuable,” it must involve something of “pecuniary, readily convertible into monetary value.” There is a potential in reading the DOJ opinion to conclude that transactions involving a transfer of something of monetary value are

necessarily transactions involving “valuable consideration.” This appears to be incorrect.

The DOJ concluded that “valuable consideration” in Section 301 of NOTA refers to the “buying and selling of organs for monetary gain or to organ exchanges that are otherwise commercial.” (DOJ Opinion pp 6-7.) While a transaction must involve monetary gain to fall within NOTA’s prohibition, one must conclude that not all monetary transactions would necessarily be prohibited because the transaction must first be a commercial transaction—that means one involving a buying and selling arrangement. Therefore, the ultimate distinction drawn by the DOJ in interpreting NOTA 301 is not between monetary and non-monetary gain but between commercial as opposed to non-commercial transfers of human organs. This reinforced that there is a distinction to be made between commercial transactions and gifts in the context of organ donation.

DOJ found, however, that the full scope of the phrase “valuable consideration” remained open to some question and that the language of NOTA was not “clear and definite” on the point. Moreover, DOJ stated that the prohibition in NOTA must be read narrowly, or less harshly, because NOTA lacked complete clarity on the issue of what constitutes “valuable consideration” and because as a criminal statute, the rule of lenity required a narrow reading of the prohibition. Such a *narrow* reading of NOTA’s prohibition, arguably allows for the potential consideration of carefully crafted financial incentives that also, upon analysis, are not “clearly and definitely encompassed [by the prohibition]... as distinct from ‘purchases’ or other transfers for profit.”

In reaching its conclusion that the kidney exchange programs did not involve transfers of human organs for valuable consideration, DOJ, however, only addressed the “valuableness” of what was being transferred and found that “valuableness” in the context of “valuable consideration” required that the thing exchanged in a transfer of a human organ had to have a *pecuniary*, readily convertible into monetary value. Since the kidney exchange programs did not involve such a pecuniary transfer, they could not be *valuable* consideration. The DOJ did not need to reach the next question—irrespective of the thing exchanged being valuable, was it *consideration*?

Since the funeral expense benefit envisioned by Act 102 would provide a monetary benefit, this unanswered question is key. The legal reasoning given by DOJ in the kidney exchange context, however, concludes that ultimately the key distinction is whether an organ transfer is commercial. Is it a buying and selling arrangement supported by a bargained-for exchange known as “consideration” or is it a gift, supported by donative intent? Only commercial activity is intended to be precluded by NOTA. It appears reasonable to conclude that as long as an organ transfer is made as a gift, any benefit, even of monetary value, provided to or on

behalf of an organ donor's family in recognition of that gift would not be commercial but only a gift made in exchange for a gift.¹⁰

At a minimum, given the DOJ's inclination to narrowly read the scope of NOTA's prohibition, a funeral benefit made in recognition of the gift of a human organ would not *necessarily* be "valuable consideration" and would, therefore not be "clearly and definitely" encompassed by the language of the prohibition. As such, it can be concluded that Pennsylvania's funeral benefit, as envisioned under Act 102, could be implemented so as to be permissible under NOTA Section 301.

Incidental Expenses: Meals and Lodging

As previously discussed, the DOH rejected the Advisory Committee's proposal to initiate a pilot funeral benefit program in 2000. At that time, the Department requested that the Advisory Committee instead explore the option of providing limited reimbursement of incidental expenses to donors and their families. This message was transmitted to the Advisory Committee co-chair in January 2001.

As a result, the Advisory Committee deferred its funeral expense pilot proposal and examined the potential reimbursement of donor families from the Trust Fund to help defray lodging and meal expenses under the "incidental expense" language in Act 102.¹¹ The reimbursement of lodging and meal expenses for organ donors and their families began in January 2002 as a pilot program known as the Organ Donation Expense Benefit Pilot Program.¹² Prior to the launch of the pilot program, the Department of Health contacted hospitals statewide to solicit participation in the program.

The Department of Health, Pennsylvania hospitals, and the state's OPOs participate in this collaborative effort. The hospital designated requestor or a member of the OPO staff informs eligible organ donors and their families with lodging and meal expenses of the availability of up to \$300 to defray these costs under the expense benefit program following confirmation of the decision to donate. Hospital or OPO staff also informs organ donors or their family of their responsibility to cover any lodging and meal expenses exceeding \$300. Participation in the expense benefit pilot program is voluntary.

¹⁰A gift is, or imports, a transfer of property *gratuitously, without consideration*, as distinguished from a sale, which imports a transfer for a consideration. See, 38A C.J.S. Gifts §8. In fact, Pennsylvania's Superior Court has held that a gift is still a gift even though it is made with the understanding and stipulation that the donor's funeral expenses will be paid with a part of the gifted property. See, Reynolds v. Maust, 142 Pa. Super. 109, 15 A. 2d 853, at 855 (1940).

¹¹Pennsylvania citizenship is not a requirement to participate in the pilot program. According to CORE officials, several out-of-state living donors and their families have participated in the expense benefit program.

¹²Following an initial three-year pilot program, the pilot status of the program was extended in 2005.

The Department of Health’s Bureau of Family Health administered the expense benefit pilot program prior to 2006, at which point the Bureau of Health Promotion and Risk Reduction assumed administrative authority over the program. Tissue donors or their families are not eligible to participate in the expense benefit pilot program.

While Act 102 authorizes a maximum of \$3,000 in voluntary expense benefits per donor (or donor family), the Department of Health established an invoicing protocol for the voluntary expense benefit program in which hospitals and their designated referral hotels (hotels which have established an arrangement with participating hospitals to receive donors and/or their families) choosing to participate in the program may invoice the Department up to \$300 per each donor and/or donor’s family for lodging and meal expenses associated with the vital organ donation.¹³ Further, the Department’s invoicing protocol established a fiscal year limit of \$3,000 that each participating hospital and its designated referral hotels may invoice the Department for these expenses. The reimbursement may not be made directly to the organ donor or their family.

Table 16 provides total Trust Fund disbursements for the voluntary benefits program in the period FY 2001-02 through FY 2005-06.

Table 16

Expense Benefit Program Trust Fund Disbursements	
(FY 2001-02 Through FY 2005-06)	
<u>Fiscal Year</u>	<u>Amount Disbursed</u>
2001-02.....	\$ 2,717
2002-03.....	17,633
2003-04.....	28,241
2004-05.....	24,327
2005-06.....	<u>20,953</u>
Total.....	\$93,781

Source: Developed by LB&FC staff using information obtained from the PA Department of Health.

In the period FY 2001-02 through FY 2005-06, a total of \$93,781 was expended for voluntary benefits to organ donors and their families. The highest amount expended for this purpose was \$28,241 in FY 2003-04, which was the second full fiscal year of the implementation of the pilot program. Since that time, the

¹³Hospitals with on-site facilities for meals and lodging may incur costs for these purposes to be invoiced directly to the Department of Health. An official from a participating hospital indicated that the \$3,000 fiscal year limit for reimbursement per hospital may have the practical effect of limiting the number of donors and their families able to participate in the program, as costs incurred by hospitals for on-site lodging and meals may be significantly less than hotel costs.

amount expended for the expense benefit program has gradually declined to \$20,953 in FY 2005-06.

As of June 2006, 473 donors or their families had received expense benefits for lodging and meal expenses associated with making a vital organ donation. All but one of the invoices submitted for reimbursement of lodging and meal expenses were for living donors and their families. Table 17 lists the hospitals that have participated in the pilot program during the period January 2002 through June 2006, and the number of program recipients receiving benefits.

Table 17

Expense Benefit Program Recipients, by Participating Hospital (January 1, 2002-June 1, 2006)	
<u>Hospital</u>	<u>Number of Recipient Donors/Families^a</u>
UPMC Presbyterian Hospital (Pittsburgh).....	157 ^b
Hospital of the University of Pennsylvania (Philadelphia)....	113
Pinnacle Health (Harrisburg).....	88
Geisinger Medical Center (Danville)	59
Thomas Jefferson University Hospital (Philadelphia)	38
Milton S. Hershey Medical Center.....	17
Hahnemann University Hospital.....	1
Total (June 2006)	473

^aTotals are for living donors and their families.

^bIncludes 156 living donors and one deceased donor.

Source: Developed by LB&FC staff using information obtained from the PA Department of Health.

As shown, seven Pennsylvania transplant hospitals (out of 17 transplant hospitals statewide) participated in the expense benefits program between January 2002 through June 2006. Of the seven participating hospitals, six are in GLDP's service area and one is in CORE's service area.

Family Grief Counseling Through Community-Based Providers

Because the Organ Donation Expense Benefit Pilot Program is primarily serving living donors, the Advisory Committee sought another avenue to provide a Trust Fund benefit to families of deceased donors. To accomplish this objective, the Committee finalized a proposal in 2006 that would provide a Trust Fund supported family grief counseling and bereavement support benefit through community-based providers.

Background

Through this initiative, the Organ Donation Advisory Committee states that it is recognizing the importance of providing appropriate support to the families of deceased donors. In addressing this topic, the Advisory Committee states that there is currently a need for such services and both an opportunity and obligation to help families of deceased donors in their grief experience.

Given the above and the potential for donor families to be important advocates for donation, the Advisory Committee, along with DOH and the state's two OPOs, is seeking to develop an aftercare program to provide readily accessible short-term grief counseling to donor families throughout the state at no charge to the family.

In June 2005, the Advisory Committee formed a subcommittee to review methods of providing grief counseling to families of deceased organ donors. The sub-committee consisted of representatives from CORE, GLDP, and members of the Advisory Committee. To aid in the development of a proposal for a formal grief counseling program, representatives from GLDP informed the Advisory Committee of grief counseling services currently offered by their organization for families of deceased donors.¹⁴ Another Committee member confirmed that eight sessions was considered to be the clinical standard for grief counseling. Also discussed were cost estimates per session and the identification and availability of qualified counselors.

The Advisory Committee passed motions in 2005 to move forward with the grief counseling program and, in June 2006, passed motions to direct up to \$30,000 for the establishment of a pilot grief counseling program.¹⁵ Later in 2006, the Advisory Committee passed a motion to support the commencement of a pilot program to support grief counseling for all organ donor families in need.

Proposals for a Grief Counseling Benefit

GLDP representatives presented a proposal entitled, *Providing Family Grief Counseling Through Community-Based Providers* at the December 2005 Advisory Committee meeting. Based on and expanding upon grief counseling service provided in GLDP's service area, the proposal sought to identify grief counselors

¹⁴The Gift of Life Donor Program (GLDP) currently provides families of deceased organ donors with the option of receiving grief counseling. GLDP's Family Support Services staff provides individual counseling, group sessions, monthly support groups, and other special programs as well as up to eight counseling sessions for deceased donor families at no cost to the families. The ability for OPOs to focus on grief counseling is, however, limited due to geographic location of families and counselors, financial issues, and staffing.

¹⁵This amount was a portion of the \$500,000 that was reallocated in FY 2006-07 from the planned implementation costs for an OTDAP program evaluation to additional grant monies for the state's OPOs for the purposes of marketing the PENNDOT online donor designation website, minority awareness initiatives, to reimburse PENNDOT for costs associated with establishing the online donor designation capability, and for a pilot grief counseling program.

statewide that have some professional knowledge or familiarity with organ donation and transplantation. To this end, several organizations were identified with which the OPOs have a working relationship as starting points to locate qualified counselors. Following this discussion, the Committee co-chairperson proposed that the OPOs work with the Department of Health to develop a more detailed proposal for a statewide grief counseling program.

At the March 2006 Advisory Committee meeting, the subcommittee tasked to review methods of providing a grief counseling program presented a handout entitled, *Recommendations and Proposal for Providing Family Grief Counseling Through Community-Based Providers*. This proposal built upon subcommittee conference calls, results from a donor family survey completed by GLDP (in which 46 percent of respondent families indicated that they would use free grief counseling if it were available), and the preliminary identification of approximately 165 mental health practitioners who self-identify as having a specialty in grief and bereavement counseling in Pennsylvania.

The proposal utilizes Pittsburgh, Erie, Harrisburg, and Scranton as pilot cities where counselors are to be trained. Families eligible for grief counseling under the pilot program are:

- donor families who are Pennsylvania residents;
- donor families of organ donors who donated in Pennsylvania;
- donor families who gave consent and recovery was attempted, regardless of outcome; and
- any member of the next of kin family. Next of kin, as defined in Act 102, constitutes the donor’s spouse, son or daughter, parent, brother or sister, a guardian of the person at the time of death, and any other person authorized or under obligation to dispose of the body.

Families of deceased tissue donors would not be eligible to receive this benefit. This exclusion is based on the language of Act 102 and 20 Pa.C.S. § 8622 (b) that only authorizes the expenditure of Trust Fund monies for “incidental expenses incurred by the donor or donor’s family in connection with making a vital organ donation.” This exclusion has been a point of contention among some members of the Advisory Committee during discussion of this proposed initiative.

To identify qualified grief counselors for inclusion in the pilot program, the Plan calls for working with statewide community agencies and organizations, including the (1) National Association of Social Workers; (2) Pennsylvania Psychological Association; (3) Association of Death Education and Counseling; and (4) the Caring Place. The plan was to send an interest letter explaining the program and training requirements to identified counselors, together with a questionnaire

soliciting more information from the counselors regarding their training and experience with grief and bereavement counseling.

Specialized training specific to donation and transplantation would be developed including the following topic areas:

- brain death vs. cardiac death;
- sudden loss;
- impact of donation and donation process;
- family expectations and dynamics; and
- donor family to share personal story/experience

Workshops in the four pilot cities would be held, with four training sessions to be completed by June 2007. A conference fee of \$50 would first be collected for counselors to attend the program, and used to help defray the costs of the training sessions prior to the use of any Trust Fund monies for this purpose. The Plan established a goal of 60 counselors completing the first set of training sessions. The Plan provides a timeline for implementation of the pilot program with counselors to be available to provide services beginning in July 2007 (see Exhibit 13).

The Plan calls for OPOs to include brochures with each “donation outcome letter” (received by the next of kin of every donor) explaining the availability of grief counseling services and the names of counselors who have completed the training. In this notification, the OPOs will include a statement that endorsement of these counselors is not implied.

Each eligible donor family member, if they choose, would be entitled to up to eight grief counseling sessions at no charge. If further counseling is requested, individuals with medical insurance are to be encouraged to contact their insurance provider to determine if their coverage provides for behavioral health interventions.

All sessions are coordinated by the OPO in whose service area the vital organ donation of the deceased family member was made or in which recovery was attempted.

The OPOs will send a receipt to each individual receiving counseling indicating the dates of services for which the counselor is billing and an evaluation of the services they received. The counselor providing service would then submit an invoice for payment to the OPO which coordinated the donation. The OPO would then submit an invoice for reimbursement to the Department of Health. The Plan also includes an evaluation component.

Timeline for Implementation of the Pilot Grief Counseling Program

October 2006-May 2007

- Development of the curriculum.
- Sending interest letters and questionnaires to identified counselors.
- Screening interested counselors.
- Obtaining approval for Continuing Education Unit (CEU) credits for counselors participating in the training session.
- Securing conference locations and details.
- Sending the training schedule to selected counselors.

May 2007-June 2007

- Conduct four training sessions.
- Compile a list of counselors who have completed trainings for OPOs to distribute to donor families.

July 2007

- Counselors are available to provide services.

Source: *Proposal for Providing Family Grief Counseling Through Community-Based Providers*, DOH and Organ Donation Advisory Committee, 2006.

The Plan estimated that, based on a total of 443 organ donors in Pennsylvania in 2005 and assuming that 20 percent of donor families would utilize the statewide grief counseling program, 88 families would have requested services through this program.

We calculated a separate estimate if families of deceased tissue donors were authorized to receive grief counseling, based on the assumption that one member from each of 20 percent of tissue donor families would utilize the grief counseling program, and assuming further that the family member would utilize the entire eight sessions to which they would be entitled.

In 2006, GLDP and CORE coordinated the recovery of 1,201 tissue donors in Pennsylvania. Assuming that one member of 20 percent of the families of these tissue donors received eight sessions of grief counseling (at \$100 per session, or \$800 per family), the total cost to the program would be an additional \$192,800.

If the same assumption of participation were used for families of deceased organ donors in 2006, the cost to the program to provide services to one member from each 20 percent of the families (each receiving eight sessions) of 587 deceased organ donors in 2006 would be \$94,400. Combined with the estimated cost of providing

grief counseling to families of the 1,201 deceased tissue donors in 2006 (\$192,800), the program would incur costs of approximately \$287,200.

The proposed budget for implementation of the pilot program in FY 2006-07 is as shown on Table 18.

Table 18

Budget for Start-Up of the Grief Counseling Pilot Project (October 1, 2006-June 30, 2007)	
Four-Hour Counselor Training Sessions (Location, Meals, Equipment, Lodging, Travel Expense for Speakers, Cost of CEUs, and Training Materials).....	\$24,000
Honorarium for Speakers	4,000
Printing of Materials (Program Brochure, Letterhead, Envelopes)	1,600
Postage	<u>400</u>
Total.....	\$30,000

Source: Developed by LB&FC staff using information obtained from the PA Department of Health.

Implementation Status

As of April 2007, the training of grief counselors had not yet begun. Although funding had been authorized for this purpose, delays in execution of the grant between the Department of Health and Pennsylvania’s OPOs for the statewide awareness campaign and the unavailability of the individual designated to coordinate the commencement of the program prevented further action on the start-up plan.¹⁶ In FY 2007-08, the Department plans to commence the counseling sessions and implement the previously described invoicing protocols by including reimbursement in grant monies awarded to the state’s OPOs.¹⁷

¹⁶This individual is a member of the Family Support Services staff of the Gift of Life Donor Program.

¹⁷Discussion included under the first subpart of this Section of the report relates to the legality under federal law of providing certain benefits to the families of organ donors. While no one during the course of this study raised a concern with the LB&FC as to the legality of the Advisory Committee’s proposed grief counseling program, the program would, like the funeral benefit program, grant assistance of monetary value to or on behalf of a donor’s family in connection with a vital organ donation, thereby raising a question as to the legality under NOTA §301 of such a grief counseling program. This should be addressed by DOH prior to proceeding with the program

F. Hospital Compliance With Required Request and Routine Referral Requirements Related to Organ Donation

Findings

- F-1. Nationally, various initiatives have focused on increasing the organ and tissue donation rates by ensuring that all potential donor families are asked about donation (required request) and that hospitals notify OPOs of all imminent deaths (routine referral). Pennsylvania law requires both.*
- “Required request” laws obligate hospitals to tell the families of suitable donors that their loved one’s organs and tissues can be used for transplant and to inquire about organ and tissue donation. These laws have directed hospitals to develop policies to assure that families of all donor-eligible patients would be given the option to donate.*
 - Act 102 also required that hospitals have a “routine referral” agreement with an OPO and put in place mechanisms to contact the OPO in a timely manner about individuals who die or whose death is imminent. Underlying this requirement is the premise that health professionals were not effectively communicating with families about donation.*
- F-2. The practice of ensuring that the OPO is brought into the process was pioneered in Pennsylvania. The Center for Organ Recovery and Education in Pittsburgh was reportedly the first OPO in the country to broker an agreement with an acute care hospital for voluntary routine referral in 1989. Pennsylvania’s Act 102 then mandated routine referral in the state in 1994, and Pennsylvania’s law was the impetus for its adoption in other states and for its inclusion in the federal requirement in 1998. (The federal Conditions of Participation “Final Rule.”)*
- F-3. The Department of Health conducts “annual death record reviews” at the Commonwealth’s acute care general hospitals to determine their compliance with the required request and routine referral provisions of the Uniform Anatomical Gift Act. We found that between July 1, 2001, and June 30, 2006, a total of 47 hospitals were cited for failure to comply with some aspect of the UAGA but that only one facility was fined for continued deficient practice related to organ procurement.*
- F-4. The state’s organ procurement organizations also have agreements with hospitals through which the OPOs are permitted to review medical records and charts to help identify any lost potential for organ, tissue, and eye donation. Both the GLDP and CORE are engaged in an ongoing effort to determine whether potential organ donors are routinely being identified and referred to them as required by law.*
-

Required Request

“Required request” laws obligate acute care hospitals¹ to tell the families of suitable donors that their loved one’s organs and tissues can be used for transplant and to inquire about organ and tissue donation. These laws have directed hospitals to develop policies to assure that families of all donor-eligible patients would be given the option to donate. Beginning in 1986, the Health Care Financing Administration (HCFA) made hospital reimbursements for Medicare subject to hospitals having “required request” policies in place.² Moreover, the Joint Commission on Accreditation of Health Care Organizations has incorporated “required request” into its accreditation policies for hospitals.

Under Act 102, if it is determined by the regional OPO, in consultation with a patient’s attending physician, that a patient is a suitable candidate for anatomical donation, the hospital is required to initiate a request through either an OPO representative or a “designated requestor.”

Act 102 requires the “request” follow certain general guidelines:

- The OPO representative or “designated requestor” must ask the persons listed under section 8611(b) whether the deceased was an organ donor.
- If it is not known if the deceased was an organ donor, the listed person is to be informed of the option to donate organs and tissues.
- In making the request, the requestor is encouraged to use discretion and sensitivity to family circumstances in all discussions regarding donations of tissue or organs.
- Requestors are to take into account the deceased individual’s religious beliefs or nonsuitability for organ and tissue donation.

Routine Referral

Beginning in 1998, HCFA required that hospitals had to have an agreement with an OPO and to put in place mechanisms to contact the OPO in a timely manner about individuals who die or whose death is imminent. Underlying this “routine referral” requirement is the premise that health professionals were not effectively communicating with families about donation. Ensuring that the OPO is brought into the process began in Pennsylvania. The Center for Organ Recovery and Education in Pittsburgh was the first OPO in the country to broker an agreement with an acute care hospital for *voluntary* routine referral in 1989.

¹Defined as any hospital which has an emergency room facility.

²Federal hospital protocols for organ procurement require that participation in Medicare can happen only if: (A) the hospital or critical access hospital establishes written protocols for the identification of potential organ donors that— (i) assure that families of potential organ donors are made aware of the option of organ or tissue donation and their option to decline.

Pennsylvania's Act 102 then *mandated* routine referral in the state in 1994, and Pennsylvania's law was the impetus for the federal requirement in 1998.

Pennsylvania's Act 102 provides that hospitals must develop, "with the concurrence of hospital medical staff," protocols for identifying potential organ and tissue donors. Under Act 102, those protocols must provide that at or before a person's death in an acute care hospital, the hospital is *required* to contact its regional OPO to determine the suitability of the person for organ, tissue, and eye donation. Hospital protocol must also require hospitals to contact the OPO by telephone and provide the following information:

- patient's identifier number;
- patient's age;
- cause of death; and
- past available medical history.

If the patient is determined to be a suitable candidate for anatomical donation, the hospital is then required by law to initiate the "request" process.

DOH Death Record Reviews

Act 102 requires that the Department of Health conduct "annual death record reviews" at the Commonwealth's acute care general hospitals to determine their compliance with the required request and routine referral provisions of the Anatomical Gift Act. (See Exhibit 14.) The statute requires that the Department select the federally-designated OPO for the region in which the hospital is located to conduct the review. If the OPO is unwilling to carry out such reviews or if it operates or has an ownership interest in an entity which provides all of the functions of a tissue procurement provider, the Department of Health is to conduct the reviews using its own trained personnel.

Because both Pennsylvania OPOs operate as tissue procurement providers, the Department of Health conducts the required reviews to assess hospital compliance.³ The reviews are conducted by the staff of the Division of Acute and Ambulatory Care (DAAC) located in the Department's Bureau of Facilities Licensure and

³However, the OPOs have agreements with the participating hospitals through which the OPOs are permitted to review medical records and charts to help identify any lost potential for organ, tissue, and eye donation. Information from the OPOs record reviews is routinely shared with the hospitals with recommended follow-up, which may include added education or training. For example, if an OPO chart review indicates untimely referral of an imminent death at a hospital, the OPO will work with the hospital to identify areas that may need additional training.

Required Request and Routine Referral Requirements and DOH Survey

Requirement	DOH Survey Technique
<p>Hospital Protocols for identifying potential organ and tissue donors (developed with concurrence of hospital medical staff)</p>	<p>Review policies and procedures and confirm approved by hospital governing body.</p>
<p>“Routine Referral”– hospitals must,</p> <ul style="list-style-type: none"> • at or near the time of every individual death, • contact OPO by telephone with following info: <ul style="list-style-type: none"> -patient ID number -patient age -patient CO -available past medical history. 	<p>Review policies and procedures to see how the facility defines “imminent death” and assures notification of the OPO by telephone as soon as possible after an individual dies, been placed on a ventilator due to a severe brain injury, or been declared brain dead.</p>
<p>Determination of Suitability - OPO (in consultation with attending physician (or designee) determines suitability for donation.</p>	<p>DOH pulls sample of records of patients who have died within the past six months.</p>
<p>Follow-up on Suitability Determination</p> <ul style="list-style-type: none"> • If “no” on suitability, hospital notes on patient’s record and no further action needed. • If “yes” on suitability, hospital <u>must</u> initiate “request” through either <ul style="list-style-type: none"> - OPO rep, or -“Designated requestor” 	<p>Review open and closed patient records for documentation concerning patients who are within the parameters of patients included in the requirements.</p> <p>See if all who approached families were “designated requestors.”</p>
<p>“Request” Process: The OPO representative or “designated requestor” must ask persons pursuant to section 8611(b)</p> <ul style="list-style-type: none"> • whether the deceased was an organ donor; • if it is not known if the deceased was an organ donor, the person is to be informed of the option to donate organs and tissues; • In making the request, the requestor is encouraged to use discretion and sensitivity to family circumstances in all discussions regarding donations of tissue or organs; • Requestors are to take into account the deceased individual’s religious beliefs or nonsuitability for organ and tissue donation. 	<p>Compare documented “designated requestor” with list of trained “designated requestors” to assure that only those with training are functioning in the role.</p> <p>Inquire as to any complaints concerning the organ donation process in the facility compliant file.</p>

Sources: LB&FC review of Act 102 and DOH training documents.

Certification. This occurs at the time of routine licensure survey, every two years, or during investigation of complaints or events related to organ procurement matters.

The Division's approved complement, as of February 2007, included 46 Health Facilities Quality Examiners (HFQEs) supported by six regional managers (Health Quality Administrators), the Division Director, one Program Analyst, and nine clerical support staff. HFQEs, registered nurses, and one social worker, conduct surveys and investigations.

Training for survey activities is accomplished through Department-based orientation, training, and mentoring, and through Centers for Medicare and Medicaid Services (CMS) training for Basic Hospital Survey and specialty training. CMS has developed a 21-page questions and answers resource for use by surveyors on the Medicare Condition of Participation (42 C.F.R. 482.45), Organ, Tissue and Eye Procurement. The two Organ Procurement Organizations (OPOs) have also provided orientation sessions to the division survey staff on the OPOs' responsibilities and related background on organ transplantation services.

Designated requestor training is available from OPOs upon request of the hospitals. Both Pennsylvania OPOs indicated that hospitals have not historically requested training for hospital personnel to become "designated requestors" and more generally rely on OPO staff to serve as requestors, which is preferable to OPOs.

During licensure or certification survey or complaint investigation, compliance with the act is determined through review of policies and procedures, record review, and staff interviews. Surveyors compare the List of Referrals provided by the OPO responsible for the hospital being surveyed with the hospital death log to assess compliance with the Anatomical Gift Act (20 Pa.C.S.A. §8617). As part of their duties, surveyors ascertain a sample of death records since the previous time the facility was surveyed. A comprehensive record review is conducted on those selected deceased individuals to assure that proper education was provided and consents were obtained from the terminally ill patient and/or their custodians for organ donation purposes. Surveyors also assure that the appropriate OPO was contacted and that protocols outlined by the Center for Medicare and Medicaid Services were upheld.

When surveyors are unable to reconcile the hospital death log with the OPO referrals list, the individual medical records are reviewed to determine if documentation in the record is sufficient to assess hospital compliance. If it is found that the hospital failed to comply, the policies and procedures of the hospital related to anatomical gifts are reviewed to determine if they reflect the requirements of Act 102.

Should a facility fail to demonstrate compliance with the act, a citation, or statement of deficiency (SoD), is provided to the facility. A SoD states the statutory requirements as well as the findings during survey or investigation that support a finding that the facility failed to comply with the identified requirements. Upon receipt of a SoD, the facility must submit a plan of correction for Department review and acceptance. Follow-up surveys or revisits are conducted after the date on which the hospital has stated the plan of correction will be complete to determine if the facility has returned to compliance with the regulations.

The survey findings for Pennsylvania hospitals are found on-line through the Department of Health website at www.health.state.pa.us by using the link: Find A Health Care Facility under *Professionals and Providers*. On-line reports are available for surveys conducted on or after May 1, 2001. Where facilities participate in the on-line plan of correction program, the approved facility plans of correction for surveys after December 1, 2001, are also available through this site. All hospitals have used on-line submission since July 1, 2005. Survey reports are released to the public website 40 days after the survey exit date.

The Department may impose an administrative fine up to \$500 for each instance of non-compliance. However, monetary penalties are rarely applied; compliance is generally achieved by the hospital submitting a plan of correction specific to the identified deficiency.

Considerations in imposing a fine or other penalty include repeat or continuing violations of the regulations as well as the severity and extent of the problem identified during the survey. According to information provided by the Division of Acute and Ambulatory Care, between July 1, 2001, and June 30, 2006, a total of 47 hospitals were cited for failure to comply with some aspect of the Anatomical Gift Act. (See Table 19.) However, only one facility was fined for continued deficient practice related to organ procurement. During FY 2001-02, this facility was fined a total of \$2,000, including \$1,500 for failure to refer three deaths to the applicable OPO, and an additional \$500 for other statutory non-compliance. No fines or licensure actions related to the act have been imposed since FY 2001-02.

The Director of the Division of Acute and Ambulatory Care informed the LB&FC staff that, in relation to the Anatomical Gift Act, most of the deficiencies cited during the surveys result from facilities not adhering to their own established policies rather than failure to have required policies and protocols in place. Generally speaking, hospitals are highly motivated to demonstrate compliance with the federal Medicare Condition of Participation requirements. When deficiencies are found, follow-up visits, generally within six months, have ensured the hospital's compliance based on an acceptable plan of correction.

Table 19

Hospital Compliance With Anatomical Gift Act
(FY 2001-02 Through FY 2005-06)

<u>Fiscal Year</u>	<u>No. of Hospitals Cited</u>	<u>No. of Hospitals Fined</u>	<u>Dollar Value of Fines</u>
2001-02	20	1	\$2,000
2002-03	6	0	0
2003-04	6	0	0
2004-05	5	0	0
2005-06	<u>10</u>	<u>0</u>	<u>0</u>
Total	47	1	\$2,000

Source: Developed by LB&FC staff using information provided by the PA Department of Health, Bureau of Facilities Licensure and Certification, Division of Acute and Ambulatory Care.

Fines collected as a result of the Department of Health surveys are deposited into a “civil penalties restricted revenue account” pursuant to the Health Care Facilities Act, 35 P.S. §448.817 rather than into Governor Robert P. Casey Memorial Organ and Tissue Donor Awareness Trust Fund.⁴

⁴Although Act 1994-102 and 20 Pa.C.S. §8617(g) states that fines of \$500 for each instance of hospital noncompliance with reporting requirements of Pennsylvania’s Anatomical Gift Act are to be deposited into the Trust Fund, the Department of Health has chosen to identify any such fines as civil penalties under Section 817 of the Health Care Facilities Act. Funds deposited into this civil penalties restricted revenue account may be used to maintain management and operations of a health care facility pending correction of deficiencies or closure.

G. Organ and Tissue Donation and Transplantation Activity in Pennsylvania Since the Passage of Act 1994-102

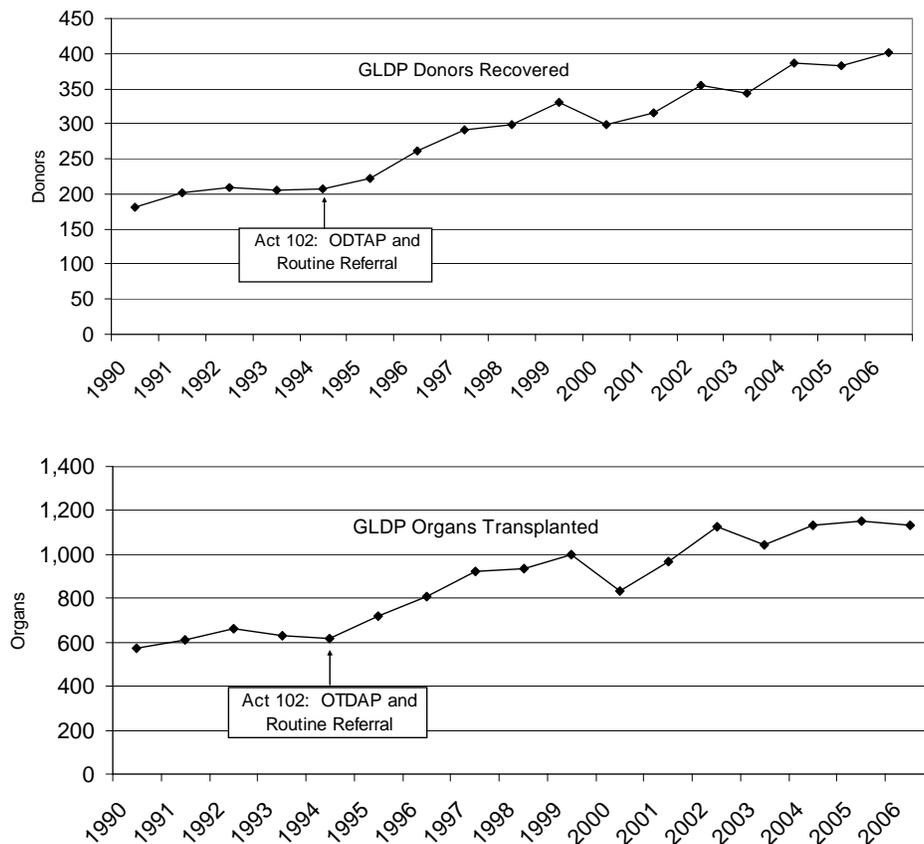
Findings

- G-1. Pennsylvania is a national leader in organ donation and transplantation. Both the state as a whole and its two organ procurement organizations (OPOs) rank at or near the top in several key measures used to compare organ donation and transplantation activity levels and performance nationwide. While such performance cannot be attributed solely to the initiation of the Organ and Tissue Donation Awareness Program, OPO officials and others cite Act 1994-102 and the resulting increase in public education and the incorporation of “routine referral” requirements into the process as being very instrumental in the gains that have been made in Pennsylvania.*
- G-2. Among the nation’s most populous states, Pennsylvania ranks first in two key measures: the number of deceased organ donors recovered (47.2 per million population in 2006) and the number of deceased donor transplants performed (149.4 per million population in 2006).¹ As used here, the measure, “donors recovered” is the total number of living and deceased donors from which at least one organ or tissue is recovered for the purpose of transplantation. A deceased donor is a patient who has been declared dead using either brain death or cardiac death criteria, from whom at least one vascularized solid organ is recovered for the purpose of organ transplantation.*
- G-3. Pennsylvania also ranks among the leaders nationally in the number of living donors and living donor transplants. A living donor is a living person who donates an organ for transplantation, such as a kidney or a segment of the lung, liver, pancreas, or intestine. Living donors may be blood relatives, emotionally related individuals, or altruistic strangers. In Pennsylvania in 2006, there were 409 living donors and 390 living donor transplants. Among the nation’s most populous states, this ranks Pennsylvania fourth in the number of living donors per million population (at 32.9 per million) and fourth in the number of living donor transplants per million population (at 31.4 per million population).*
- G-4. The Commonwealth’s two organ procurement organizations (OPOs), the Gift of Life Donor Program (GLDP) and the Center for Organ Recovery and Education (CORE) rank at or near the top in the number of donors recovered and transplants performed per million population among the nation’s 14 most populous OPOs. In 2006, Pennsylvania’s Gift of Life Donor Program ranked first among the nation’s 14 most populous organ procurement organizations in terms of both the number of donors and transplants conducted per one million population at 40.9 donors per million and 115.4 transplants per million. In*

¹The calculation of these rates includes data from the entire service areas of Pennsylvania’s two OPOs and may include some activity in Delaware, portions of West Virginia, New Jersey, and in one county in New York.

the same year, the Center for Organ Recovery and Education ranked second in donors per million population at 33.8 per million and among the top five in transplants per million population at 91.8 per million.

G-5. In all but two years between 1990 and 2006, the Philadelphia-based Gift of Life Donor Program coordinated more organ donations than any other OPO in the country. The number of donors GLDP recovered (from which at least one organ was recovered for the purpose of transplantation) was the highest in the nation in all but two years between 1990 and 2006, and was significantly above the national average. In 1999, GLDP exceeded 300 donors for the first time and in 2006 passed the 400 donor mark. Only one other OPO in the country has had more than 400 donors in a single year (Onelegacy OPO in Los Angeles in 2006). The graphs shown below illustrate the trend in GLDP's number of donors recovered and organs transplanted since 1990, with a definite upward trend evident following the passage of Act 1994-102.



G-6. Both of Pennsylvania's OPOs, GLDP and CORE, have been and continue to be active participants in the series of national Organ Donation Breakthrough Collaboratives and the Organ Transplantation Breakthrough Collaborative. Increasing the number of donations after cardiac death (DCD) is a component and outcome measure of a long-term goal of the federal Organ Transplantation Program and is a goal of the ongoing Collaboratives. Both GLDP and CORE have been particularly focused on increasing rates of DCD recoveries.

Statewide Data: Donors Recovered and Transplants Performed

Organ and tissue transplantation involves a complex, collaborative set of interactions among patients, family members, healthcare professionals, organ procurement and transplant coordinators, the hospital where the donation occurs, the organ procurement organization (OPO) that facilitates the acquisition and the distribution of organs and tissues, and the transplant center. This section provides statistical and trend data on organ and tissue donation and transplantation activity in Pennsylvania. The analysis uses statistical data obtained from the Organ Procurement and Transplantation Network (OPTN).^{2,3} We also examined data from Pennsylvania's two organ procurement organizations, the Gift of Life Donor Program (GLDP) and the Center for Organ Recovery and Education (CORE), as well as comparative statistical measures that are used by the Association of Organ Procurement Organizations (AOPO) that gauge the donation and transplantation activity levels of OPOs nationwide.

The OPTN maintains data both on deceased and living donors recovered. A deceased donor, according to the OPTN, is “an individual from whom at least one solid organ is recovered for the purpose of transplantation after suffering brain death or cardiac death.”

The OPTN defines a living donor as, “a living person who donates an organ for transplantation, such as a kidney or a segment of the lung, liver, pancreas, or intestine. Living donors may be blood relatives, emotionally related individuals, or altruistic strangers.”⁴

To gain perspective on Pennsylvania organ recovery and transplantation activity statistics, we calculated these measures on a per million population basis for the 15 most populous states, including Pennsylvania.

Organs recovered may subsequently be used for a transplant or research. Some organs are recovered exclusively for the purpose of research, while other

²Statistical data retrieved from the OPTN is tracked nationally using the United Network for Organ Sharing's online database system called UNet. Initiated in 1999, this system contains data regarding every organ donation and transplant event occurring in the U.S. since 1986. UNet provides for the collection, storage, analysis, and publication of all OPTN data pertaining to the patient waiting list, organ matching, and transplants. UNet is a continuously-operating secure Internet-based transplant information database created to enable the nation's organ transplant institutions to: (1) register patients for transplants; (2) match donated organs to waiting patients; and (3) manage the time-sensitive, life-critical data of all patients, before and after their transplants.

³UNOS requests that the following acknowledgment be provided concerning use of its data. “This work was supported in part by Health Resources and Services Administration contract 234-2005-370011C. The content is the responsibility of the authors alone and does not necessarily reflect the views or policies of the Department of Health and Human Services, nor does mention of trade names, commercial products, or organizations imply endorsement by the U.S. Government.”

⁴The OPTN's definition of a living donor also includes “domino” heart or liver transplants, “a procedure in which an organ is removed from one transplant candidate and immediately transplanted into a second patient, with the first patient receiving a new organ from a deceased donor.”

organs may be recovered for the intended purpose of transplantation and, following a determination of unsuitability for transplantation, may be used for the purpose of research. In addition, with the assistance of the responsible OPO overseeing recovery, tissues recovered are then transferred to the tissue procurement provider designated for the transplant hospital in which recovery occurred.^{5, 6}

In presenting several nationally recognized statistical measures for each of the OPOs, we also present notable achievements, initiatives, and awards received by each OPO relative to these measures. Both GLDP and CORE have been and continue to be active participants in the series of Organ Donation Breakthrough Collaboratives and the Organ Transplantation Breakthrough Collaborative.

Donors Recovered Per Million. Using statistics retrieved from the OPTN database and population data from the U.S. Census Bureau, we calculated ratios of both deceased and living donors recovered on a per million population basis for the 15 most populous states, including Pennsylvania, for 2006. Table 20 presents these data.

As shown, while Pennsylvania is the sixth most populous state in the U.S., it had the third highest number of deceased donors recovered and the third highest number of combined total of deceased and living donors recovered among the 15 most populous states in 2006, with 996 deceased and living donors recovered. This is more than double the 1994 total of 487 total donors recovered.

Pennsylvania achieved a ratio of just above 47 deceased donors recovered per million in 2006, which equals the highest per million total of deceased donors among the 15 most populous states. This represents an increase of approximately 68 percent compared to Pennsylvania's 1994 ratio of 28 deceased donors per million. Further, Pennsylvania's ratio of living donors per million nearly tripled in 2006 compared to 1994, increasing from just above 12 living donors per million in 1994 to nearly 33 living donors per million in 2006.

Also in 2006, Pennsylvania had the second-highest combined ratio of deceased and living donors recovered per million among the sample states, at a rate just above 80 donors recovered per million. This combined total ratio is double the combined ratio of just over 40 deceased and living donors recovered per million in 1994.

⁵The federal Food and Drug Administration's Center for Biologics Evaluation and Research (CBER) has had regulatory and oversight authority over human tissues intended for transplantation since 1993. Human cells or tissues intended for implantation, transplantation, infusion, or transfer into a human recipient are regulated as a human cell, tissue, and cellular and tissue-based product (or HCT/P). A transplant database comparable to the UNet database for organ transplantation is not available for tissues.

⁶According to the Musculoskeletal Transplant Foundation (MTF), after tissue recovery and processing the tissue is matched with a potential recipient and prioritized as follows: (a) the hospital where the donation was recovered, (b) the geographical area within the OPO where the hospital is located, and (c) any other hospital where there is a need.

Table 20

**Number of Donors Recovered Per Million
Population in 2006, PA, and Sample States**

	Number of Donors			Population Estimate	Donors Per Million Population		
	Deceased	Living	Total		Deceased	Living	Total
Pennsylvania ...	587	409	996	12,440,621	47.18	32.88	80.06
Massachusetts ..	229	331	560	6,437,193	35.57	51.42	86.99
Michigan	292	249	541	10,095,643	28.92	24.66	53.59
Georgia	267	110	377	9,363,941	28.51	11.75	40.26
North Carolina ...	250	124	374	8,856,505	28.23	14.00	42.23
Florida	504	223	727	18,089,888	27.86	12.33	40.19
Ohio	312	406	718	11,478,006	27.18	35.37	62.55
Texas	629	356	985	23,507,783	26.76	15.14	41.90
California	894	673	1,567	36,457,549	24.52	18.46	42.98
New York	469	554	1,023	19,306,183	24.29	28.70	52.99
Illinois	305	425	730	12,831,970	23.77	33.12	56.89
Indiana	141	107	248	6,313,520	22.33	16.95	39.28
Washington	139	113	252	6,395,798	21.73	17.67	39.40
New Jersey	162	171	333	8,724,560	18.57	19.60	38.17
Virginia	132	172	304	7,642,884	17.27	22.50	39.78

Source: Developed by LB&FC staff using OPTN data current as of March 9, 2007. Population data represents annual estimates compiled by the U.S. Census Bureau Population Division as of July 1, 2006.

Transplants Per Million. Using OPTN and U.S. Census Bureau data, Table 21 presents the number of transplants and transplants per million in 2006 for the 15 most populous states. As shown, Pennsylvania had the second highest number of transplants performed from organs recovered from deceased donors among the sample states in 2006. The 1,859 transplants performed in Pennsylvania using organs recovered from deceased donors in 2006 represents an increase of over 50 percent from the 1,231 transplants of this type completed in 1994. Moreover, the 2,249 total transplants performed (using organs recovered from both deceased and living donors) in Pennsylvania in 2006 is an increase of approximately 64 percent from the 1994 total of 1,370 transplants performed.

Pennsylvania achieved a ratio of approximately 149 transplants per million using organs recovered from deceased donors in 2006, which was the highest among the sample states in that year. Also in 2006, Pennsylvania had the highest combined ratio of transplants performed using organs recovered from both deceased and living donors, at above 180 per million.

Both of these ratios represent significant increases from 1994 totals. An increase of nearly 59 percent in the total number of transplants performed per million occurred in 2006 (181 per million) compared to 1994 (114 per million). The number of transplants performed per million using organs recovered from deceased donors

increased by more than 46 percent in 2006, at 149 per million, compared to 102 per million in 1994. Moreover, the number of transplants performed per million using organs recovered from living donors per million nearly tripled in 2006 (31.35 per million) compared to 1994 (11.54 per million).

Table 21

**Number of Transplants Per Million
Population in 2006, PA, and Sample States**

	Number of Transplants			Population Estimate	Transplants Per Million Population		
	Deceased	Living	Total		Deceased	Living	Total
Pennsylvania....	1,859	390	2,249	12,440,621	149.43	31.35	180.78
New York	1,731	542	2,273	19,306,183	89.66	28.07	117.73
Florida.....	1,566	223	1,789	18,089,888	86.57	12.33	98.90
Massachusetts...	522	243	765	6,437,193	81.09	37.75	118.84
Ohio	887	406	1,293	11,478,006	77.28	35.37	112.65
North Carolina ...	652	125	777	8,856,505	73.62	14.11	87.73
California	2,636	672	3,308	36,457,549	72.30	18.43	90.74
Texas.....	1,696	356	2,052	23,507,783	72.15	15.14	87.29
Illinois.....	905	426	1,331	12,831,970	70.53	33.20	103.73
Virginia.....	536	209	745	7,642,884	70.13	27.35	97.48
Michigan	679	249	928	10,095,643	67.26	24.66	91.92
Indiana.....	417	107	524	6,313,520	66.05	16.95	83.00
Washington.....	408	113	521	6,395,798	63.79	17.67	81.46
Georgia.....	515	110	625	9,363,941	55.00	11.75	66.75
New Jersey.....	362	171	533	8,724,560	41.49	19.60	61.09

Source: Developed by LB&FC staff using OPTN data current as of March 9, 2007. Population data represents annual estimates compiled by the U.S. Census Bureau Population Division as of July 1, 2006.

Statistical Data for Pennsylvania’s OPOs

This section presents statistical data on organ, tissue, and eye donation and transplantation for Pennsylvania’s OPOs for the period 1990 through 2006.

The Gift of Life Donor Program

The Gift of Life Donor Program’s (GLDP) service area includes a population of 9.8 million in eastern Pennsylvania, southern New Jersey and all of Delaware. GLDP’s Pennsylvania service area includes 35 counties covering approximately 7.8 million Pennsylvanians. The following is a summary of organ, tissue, and eye donation and transplant activity in the GLDP service area.

GLDP Organ Donation/Transplantation.⁷ Table 22 summarizes solid organ donation and transplantation activity in the GLDP service area during the period 1990 through 2006. The first column indicates the number of “referrals” to the GLDP in these years. Referrals are the number of patients at or near death who are referred to GLDP by hospitals in their designated service area.

Referrals from hospitals serviced by GLDP of individuals at or near death have had a fivefold increase over the period 1990 through 2006. In 1995, the first full year following passage of Act 102, the number of referrals increased by 192, or 30.4 percent over the 1994 level. The number of annual referrals first exceeded 1,000 in 1997, and topped 2,000 in 2005. The largest one-year increase occurred between 2004 and 2005, in which the number of referrals increased by 500, or 28.8 percent.

The number of potential donors identified increased by 141 between 1994 and 1995 (an increase of approximately 52 percent). Of these potential donors, the number of donors recovered (from which at least one organ was recovered for the purpose of transplantation) was the highest in the nation in all but two years between 1990 and 2006, and was significantly above the national average. In 1999, GLDP exceeded 300 donors recovered for the first time and, in 2006, passed the 400 donor mark. Only one other OPO in the country has had more than 400 donors in a single year (OneLegacy OPO in Los Angeles).

From the total recovered donors, the number of organs recovered by GLDP has increased steadily from 692 in 1994 to 1,319 in 2006. The average number of organs recovered per donor by GLDP (3.4 recovered per donor) was approximately equal to the national average in the years 2003, 2004, and 2005.

The number of organs transplanted by GLDP has grown from 616 in 1994 to 1,131 in 2006, an increase of almost 84 percent. In 2005, GLDP transplanted an average of three organs per donor, which approximates the national average. Also shown in Table 22 are organs provided for research by GLDP in the period 1990 through 2006.

GLDP Tissue Donation/Transplantation.⁸ Eight tissue procurement providers are located in GLDP’s service area.⁹ Tissue donation may be a viable option for both deceased solid organ donors and deceased potential donors determined to be

⁷While evaluations of suitability for both organ and tissue donation may occur at the same time, eligibility for tissue donation is higher than that of solid organ donation due to the more limited frequency of patient viability for organ donation, the increased complexity of organ recovery, and the greater ease by which tissue recovery may be possible following circulatory determination of death.

⁸While evaluations of suitability for both organ and tissue donation may occur at the same time, eligibility for tissue donation is higher than that of solid organ donation due to the more limited frequency of patient viability for organ donation, the increased complexity of organ recovery, and the greater ease by which tissue recovery may be possible following circulatory determination of death.

⁹This includes the Gift of Life Donor Program, which also serves as a tissue procurement provider.

Table 22

GLDP Organ Donation and Transplantation Statistics
(1990 Through 2006)

	<u>Referrals^a</u>	<u>Potential Donors^b</u>	<u>Donors Recovered^c</u>	<u>Organs Recovered^{d,e}</u>	<u>Organs Transplanted^f</u>	<u>Organs Provided for Research^g</u>
1990	453	182	182	616	571	81
1991	580	202	201	668	612	60
1992	505	211	210	715	665	43
1993	593	205	205	692	632	135
1994	631	270	208	692	616	120
1995	823	411	222	793	722	72
1996	951	540	262	933	807	131
1997	1,104	575	292	1,072	921	175
1998	1,164	555	298	1,071	933	151
1999	1,280	581	331	1,166	998	103
2000	1,366	614	298	1,028	831	186
2001	1,359	595	315	1,121	966	251
2002	1,507	684	354	1,266	1,124	225
2003	1,540	647	344	1,166	1,045	247
2004	1,734	648	387	1,316	1,134	355
2005	2,234	664	382	1,310	1,149	313
2006	2,466	723	401	1,319	1,131	361

Note: Table does not include statistical data on living donations. A living donor is a living person who donates an organ for transplantation, such as a kidney or a segment of the lung, liver, pancreas, or intestine. Living donors may be blood relatives, emotionally related individuals, or altruistic strangers.

^a"Referrals" represent all patients referred by hospitals in the GLDP Designated Service Area.

^b"Potential Donors" are referrals from hospitals who are determined to be medically suitable for organ donation who appeared to be brain dead, in addition to actual donation after cardiac death (DCD) donors, including some patients over 75 years of age. Electronic tracking of medical suitability on all donor referrals began in 1995.

^cDonors counted include only those who had at least one organ recovered for the purpose of transplant. Donors counted represent Standard Criteria Donors (SCD), Donors After Cardiac Death (DCD), and Expanded Criteria Donors (ECD).

^dThe number of organs recovered for transplantation. Organs divided into segments (liver, lung, pancreas, intestine) are counted as being recovered only once for that organ; however, if they are divided, more than one transplant may be counted.

^eThe sum of "Organs Transplanted" and "Organs Provided for Research" is not equal to total "Organs Recovered" due to GLDP receipt of organs from outside of its service area for transplantation. GLDP, in kind, exports organs not used within its service area to other service areas.

^fThe number of organs transplanted from donors coordinated by GLDP.

^gThe number of organs recovered for and sent to research. Also includes some organs recovered for transplantation that could not be placed in a recipient and were sent to research.

Source: The Gift of Life Donor Program (GLDP) data current as of March 12, 2007.

medically unsuitable for solid organ donation. With the assistance of the responsible OPO, recovered tissues are transferred to the tissue procurement provider designated for the transplant hospital in which recovery occurred. According to the Musculoskeletal Transplant Foundation (MTF), after tissue recovery and processing the tissue is matched with a potential recipient and prioritized as follows: (a) the hospital where the donation was recovered, (b) the geographical area within the OPO where the hospital is located, and (c) any other hospital where there is a need.

Table 23 provides statistics for tissue donor recovery and tissue grafts produced by GLDP in the period 1990 through 2006. As can be seen, the number of tissue donors recovered increased annually between most years between 1990 and 2006. The number of tissue donors recovered by GLDP first surpassed 500 in 2001, and totaled over 700 by 2005. By 2006, the number of tissue donors recovered by GLDP reached nearly 800. The largest increase in the number of tissue donors recovered occurred between 2004 and 2005, in which the number of tissue donors recovered increased by 170, or over 31 percent from the 2004 total.

Table 23

GLDP Tissue Donation and Transplantation Statistics
(1990 Through 2006)

	<u>Referrals^a</u>	<u>Potential Donors^b</u>	<u>Donors Recovered</u>	<u>Tissue Grafts Produced^c</u>
1990	947	947	171	6,840
1991	1,331	1,331	249	9,960
1992	1,273	1,273	227	9,080
1993	1,581	1,581	237	9,480
1994	2,861	2,861	278	11,120
1995	14,151	14,151	294	11,760
1996	36,843	36,843	308	12,320
1997	38,893	38,893	376	15,040
1998	39,897	39,897	412	16,480
1999	45,054	45,054	400	16,000
2000	46,616	46,616	494	19,760
2001	45,320	45,320	506	20,240
2002	45,291	3,607	506	20,240
2003	45,134	3,370	537	21,480
2004	43,414	3,562	541	21,640
2005	44,764	3,746	711	28,440
2006	35,562	3,648	799	31,960

Note: Tissue donation figures provided in this table do not include donations of bone marrow, cord blood, or peripheral blood cells (PBSC).

^aRepresents death notifications from institutions within GLDP's Designated Service Area.

^bReferrals with the potential for donation of at least one (1) musculoskeletal tissue based on FDA and processor requirements. Prior to 2002, data was not maintained measuring the number of potential donors exclusively, thus each referral was counted as a potential donor. In addition, not all referrals were recorded prior to 1995.

^cThe estimated number of tissue grafts produced based on an average of 40 grafts produced per tissue donor.

Source: The Gift of Life Donor Program (GLDP) data current as of March 12, 2007.

Tissue grafts produced from recovered donors increased by more than four and half times from the 1990 total of 6,840 to 31,960 in 2006. The number of tissue grafts produced first exceeded 20,000 per year in 2001. After remaining constant in 2001 and increasing slightly in 2003 and 2004, total grafts produced increased by 6,800, or over 31 percent, between 2004 and 2005. Tissue grafts produced from recovered donors by GLDP increased an additional 12 percent to reach 31,960 in 2006.

GLDP Eye Donation/Transplantation. GLDP, in conjunction with two additional eye procurement providers in its service area, coordinates the recovery of eyes for transplant. Corneas from recovered eyes are then used for transplant. Table 24 provides GLDP eye donation statistics between 1990 and 2006.

As indicated in Table 24, the number of potential donors was not measured exclusive from referrals prior to 2002. In that year, 6,833 potential eye donors were identified, with 898 eye donors recovered. The number of potential eye donors remained above 5,000 in the years 2003 through 2006, and the number of eye donors recovered reached a 17-year high of 1,325 in 2006.

Table 24

GLDP Eye Donation Statistics
(1990 Through 2006)

	<u>Referrals^a</u>	<u>Potential Donors^b</u>	<u>Donors Recovered</u>
1990	947	947	451
1991	1,331	1,331	592
1992	1,273	1,273	519
1993	1,581	1,581	623
1994	2,861	2,861	801
1995	14,151	14,151	1,038
1996	36,843	36,843	1,028
1997	38,893	38,893	885
1998	39,897	39,897	880
1999	45,054	45,054	743
2000	46,616	46,616	900
2001	45,320	45,320	811
2002	45,291	6,833	898
2003	45,134	5,214	743
2004	43,414	5,630	865
2005	44,764	5,749	1,208
2006	35,562	5,528	1,325

^aReferrals are death notifications from institutions within Gift of Life Donor Program's Designated Service Area.

^bPotential Donors are referrals with the potential for eye donation based on FDA and processor criteria. Prior to 2002, data was not maintained measuring the number of potential donors exclusively, thus each referral was counted as a potential donor. In addition, not all referrals were recorded prior to 1995.

Source: The Gift of Life Donor Program (GLDP).

The Center for Organ Recovery and Education (CORE)

CORE's service area includes western Pennsylvania, all of West Virginia, and Chemung County, New York. CORE's Pennsylvania service area includes 31 counties covering approximately 4.2 million Pennsylvania citizens. The following provides a summary of organ, tissue, and eye donation and transplant activity in the CORE service area.

CORE Organ Donation/Transplantation. Table 25 summarizes solid organ donation and transplantation activity in the CORE service area during the period 1990 through 2006. The first column on the table reports on the number of "referrals" to CORE in these years. Referrals are the number of patients at or near death who are referred to CORE by hospitals in their designated service area.

Referrals from hospitals serviced by CORE regarding individuals at or near death have more than doubled since 1991. The number of annual referrals first exceeded 400 in 1998, and reached a high of 604 in 2004.

The number of potential donors identified from referrals received by CORE reached a high of 394 in 1999. The number of donors recovered from potential donors identified reached a high of 196 in 2000. According to the Scientific Registry of Transplant Recipients (SRTR), CORE remained above the national average for the number of donors recovered in the years 2003-2005.

CORE recovered 680 organs in 2006, which was the highest amount in the period 1990-2006. This also represented an increase of nearly 38 percent from the 1992 total of 493 organs recovered. The number of organs recovered per donor by CORE remained at or above the national average in the period 2003-2005. While the number of organs transplanted by CORE varied from year to year, a high of 475 organs were transplanted in 2003. In 2006, the 465 organs transplanted by CORE represented a 25 percent increase over the number of organs transplanted in 2005.

CORE Tissue Donation/Transplantation.¹⁰ CORE has a total of five tissue procurement providers in its service area.¹¹ Tissue donations are recovered from both deceased solid organ donors and deceased potential donors determined to be medically unsuitable for solid organ donation.

¹⁰While evaluations of suitability for both organ and tissue donation may occur at the same time, eligibility for tissue donation is higher than that of solid organ donation due to the more limited frequency of patient viability for organ donation, the increased complexity of organ recovery, and the greater ease by which tissue recovery may be possible following circulatory determination of death. Nationally, about 1 million tissue transplants are performed annually.

¹¹This includes CORE, which also serves as a tissue procurement provider.

Table 25

CORE Organ Donation and Transplantation Statistics
(1990 Through 2006)

	<u>Referrals^a</u>	<u>Potential Donors^b</u>	<u>Donors Recovered^c</u>	<u>Organs Recovered^{d,e}</u>	<u>Organs Transplanted^f</u>	<u>Organs Provided for Research^g</u>
1990	NA	NA	NA	NA	NA	NA
1991	190	NA	96	NA	NA	NA
1992	335	226	139	493	376	52
1993	292	225	144	544	404	53
1994	330	262	132	508	370	69
1995	342	298	150	593	422	22
1996	310	302	145	533	396	38
1997	377	302	143	566	397	41
1998	470	314	146	585	394	45
1999	518	394	184	651	459	32
2000	412	388	196	530	393	37
2001	515	307	182	612	367	91
2002	599	246	156	614	402	130
2003	507	304	167	656	475	154
2004	604	320	151	583	334	121
2005	481	242	156	587	371	108
2006	456	233	186	680	465	59

Note: Table does not include statistical data on living donations. A living donor is a living person who donates an organ for transplantation, such as a kidney or a segment of the lung, liver, pancreas, or intestine. Living donors may be blood relatives, emotionally related individuals, or altruistic strangers.

^a"Referrals" represent all patients referred by hospitals in CORE's Designated Service Area.

^b"Potential Donors" are referrals from hospitals who are determined to be medically suitable for organ donation who appeared to be brain dead, in addition to actual donation after cardiac death (DCD) donors.

^cDonors counted include only those who had at least one organ recovered for transplant. Donors counted represent Standard Criteria Donors (SCD), Donors After Cardiac Death (DCD), and Expanded Criteria Donors (ECD).

^dThe number of organs recovered for transplantation. Organs divided into segments (liver, lung, pancreas, intestine) are counted as being recovered only once for that organ; however, if they are divided, more than one transplant may be counted.

^eThe sum of "Organs Transplanted" and "Organs Provided for Research" are not equal to total "Organs Recovered" due to CORE receipt of organs from outside of its service area for transplantation. CORE, in kind, exports organs not used within its service area to other service areas.

^fThe number of organs transplanted from donors coordinated by CORE.

^gThe number of organs recovered for and sent to research. Also includes some organs recovered for transplantation that could not be placed in a recipient and were sent to research.

Source: The Center for Organ Recovery and Education (CORE).

Table 26 presents tissue donation and transplantation statistics for CORE in the period 1990-2006.

Table 26

CORE Tissue Donation and Transplantation Statistics
(1990 Through 2006)

	<u>Referrals</u>	<u>Potential Donors</u>	<u>Donors Recovered</u>	<u>Tissue Grafts Procured</u>	<u>Tissue Grafts Provided for Research</u>
1990.....	NA	NA	NA	NA	NA
1991.....	6,875	NA	131	NA	NA
1992.....	13,552	684	180	345	0
1993.....	17,529	1,918	181	350	1
1994.....	15,723	1,520	241	439	1
1995.....	26,137	1,492	272	490	2
1996.....	31,022	1,851	335	465	1
1997.....	31,755	1,802	326	518	2
1998.....	31,755	1,744	351	593	7
1999.....	33,944	2,684	556	969	92
2000.....	34,638	3,032	633	1,052	98
2001.....	35,659	2,398	620	994	24
2002.....	33,524	2,245	618	1,396	23
2003.....	33,239	2,140	646	1,285	34
2004.....	31,487	2,907	647	1,281	4
2005.....	30,351	3,291	627	1,563	19
2006.....	29,101	2,956	708	2,120	23

Note: Tissue donation figures provided in this table do not include donations of bone marrow, cord blood, or peripheral blood cells (PBSC).

Source: The Center for Organ Recovery and Education (CORE).

As shown, the number of referrals received by CORE for the purpose of tissue donation greatly exceeds that for solid organ donation. Potential donors identified from these referrals are often less than 10 percent of the total referrals received during any year. The number of potential donors identified from referrals received reached a high of 3,291 in 2005.

The number of tissue donors recovered increased annually between 1991 and 1996. Between 1998 and 1999, the number of tissue donors recovered increased by 205 (over 58 percent) to reach a total of 556. In 2006, the number of tissue donors recovered by CORE reached a 17-year high of 708.

The number of tissue grafts produced by CORE generally increased from 1992 through 1999. In 2000, the number of tissue grafts procured by CORE first exceeded 1,000. By 2006, this total more than doubled to reach a new high of 2,120.

CORE Eye Donation/Transplantation. CORE coordinates the recovery of eyes, from which corneal transplants are performed, serving as its own eye procurement provider and in partnership with two additional eye procurement providers located within the CORE service area.

Table 27 provides eye donation and transplantation statistics for CORE for the period 1990-2006.

Table 27

CORE Eye Donation and Transplantation Statistics (1990 Through 2006)						
	<u>Referrals</u>	<u>Potential Donors</u>	<u>Donors Recovered</u>	<u>Eye Tissue Procured</u>	<u>Eye Tissue Transplanted</u>	<u>Eye Tissue Provided for Research</u>
1990	NA	NA	NA	NA	NA	NA
1991	6,875	NA	NA	NA	NA	NA
1992	13,552	645	141	282	282	0
1993	17,529	1,912	175	350	350	0
1994	15,723	1,484	205	410	410	0
1995	26,137	1,487	267	534	534	0
1996	31,022	1,927	411	822	822	0
1997	31,758	3,868	449	890	666	55
1998	32,233	4,191	512	1,024	775	18
1999	33,948	3,925	528	1,055	833	48
2000	34,638	3,486	541	1,071	816	61
2001	34,659	3,081	571	1,130	890	33
2002	33,524	3,078	660	1,304	956	42
2003	33,239	2,556	631	1,252	893	56
2004	31,487	2,717	564	1,121	659	68
2005	30,351	2,676	526	1,043	533	66
2006	29,101	2,444	568	1,090	513	110

Source: The Center for Organ Recovery and Education (CORE).

With a few exceptions, the number of individuals referred to CORE for potential eye donation equaled the number referred to CORE for potential tissue donation. The number of potential eye donors identified by CORE exhibited the largest increase between 1996 in 1997, in which the number of potential donors more than doubled to a total of 3,868.

The largest increase in the number of eye donors recovered occurred between 1995 and 1996, in which the total increased by 144 (nearly 54 percent) to reach 411 in 1996. The number of eye donors recovered reached a high of 660 in 2002.

The number of eye tissues procured first exceeded 1,000 in 1998. Thereafter, the number of eye tissues procured varied moderately, but remained above 1,000 through 2006. The number of eye tissues recovered that were transplanted also showed moderate variance, with a high of 956 eye tissues transplanted in 2002.

Pennsylvania OPOs Compared to Other Large OPOs on Selected Statistical Measures

To put the GLDP and CORE statistical data in national context, we compared their donation and transplantation activity levels in key measurement areas to those in 12 other large metropolitan areas. The service area populations of the OPOs examined ranged from a low of 5.5 million for CORE (Pittsburgh) to a high of 18.7 million for Onelegacy (Los Angeles).

The following are statistical highlights that illustrate how Pennsylvania's OPOs rank in relation to the other OPOs in the sample.

- In all but two years between 1988 and 2006, GLDP recovered more deceased organ donors (deceased donors from which at least one organ was recovered for the intended purpose of transplantation) than any other OPO in the U.S.
- In Calendar Year 2003, CORE had the second-highest ratio of donors per million population (30.4 per million) among the top 14 OPOs by population served, as well as the second-highest ratio of transplants per million (89.5 transplants per million). As a seven-year cumulative average among the nation's top 14 OPOs by population served, CORE had the third-highest ratio of donors per million (29.3 donors per million). In addition, CORE recovered a total of 107 donations after cardiac death (DCD) in the period 2000 through 2006, inclusive, ranking fifth in DCD donors recovered among the 14 OPOs sampled.
- As a cumulative total in the years 2000 through 2006, inclusive, GLDP recovered the most donations after cardiac death (DCD) donors (309) in this seven-year period, as well as the most organs recovered (8,582), the highest ratio of donors per million population (36.2 donors per million), and the highest ratio of transplants per million population (107.9 transplants per million) among the top 14 metropolitan area OPOs, by population.

Other Measures of Organ and Tissue Donation and Transplantation Activity in Pennsylvania

The following is a summary of some of the measures that reflect Pennsylvania OPO involvement and accomplishments through the national Organ Donation Breakthrough Collaboratives to date:

- Seven Pennsylvania hospitals in GLDP's service area and five hospitals in CORE's Pennsylvania service area participated in the Organ Donation Breakthrough Collaborative. This effort sought to spread "known best

- practices' to the nation's largest hospitals to achieve organ donation rates of 75 percent or higher in these hospitals.”
- At the Second Annual National Learning Congress on Organ Donation and Transplantation held in October, 2006, the Department of Health and Human Services (HHS) honored 371 of the nation's largest hospitals “for substantially raising the organ donation rates of eligible donors from their facilities.” Winning hospitals “had to achieve and sustain a donation rate of 75 percent or more from among eligible donors for at least a year.” In comparison, HHS reported that “the national average donation rate in all hospitals was 59 percent in 2005.” A total of 22 Pennsylvania hospitals received HHS Medals of Honor for Organ Donation, comprised of 6 hospitals in CORE's service area and 16 in GLDP's service area.
 - GLDP received a HHS award for “DCD with level Donation After Brain Death Sub-Goal Award” for achieving 10 percent of donors with DCD criteria for a consecutive six-month period (November 2005 to July 2006) at the Second Annual National Learning Congress on Organ Donation and Transplantation held in October, 2006.
 - GLDP was selected as one of six “best practice sites” for an evaluation report of the Organ Transplantation Breakthrough Collaborative. These sites were selected based upon their status as “among the national leaders in organs recovered and transplanted per donor.” As a result, seven overarching principles and 27 best practices were identified based on case studies of these high-performing OPOs.

Donors Recovered and Transplants Performed Among Selected Minority Populations

Because awareness and willingness to donate have been somewhat problematic among minority populations nationally, we examined trend data for two groups who are receiving focused attention in part of Pennsylvania's statewide organ and tissue donor awareness efforts. The following is a brief review of trend data among the state's African-American and Hispanic populations.

As of July 1, 2005, the U.S. Census Bureau estimated that 1,391,756 Pennsylvanians were African-American, representing 11.2 percent of Pennsylvania's population as of that date. As shown on Table 28, both the percentage of African-American donors and transplant recipients in Pennsylvania in 2005 were higher, proportionately, than the corresponding population percentage.

As can be seen, while small between-year decreases have occurred in the number of African-American donors recovered in Pennsylvania in the period 1995-2005, the 2005 total of 128 recovered African-American donors is more than double the 1995 total of 56 donors recovered. A similar pattern emerged with African-American transplant recipients, insofar as while a few small decreases between

years occurred in the number of African-American transplant recipients in the period 1995-2005, the 2005 total of 415 African-American transplant recipients represents a 93 percent increase from 1995.

Table 28

**African-American Organ Donors and Transplant Recipients
(1996-2005)**

Year	Number of Organ Donors Recovered ^a	% of all Donors Recovered	Number of Transplant Recipients	Percentage of all PA Transplant Recipients
1995.....	56	10.5%	215	14.0%
1996.....	56	9.3	289	17.8
1997.....	77	12.2	282	16.6
1998.....	68	10.7	277	16.9
1999.....	65	9.0	276	16.7
2000.....	95	12.6	275	17.1
2001.....	99	12.2	320	18.6
2002.....	115	13.0	345	18.2
2003.....	135	14.6	399	19.9
2004.....	145	14.8	369	17.9
2005.....	128	13.7	415	19.7

^aIncludes both deceased and living donors.

Source: Compiled by LB&FC staff using data obtained by the OPTN as of April 20, 2007, and from the U.S. Census Bureau.

The U.S. Census Bureau estimated that 506,084 Pennsylvanians are of Hispanic or Latino origin as of July 1, 2005, representing 4.1 percent of Pennsylvania's population as of that date. As shown on Table 29, the percentage of Hispanic organ donors was higher, proportionately, than the corresponding population percentage in 2005. However, the percentage of Hispanic transplant recipients was slightly lower than the population percentage in 2005, proportionately.

Similar to the number of recovered African-American donors, the number of recovered Hispanic donors variably increased and decreased from year to year in the period 1995-2005. For example, while the number of Hispanic donors recovered in 2005 was double the number recovered in 1995, the total in 2005 (40) was a decrease of 14, or over 25 percent, from the 11-year high of 54 Hispanic donors recovered in 2003.

The number of Hispanic transplant recipients reached a high of 88 in 2004. By 2005, the number of Hispanic transplant recipients (71) was lower than the number of Hispanic transplant recipients in 1995 (75).

Table 29

**Hispanic Organ Donors and Transplant Recipients
(1996-2005)**

<u>Year</u>	<u>Number of Organ Donors^a</u>	<u>% of all Donors Recovered</u>	<u># of Transplant Recipients</u>	<u>% of all PA Transplant Recipients</u>
1995	20	3.8%	75	4.9%
1996	26	4.3	51	3.1
1997	25	4.0	66	3.9
1998	20	3.1	61	3.7
1999	30	4.2	56	3.4
2000	26	3.5	61	3.8
2001	26	3.2	49	2.9
2002	35	3.9	57	3.0
2003	54	5.8	68	3.4
2004	45	4.6	88	4.3
2005	40	4.3	71	3.4

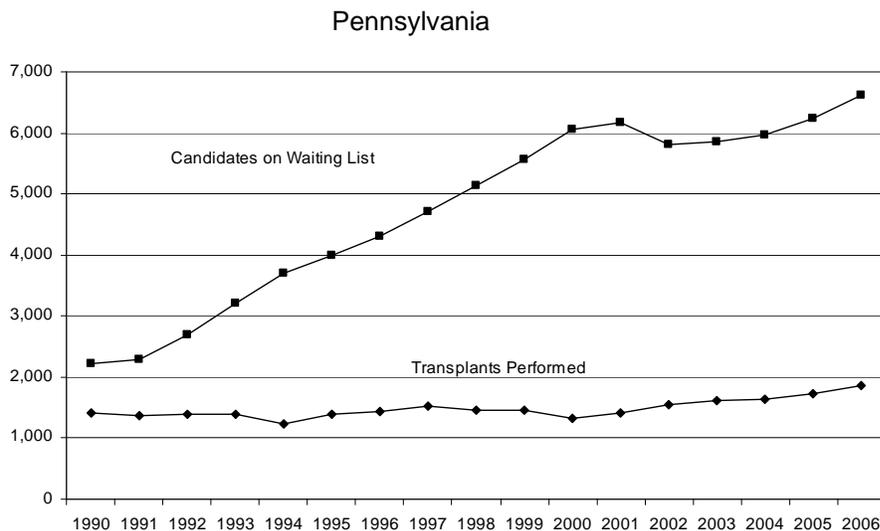
^aIncludes both deceased and living donors.

Source: Compiled by LB&FC staff using data obtained by the OPTN as of April 20, 2007, and from the U.S. Census Bureau.

H. Transplant Waiting Lists and the Continued Need for Program Services and Expansion of the Organ and Tissue Donor Registry

Findings

- H-1. *Despite recent increases in donation, the growing shortage of donated organs and tissues for transplantation is a pressing public health issue. As of March 9, 2007, 94,857 people were waiting to receive an organ transplant in the United States and approximately 18 persons die each day because too few organs are available. Every 13 minutes a new name is added to the national waiting list. Pennsylvania's waiting list as of March 9, 2007, was 6,672.*
- H-2. *There is a widening gap both nationally and in Pennsylvania, between the supply of transplantable organs and the number of patients on the waiting list. In Pennsylvania, between 1990 and 2006, the number of candidates on the waiting list nearly tripled while the number of transplants performed rose by 48 percent. This pattern underscores the need for increased donor designation and donation rates as well as the need for and importance of a state organ and tissue donation awareness program.*



- H-3. *The size of the waiting list is largely driven by the need for kidneys. Of the 94,857 eligible transplant candidates on the national waiting list for at least one organ as of March 9, 2007, about 74 percent (or 70,412) were candidates for kidney transplantation. Candidates on the national waiting list for liver transplants represented the second highest proportion at 17.9 percent. In Pennsylvania, kidney transplant candidates also represented the highest proportion, at 64 percent, as of March 2007. Candidates for liver transplants were second-highest by proportion in Pennsylvania at nearly 23 percent.*

H-4. There is a closely related complicating factor to consider when discussing the challenge of closing the gap between the number of candidates on the waiting list and the number of transplants performed. The extent to which the current system will be able to accommodate large increases in the number of donors and transplant recipients is unclear due to ongoing concerns about the serious shortages of nurses and other personnel. In a 2006 report, the Institute of Medicine cited this issue and called for strategic planning for such system challenges.

Transplant Waiting Lists

All patients accepted onto a transplant hospital's waiting list are registered with the national United Network for Organ Sharing (UNOS) Organ Center, where a centralized computer network links all organ procurement organizations (OPOs) and transplant centers. Staffed 24 hours a day throughout the year, the Organ Center assists with the matching, transporting, and sharing of organs throughout the U.S.

For each organ that becomes available from a deceased donor, a computer program generates a list of potential recipients ranked according to objective criteria (i.e., blood type, tissue type, size of the organ, medical urgency of the patient, time on the waiting list, and distance between donor and recipient). The matching criteria, or algorithms, are based on organ allocation policies, transplant center acceptance criteria, and local variances (UNOS/OPTN-approved variations of UNOS/OPTN allocation policies). Each organ has its own specific criteria. Ethnicity, gender, religion, and financial status are not part of the computer matching system.

As per OPTN policy, all candidates who are potential recipients of deceased organ transplants must be listed on the Waiting List. Candidates may be listed on multiple transplant center local waiting lists. However, each hospital may have its own rules for allowing its patients to be on the list at another hospital. Being listed in more than one area does not guarantee an organ will become available faster than for patients registered at only one transplant hospital.

Generally, each transplant center will require the patient to go through a separate evaluation, even if the patient is already listed at another hospital. Patients may switch to a different transplant hospital and transfer their waiting time to that hospital. Waiting time from the original center is added to the time collected at the new hospital. Each time a new patient is added to the waiting list, a Transplant Candidate Registration Form is generated and mailed to the member hospital. When returned to UNOS, this form provides additional clinical data about the potential transplant recipient.

When a patient lists at a transplant hospital, they are generally considered for organs from a donor in that local area first. If a patient is put on the list at more than one transplant hospital, they will be considered for donor organs that become available in more than one local area. There is no advantage to being listed at more than one hospital that is served by the same OPO. Hospitals can vary widely in the number of transplants they perform and the characteristics of the donor and recipient pool. OPOs can vary widely in the number and types of donors they receive each year.

According to the OPTN, the amount of time a patient remains on the waiting list depends on many factors, including:

- blood type (some are rarer than others),
- tissue type,
- height and weight of transplant candidate,
- size of donated organ,
- medical urgency,
- time on the waiting list,
- the distance between the donor's hospital and the potential donor organ,
- how many donors there are in the local area over a period of time, and
- the transplant center's criteria for accepting organ offers.

Depending on the kind of organ needed, some factors are more important than others.

Individuals may be removed from the waiting list for the following reasons: (1) receipt of an organ from a deceased or living donor; (2) death while waiting for a transplant or during the transplant procedure; (3) medical unsuitability for a transplant; (4) determined to be too sick for a transplant; (5) condition improved while on the waiting list; and (6) patient refusal of transplant.

Waiting List Data: U.S. and Pennsylvania

Number of Patients Awaiting Transplants

Even with the steady increase in the number of organs recovered and the increasing number of transplants being performed each year, the demand for transplantation far exceeds the supply of available organs.

The National Waiting List. The growth in the size of the national waiting list has been dramatic. At the end of 1988, there were 10,827 individuals on the national waiting list for an organ transplant. By 1995, the waiting list had nearly quadrupled to 41,179, and it has since again more than doubled. As of March 9, 2007, the waiting list totaled 94,857. The pattern is clear—a widening gap between the supply of transplantable organs and the number of patients on the waiting list.

Table 30 shows the annual increases in the number of candidates¹ for an organ transplant nationally in the period 1988 through 2007. As shown, the largest between-year percentage increase in the number of waiting list candidates occurred between 1988 and 1989, in which the number of candidates increased by 45.6 percent. The largest between-year increase in the number of candidates occurred between 1997 and 1998, when 7,176 candidates were added to the waiting list nationally.

Table 30

**The Number of Candidates on the
National Organ Transplant Waiting List
(1988 to 2007)***

Year	Number of Candidates ^{a, b}	Change Over Prior Year	
		Number	Percent
1988	10,827	--	--
1989	15,759	4,932	45.6%
1990	20,481	4,722	30.0
1991	23,198	2,717	13.3
1992	27,563	4,365	18.8
1993	31,355	3,792	13.8
1994	35,271	3,916	12.5
1995	41,179	5,908	16.8
1996	46,925	5,746	14.0
1997	53,123	6,198	13.2
1998	60,299	7,176	13.5
1999	67,101	6,802	11.3
2000	73,962	6,861	10.2
2001	79,377	5,415	7.3
2002	80,587	1,210	1.5
2003	83,514	2,927	3.6
2004	86,919	3,405	4.1
2005	90,290	3,371	3.9
2006	94,227	3,937	4.4
2007	94,857 ^c	--	--

*The Organ Procurement and Transplantation Network (OPTN) provides data on both the number of waiting list candidates and registrations. These numbers differ because one waiting list candidate may have multiple registrations. The statistics cited here are for transplant candidates.

^aRepresents the number of patients on the national waiting list for at least one organ.

^bTotals include Puerto Rico and Washington, D.C., but do not include the states of Alaska, Idaho, Montana, and Wyoming.

^cTotal as of March 9, 2007.

Source: Compiled by LB&FC staff based on OPTN data as of March 9, 2007.

¹The Organ Procurement and Transplantation Network (OPTN) provides data on both the number of waiting list candidates and registrations. These numbers differ because one waiting list candidate may have multiple registrations. For example, a patient who is listed through more than one center or for multiple organs would have multiple registrations. Unless indicated otherwise, the statistics cited are for transplant candidates.

While the number of candidates on the national waiting list never decreased between years in the period 1988 through 2007, the percentage change between years fell to under 10 percent beginning in 2001. Even with this pattern of smaller percentage increases, a continuation of the pattern of several thousand candidates being added to the waiting list each year will soon push the number of candidates waiting for an organ transplant to over 100,000.

The Pennsylvania Waiting List. Table 31 shows the number of candidates on the waiting list for a deceased donor organ in Pennsylvania between 1988 and 2007 and the increase in the number of candidates from the prior year. As shown, the largest percentage increase in the number of candidates occurred between 1988 and 1989, with a between-year increase of 131.6 percent. The largest increase in the number of candidates occurred between 1989 and 1990, in which 863 candidates were added to the Pennsylvania organ transplant waiting list.

Table 31

**The Number of Candidates on
Pennsylvania's Organ Transplant Waiting List
(1988 to 2007)***

Year	Number of Candidates ^a	Increase (Decrease) Over Prior Year	
		Number	Percent
1988	583	--	--
1989	1,350	767	131.6%
1990	2,213	863	63.9
1991	2,289	76	3.4
1992	2,700	411	18.0
1993	3,207	507	18.8
1994	3,703	496	15.5
1995	3,983	280	7.6
1996	4,302	319	8.0
1997	4,708	406	9.4
1998	5,144	436	9.3
1999	5,571	427	8.3
2000	6,066	495	8.9
2001	6,176	110	1.8
2002	5,809	(367)	(5.9)
2003	5,864	55	0.9
2004	5,964	100	1.7
2005	6,240	276	4.6
2006	6,613	373	6.0
2007	6,672 ^c	--	--

*The Organ Procurement and Transplantation Network (OPTN) provides data on both the number of waiting list candidates and registrations. These numbers differ because one waiting list candidate may have multiple registrations. The statistics cited here are for transplant candidates.

^aRepresents the number of patients on the Pennsylvania waiting list for at least one organ.

^cTotal as of March 9, 2007.

Source: Compiled by LB&FC staff based on OPTN data as of March 9, 2007.

Following a small increase between 1990 and 1991, the percentage increase in the number of waiting list transplant candidates was above 18 percent between years 1991 and 1992 and between 1992 and 1993. Beginning in 1995, the percentage increase in organ transplant candidates in Pennsylvania fell to under 10 percent, with a 5.9 percent decrease in the number of candidates occurring between 2001 and 2002.

Waiting Lists, by Organ. As shown on Table 32, the waiting list is largely driven by the need for kidney transplants. Of this number, as of March 9, 2007, there were 94,857 eligible transplant candidates on the national waiting list for at least one organ, 70,412, or about 74 percent, were candidates for kidney transplantation. Candidates on the national waiting list for liver transplants represented the second highest proportion at 17.9 percent.

In Pennsylvania, kidney transplant candidates also represented the highest proportion, at 64 percent as of March 2007. Candidates for liver transplants were second-highest by proportion in Pennsylvania at nearly 23 percent. Proportionately, the number of liver transplant candidates in Pennsylvania as of March 2007 was 5 percent greater than the proportion of liver transplant candidates nationally.

The number of candidates in Pennsylvania for an intestine transplant, while representing the second-lowest number of candidates on the Pennsylvania waiting list, represents over 48 percent of the total number of candidates for an intestine transplant on the national waiting list. The 112 candidates for an intestine transplant on Pennsylvania's waiting list as of March 2007 is the highest number of candidates for this transplant on a statewide waiting list in the nation.

In addition, Pennsylvania has the highest number of pancreas transplant candidates, lung transplant candidates, and combined heart/lung transplant candidates in the nation. Pennsylvania ranks second in the nation in the number of combined kidney/pancreas transplant candidates, third nationwide in the number of liver transplant candidates, and fourth nationwide in the number of heart transplant candidates.

Table 32

**Number of Patients on the Organ Transplant Waiting
List in Pennsylvania and the U.S., by Organ**
(As of March 2007)

Organ	Pennsylvania		United States	
	Number	% of Total	Number ^a	% of Total
Kidney	4,286	64.2%	70,412	74.2%
Liver.....	1,530	22.9	16,969	17.9
Pancreas	293	4.4	1,758	1.9
Kidney & Pancreas.....	191	2.9	2,383	2.5
Heart.....	181	2.7	2,829	3.0
Lung	389	5.8	2,809	3.0
Heart-Lung	33	0.5	131	0.1
Intestine.....	112	1.7	232	0.2
Total	6,672 ^b	100.0% ^c	94,857 ^b	100.0% ^c

^aTotals include Puerto Rico and Washington, D.C. but do not include the states of Alaska, Idaho, Montana, or Wyoming.

^bTotal is less than the sum of candidates for each organ due to patients being included in multiple categories.

^cMay not add to 100 percent due to rounding.

Source: Compiled by LB&FC staff based on OPTN data as of March 9, 2007.

Table 33 provides information on the number of persons on Pennsylvania's waiting list, by ethnicity and organ. Among all ethnicities, the largest proportion of candidates on Pennsylvania's waiting list is those waiting for kidney transplants, at over 64 percent of all candidates. Almost 88 percent of African-Americans on Pennsylvania's waiting list are candidates for a kidney transplant.

Table 33

Pennsylvania Waiting List, by Ethnicity and Organ
(As of April 13, 2007)

Ethnicity	All Organs	Kidney	Liver	Pancreas	Kidney/ Pancreas	Heart	Lung	Heart/ Lung	Intestine
All Ethnicities	<u>6,754</u>	<u>4,361</u>	<u>1,547</u>	<u>261</u>	<u>184</u>	<u>181</u>	<u>385</u>	<u>31</u>	<u>105</u>
White	4,262	2,253	1,303	219	153	146	319	24	80
Black.....	1,942	1,708	134	33	22	27	45	5	16
Hispanic.....	339	235	74	5	6	3	16	1	7
Asian	166	127	30	3	2	4	4	0	2
Am. Indian/Alaskan Native	16	13	2	0	0	1	0	0	0
Pacific Islander.....	4	4	0	0	0	0	0	0	0
Multiracial	29	23	4	1	1	0	1	1	0

Source: OPTN

Length of Time on the PA Waiting List

Table 34 provides the list of waiting times of current candidates by organ in Pennsylvania as of March 9, 2007. As a total of all organs, the highest number of current Pennsylvania candidates have been waiting between one and two years for an organ transplant, followed by candidates on the Pennsylvania waiting list between six months and one year.

Taken as a proportion of all transplant candidates for the respective organs, candidates on the Pennsylvania waiting list for liver, pancreas, heart, lung, and combined heart/lung transplants have the most patients who have been on the Pennsylvania waiting list for more than five years.

Table 34

Length of Time Patients Have Been on the Pennsylvania Waiting List, by Organ (As of March 9, 2007)

<u>Organ</u>	<u>All Organs^a</u>	<u>Kidney</u>	<u>Liver</u>	<u>Pancreas</u>	<u>Kidney/ Pancreas</u>	<u>Heart</u>	<u>Lung</u>	<u>Heart/ Lung</u>	<u>Intestine</u>
All Time	6,672	4,286	1,530	293	191	181	389	33	112
Less than 30 days...	293	182	75	9	9	16	13	0	5
30 days to less than 90 days	536	365	114	20	16	26	13	2	16
90 days to less than 6 months	652	460	133	42	26	16	10	1	19
6 months to less than 1 year	1,039	768	179	36	40	19	20	2	28
1 year to less than 2 years	1,446	1,104	252	49	51	16	24	0	22
2 years to less than 3 years	941	672	181	27	17	10	48	2	6
3 years to less than 5 years	864	507	226	46	19	17	75	6	9
5 or more years.....	969	267	376	64	14	61	186	20	7

^aTotal is less than the sum of candidates for each organ due to patients being included in multiple categories.

Source: Compiled by LB&FC staff based on OPTN data as of March 9, 2007.

The continued growth in the size of waiting lists emphasizes the need to further increase organ donor designations and donation rates. Improved rates are essential to respond to both the increasingly large waiting lists and to take advantage of continuing advancements in organ transplantation.

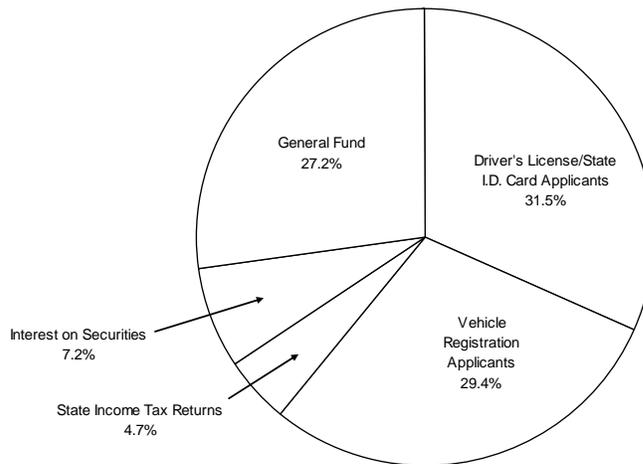
However, there is a complicating factor to consider. The extent to which the current system will be able to accommodate large increases in the number of donors and transplant recipients is unclear due to ongoing concerns about the serious shortages of nurses and other personnel. The 2006 report by the Institute of Medicine entitled *Organ Donation—Opportunities for Action* summarized this issue as follows:

Currently, specialized operating room and critical care professionals must be available for donation surgery and the subsequent transplantation procedures. In an already stressed system, shortages of nurses or anesthesiologists, for example, could limit the options for timely donation and the quality of care of either the donor or the recipient. Given these system challenges, strategic planning for such increases would need to be undertaken to ensure that these scarce resources will be able to be used the most effectively and that the necessary human resources are available.

I. Program Funding From Voluntary Contributions and Other Sources

Findings

I-1. *Since the start of the program in 1994 through June 30, 2006, revenues to the Organ and Tissue Donor Awareness Program totaled \$8.7 million. Of this amount, \$6.3 million, or nearly 66 percent, was generated through voluntary donations made by Pennsylvanians when they (1) apply for a driver's license, state I.D. Card, or vehicle registration renewal; or (2) contribute a portion of their State Income Tax refund to the Governor Robert P. Casey Memorial Organ and Tissue Donor Awareness Trust Fund. The remaining funding was derived from General Fund transfers and appropriations, and interest.*

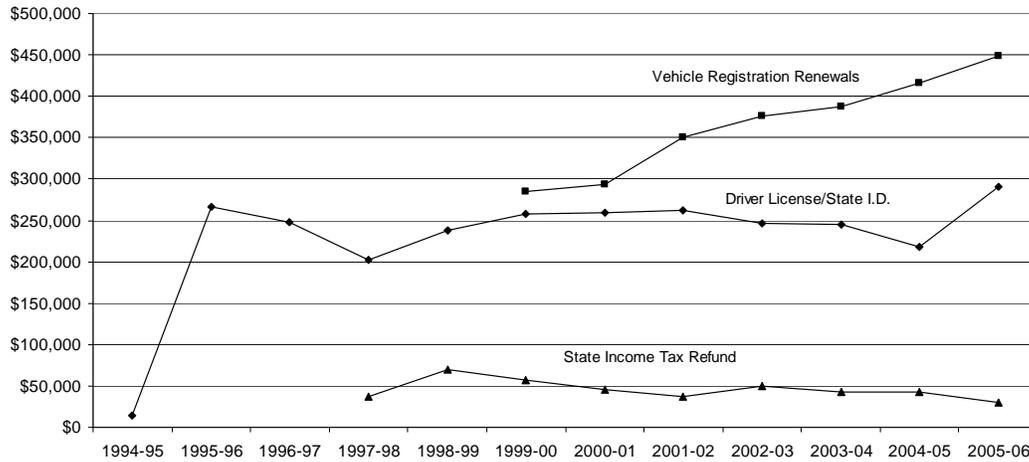


(FY 1994-95 Through FY 2005-06)

<u>Source</u>	<u>Amount</u>
Driver's License/State I.D. Card Applicants.....	\$2,746,892
Vehicle Registration Applicants.....	2,557,033
State Income Tax Returns.....	410,781
Private Donations.....	3,017
Interest on Securities.....	626,745
General Fund.....	<u>2,366,000</u>
Total.....	\$8,710,468

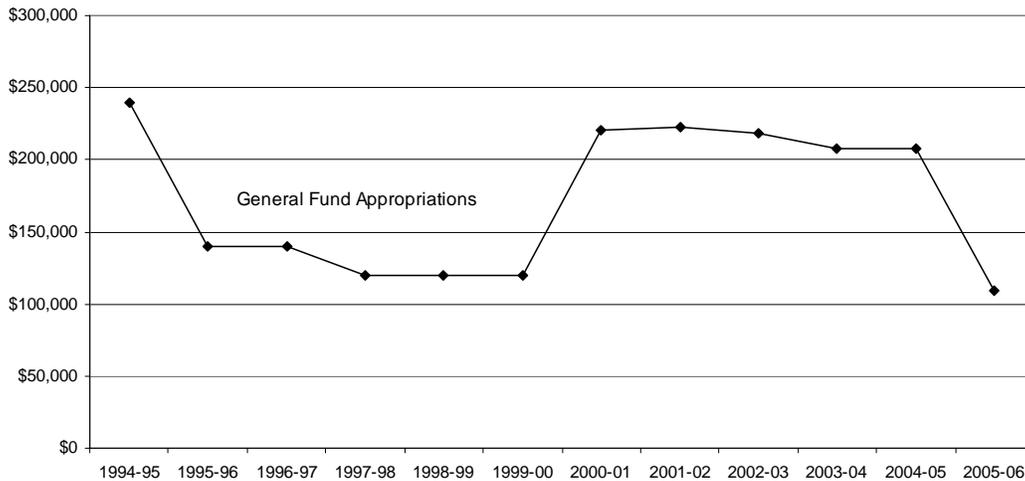
I-2. *Both donations made at the time of driver license/state identification card application/renewal and vehicle registration renewal have continued to increase annually in recent years. Revenues from voluntary state income tax check-off, however, dropped by 30 percent in FY 2005-06. This tax check-off option expires on January 1, 2008, and unless reinstated by the Legislature, will not appear on state tax forms for the 2007 tax year.*

The graph below shows the pattern of support that each of the three categories of voluntary donation have provided to OTDAP.



In FY 2005-06, revenues from these three sources totaled as follows: Driver's License and State I.D. Card Applicants - \$291,168, up 34 percent over the prior year; Vehicle Registration Renewal Applicants - \$448,960, up 7.9 percent over the prior year; and State Income Tax Voluntary Contributions - \$29,889, down by 30 percent from the prior year.

I-3. Between FY 1994-95 and FY 2005-06, the program also received a \$300,000 transfer to the Trust Fund from the General Fund for start-up costs and a total of \$2.1 million in General Fund appropriations to the Departments of Health and Transportation. The graph below shows the pattern of General Fund support for OTDAP since the program's inception.



Trust Fund Revenues

Voluntary Contributions

Act 1994-102 established the Organ Donation Awareness Trust Fund as the central funding mechanism for organ and tissue donation awareness activities in Pennsylvania. (Act 2000-120 changed the name of the Trust Fund to The Governor Robert P. Casey Memorial Organ and Tissue Donation Awareness Trust Fund.) Monies derived from voluntary contributions are deposited in the fund. The methods that can be used to make a voluntary contribution to the Trust Fund include:

- A \$1 donation when obtaining or renewing a driver's license, state photo ID card, or vehicle registration¹ (this contribution is in addition to the regular application or renewal fee)
- Designating all or part of one's individual state income tax refund via a dedicated space on the face of the individual income tax return (the amount so designated is deducted from the tax refund to which the individual is entitled and is not charged against income tax revenue due the Commonwealth)
- Taxpayers wishing to contribute to the Trust Fund but who do not receive state income tax refunds may submit contributions directly to an address furnished to the Department of Revenue by the Organ Donation Advisory Committee

Additionally, private donations, interest earned on monies in the fund and revenues from fines imposed by the Department of Health (DOH) upon hospitals who are not in compliance with the state's Anatomical Gift Act (i.e., the requirement that hospitals have a protocol for identifying potential organ and tissue donors and follow that protocol) are also to be deposited into the Trust Fund.²

Driver's License Voluntary Contribution. Act 102 directed the Pennsylvania Department of Transportation (PennDOT) to, no later than January 1, 1995, provide an applicant for an original or renewal driver's license or state identification card the opportunity to make a contribution of \$1 to the Trust Fund.³ The contribution is added to the regular fee for an original or renewal driver license or state identification card. One contribution may be made for each issuance or renewal of a license or identification card.

¹Voluntary contribution at the time of a renewal vehicle registration instituted by Act 74 of 1998. Pertinent sections of the legislation became effective on July 1, 1999.

²See page 180 for further discussion.

³A \$1 contribution to the Trust Fund may also be made when applying for a duplicate driver's license.

PennDOT must monthly determine the total amount of contributions designated and report that amount to the State Treasurer, who is to transfer that amount to the Trust Fund.

Table 35 shows total revenues generated from \$1 voluntary contributions from driver's license and state identification card applicants from FY 1994-95 through FY 2005-06.

Table 35

**Voluntary Contributions Made by Driver's License
and State Identification Card Applicants**
(FY 1994-95 Through 2005-06)

<u>Fiscal Year</u>	<u>Amount</u>	<u>Increase (+) Decrease (-)</u>
1994-95	\$ 13,660	--
1995-96	266,439	+100.0%
1996-97	247,968	-6.9
1997-98	202,427	-18.4
1998-99	237,715	+17.4
1999-00	257,669	+8.4
2000-01	259,656	+0.8
2001-02	261,571	+0.7
2002-03	246,024	-5.9
2003-04	245,241	-0.3
2004-05	217,354	-11.4
2005-06	<u>291,168</u>	+34.0
Total	\$2,746,892	

Source: Developed by LB&FC staff using the Report of Revenue and Receipts, PA Department of Revenue.

As shown, a total of \$2,746,892 in Trust Fund revenue has been generated from this source in the twelve-year period of FY 1994-95 through FY 2005-06. Revenues generated from this source began in FY 1994-95, the fiscal year within which Act 102 became effective. At the close of FY 1994-95, \$13,660 of revenue had been generated from applicants for original or renewal driver's licenses and state identification cards.

In FY 1995-96, the first full fiscal year following the passage and effective date of Act 102, \$266,439 in revenue was generated from this source. This total represents the highest amount of revenue generated from this source until FY 2005-06. Overall, revenues generated from this source remained relatively stable over the 12-year period. The largest decrease in total revenue generated occurred between FY 1996-97 and FY 1997-98, when there was a decrease in revenue of 18.4 percent (or \$45,541). However, in the following year, revenues rebounded by 17.4 percent, an increase of \$35,288.

In order to gain a perspective on how many driver license and state I.D. card applicants are choosing to make a voluntary financial contribution to the Trust Fund, we examined the amounts contributed by these applicants in FY 2003-04 through FY 2005-06 in relation to the total number of driver license and state I.D. card issuances reported by PennDOT in those years.

Given that each contribution is, by current definition, a \$1 donation, the total amount contributed in a given year translates directly to the number of persons who made a contribution. Using this information and data on the total number of driver license and state I.D. transactions reported by PennDOT, it is possible to calculate the percentage of total driver license and state I.D. card applicants who made a donation in a given year. These calculations are as shown on Table 36 for FY 2003-04 through FY 2005-06.

Table 36

The Number of Persons Making a Voluntary Contribution to the Trust Fund as a Percentage of Total Driver License and State I.D. Card Transactions

Fiscal Year	Individuals/Transactions			Amount Contributed to Trust Fund	Individuals Who Made a Donation	
	License	Photo I.D.	Total		Number	% of Total
2003-04.....	2,200,460	305,356	2,505,816	\$245,241	245,241	9.8%
2004-05.....	2,066,319	320,097	2,386,416	217,354	217,354	9.1
2005-06.....	2,010,066	320,716	2,330,782	291,168	291,168	12.5

Source: Developed by LB&FC staff using information obtained from the Department of Revenue and PennDOT.

As Table 36 shows, the percentage of applicants who contributed to the Trust Fund ranged from 9.8 percent to 12.5 percent during the period we examined.

Vehicle Registration Renewal Voluntary Contribution. Act 74 of 1998 directed PennDOT to provide applicants for a renewal vehicle registration the opportunity to make a contribution of \$1 to the Trust Fund. The contribution is added to the regular fee for a renewal of vehicle registration, and one contribution may be made for each renewal. Act 74 also directs PennDOT to, on a monthly basis, determine and report the total amount of contributions of this type designated to the State Treasurer for transfer to the Trust Fund.

While Act 74 was signed into law on June 18, 1998, the section of the Act establishing the vehicle registration voluntary donation became effective on July 1, 1999. As such, FY 1999-2000 was the first fiscal year in which revenues were received from this source.

Table 37 shows total revenues generated from this source from FY 1999-00 through FY 2005-06.

Table 37

Voluntary Contributions Made by Vehicle Registration Applicants
(FY 1999-00 Through 2005-06)

<u>Fiscal Year</u>	<u>Amount</u>	<u>% Increase (+)</u> <u>Decrease (-)</u>
1999-00	\$ 284,440	--
2000-01	293,546	+3.2%
2001-02	350,634	+19.4
2002-03	375,781	+7.2
2003-04	387,751	+3.2
2004-05	415,921	+7.3
2005-06	<u>448,960</u>	+7.9
Total	\$2,557,033	

Source: Developed by LB&FC staff using the Report of Revenue and Receipts, PA Department of Revenue.

A total of \$2,557,033 in Trust Fund revenue has been generated from vehicle registration renewals in the seven-year period of FY 1999-00 through FY 2005-06. As shown, the amount of revenue generated from this source has increased each fiscal year since the option became available.

While the total revenue generated increased by only 3.2 percent (\$9,106) between FY 1999-00 and FY 2000-01, an increase of 19.4 percent (\$57,088) occurred between FY 2000-01 and FY 2001-02. In each year thereafter, revenues generated from this source continued to increase at a fairly steady rate.

We also calculated the percentage of total vehicle registration applicants who made a voluntary contribution to the Trust Fund between 2003 and 2006. As is also true for contributions made by driver license and state I.D. card applicants, the total number of one dollar contributions made by vehicle registration applicants translates on a one-to-one basis to the number of persons making a contribution. Using this information and data on the total number of vehicles registration applicants as reported by PennDOT, it is possible to calculate the percentage of total vehicle registration applicants who make a voluntary contribution in a given year. These calculations are shown on Table 38 for the period 2003 to 2006.

As Table 38 shows, the percentage of vehicle registration applicants who made a voluntary contribution ranged from 3.5 percent to 4.2 percent during the period we examined. While vehicle registrations are renewed on an annual basis, driver licenses and state photo identification cards are renewed once every four years. As a result, approximately five times more vehicle registration renewal applications are processed annually than driver license and photo identification card renewals. Despite this difference, the percentage of driver license and photo

identification card renewal customers contributing \$1 to the Trust Fund has been approximately three times greater than the percentage contributing when renewing their vehicle registration.

Table 38

The Number of Vehicle Registration Applicants Making a Voluntary Contribution to the Trust Fund as a Percentage of Total Transactions of This Type

Year	Individuals/ Transactions	Amount Contributed to Trust Fund	Individuals Who Made a Contribution	
			Number	% of Total
2003.....	10,768,222	\$371,909	371,909	3.5%
2004.....	10,921,683	402,050	402,050	3.7
2005.....	11,058,567	436,231	436,231	3.9
2006.....	11,086,810	460,590	460,590	4.2

Source: Developed by LB&FC staff using information obtained from the Department of Revenue and PennDOT.

State Income Tax Voluntary Contributions. Act 1994-102 established a voluntary contribution system in which the Pennsylvania Department of Revenue was directed to provide a space on the face of the state individual income tax return form for the 1997 tax year and 2000 tax year⁴ whereby an individual could elect to voluntarily designate a contribution of any amount desired to the Trust Fund.⁵ Any amount so designated by an individual on the state individual income tax return form is to be deducted from the tax refund to which the individual is entitled and does not constitute a charge against the income tax revenues due the Commonwealth.

The Department of Revenue is to annually determine the total amount designated as donations on state individual income tax returns and must report that amount to the State Treasurer who is to transfer that amount to the Trust Fund. Table 39 shows total revenues generated from this source from FY 1997-98, the first fiscal year in which the option to donate was made available on individual state income tax returns, through FY 2005-06.

In the nine fiscal years we analyzed since program inception, a total of \$410,781 in revenue has been generated from voluntary taxpayer contributions on state individual income tax returns. The fiscal year in which the most revenue was

⁴Act 102 initially required this for the 1997 and 2000 tax years only. Act 1997-7 subsequently amended the Tax Reform Code to require the Department to, beginning in taxable year 1997, annually provide such a space on the state individual income tax return form. Also, in so doing, Act 1997-7 repealed Section 8618 of Title 20, Pa.C.S. (related to a voluntary contribution system) and slightly modified and recodified the provisions of the prior Section 8618 of Title 20, Pa.C.S. into Section 315.4 of the Tax Reform Code of 1971.

⁵The Department of Revenue reports that the average donation in 2005 was \$6.48 based on partial year returns.

generated from this source was FY 1998-99, in which revenues totaled \$69,614. In FY 2005-06, the smallest amount of revenue, at \$29,889, was generated from this source.

Table 39

Voluntary Contributions Made Through State Income Tax Returns
(FY 1997-98 Through FY 2005-06)

<u>Fiscal Year</u>	<u>Amount</u>	<u>% Increase (+)</u> <u>Decrease (-)</u>
1997-98	\$ 36,642	--
1998-99	69,614	+90.0%
1999-00	57,273	-17.7
2000-01	45,049	-21.3
2001-02	37,152	-17.5
2002-03	50,360	+35.6
2003-04	42,130	-16.3
2004-05	42,672	+1.3
2005-06	<u>29,889</u>	-30.0
Total	\$410,781	

Source: Developed by LB&FC staff using the Report of Revenue and Receipts, PA Department of Revenue.

Among other potential factors, revenue derived from taxpayers who contribute a portion of their individual state income tax refund to the Trust Fund may be affected by taxpayers choosing to make donations to other competing causes listed on the face of the tax return. The state income tax voluntary contributions provision for OTDAP in the Tax Reform Code is set to expire on January 1, 2008.⁶

Other Sources of Trust Fund Revenue. In addition to the above sources of Trust Fund revenue, a number of other sources of Fund revenue exist, some of which may not necessarily be recurring from year to year.

Table 40 shows total revenues generated from private donations, interest on securities, and transfers from the General Fund to the Trust Fund from FY 1994-95 through FY 2005-06.

Private Donations. Individuals may make private donations of any amount to the Trust Fund at any time. Act 102 directed the Department of Revenue to, in all taxable years beginning on or after January 1, 1995, provide on its forms or in its instructions which accompany state individual income tax return forms adequate information concerning the Organ Donor Awareness Trust Fund. These instructions are to include the listing of an address, furnished to it by the Organ Donation Advisory Committee, to which contributions may be sent by those taxpayers wishing to contribute to the Trust Fund but who do not receive refunds.

⁶See 72 P.S. §7315.9(c).

Table 40

Other Sources of Trust Fund Revenue

(FY 1994-95 Through 2005-06)

<u>Fiscal Year</u>	<u>Amount</u>		
	<u>Private Donations</u>	<u>Interest on Securities</u>	<u>Transfers From the General Fund</u>
1994-95.....	\$ 0	\$ 0	\$ 0
1995-96.....	2,531	8,876	300,000
1996-97.....	38	36,982	0
1997-98.....	25	45,156	0
1998-99.....	87	49,287	0
1999-00.....	36	45,757	0
2000-01.....	100	45,290	0
2001-02.....	6	41,662	0
2002-03.....	115	31,300	0
2003-04.....	2	82,396	0
2004-05.....	75	98,847	0
2005-06.....	<u>2</u>	<u>141,192</u>	<u>0</u>
Total	\$3,017	\$626,745	\$300,000

Source: Developed by LB&FC staff using the Report of Revenue and Receipts, PA Department of Revenue.

Additionally, on a Department of Health web page dedicated to the Trust Fund, the mailing address of the Department's Bureau of Administrative and Financial Services is provided where individuals may send direct contributions to the Trust Fund.

Hospital Fines. Pursuant to Act 102 and Title 20, Pa.C.S. the Department of Health makes annual death record reviews at acute care general hospitals to determine compliance with statutory requirements regarding the identification of potential donors and communication with the responsible OPO at or near the time of a patient's death.

If the Department finds, on the basis of this review, that a hospital is not in compliance with its accepted protocol, the Department may impose an administrative fine on the hospital of up to \$500 for each instance of noncompliance.⁷ Such fines imposed by the Department upon hospitals who are found not to be in compliance are to be deposited into the Trust Fund.

The Department's Division of Acute and Ambulatory Care, located within the Bureau of Facility Licensure and Certification, conducts these reviews at the time of routine licensure survey (which occurs every two years) or during investigation of complaints or events related to hospital requirements pertaining to the

⁷Section 8617 (h) of Act 102 defines "noncompliance" as any failure on the part of a hospital to contact an organ procurement organization as required under subsection 8617(d).

identification and notification requirements of potential donors specified in 20 Pa.C.S. §8617 et seq.

Although Act 1994-102 and 20 Pa.C.S. §8617(g) state that fines of \$500 for each instance of hospital noncompliance with reporting requirements of Pennsylvania's Anatomical Gift Act are to be deposited into the Trust Fund, the Department of Health has chosen to identify any such fines as civil penalties under Section 817 of the Health Care Facilities Act. Funds deposited into this civil penalties restricted revenue account may be used to maintain management and operations of a health care facility pending correction of deficiencies or closure.

In the period FY 2001-02 through FY 2005-06, 47 hospitals were cited for violations of Pennsylvania's Anatomical Gift Act. However, only one hospital was fined (in FY 2001-02) in the amount of \$2,000.

Interest on Securities. Interest which accrues from securities invested by the Pennsylvania Treasury Department are, under provisions of Act 102 and Title 20, transferred to the Trust Fund. While the Trust Fund has received \$626,745 from interest on securities in the period FY 1994-95 through FY 2005-06, such revenue is dependent upon the Treasury Department's role as a custodian and investor of Trust Fund monies and is an ancillary source of Fund revenue.

Transfers From the General Fund. In FY 1995-96, the Trust Fund received a "start-up" \$300,000 transfer from the General Fund. No other transfers from the General Fund to the Trust Fund occurred in the period FY 1994-95 through FY 2005-06.

General Fund Appropriations

In addition to monies deposited in the Trust Fund, the DOH and PennDOT have each received General Fund state appropriations for the purpose of funding some aspect of program operations and awareness activities since program inception.

While separate from Trust Fund expenditures, the expenditure of monies from state appropriations are costs that must be considered when planning and budgeting for current and future initiatives, when calculating the total costs for specific initiatives, and when analyzing the total cost of activities completed both by participant state agencies and the OTDA program generally.

A summary and description of state appropriations received by the DOH and PennDOT for OTDA-related operations and activities for the period FY 1994-95 through FY 2006-07 follows.

Appropriations to the Department of Health

DOH has received OTDA-related state appropriations in each of the 12 fiscal years since the start of the OTDA program. The state appropriation received by DOH entitled “Organ Donation” is part of the “Outpatient Services” element of the Health Treatment Service Program administered by DOH. The objective of the Health Treatment Services program is “to maximize the individual’s capacity for independent living through the provision of an array of service and support programs.”

A component of this larger program, the Health Promotion Program, “conducts a public information and education program to encourage organ and tissue donation as one means of managing [the Chronic Renal Disease Program] and increasing the quality of life.”

In the “Program Analysis” provided for the Health Treatment Services program in the Department of Health’s agency budget request, the purpose of the Organ Donation appropriation is described as follows:

This program promotes organ and tissue donation in Pennsylvania. The Department funds the publication and distribution of special brochures for the public and promotes voluntary organ donation via public media, use of exhibits at local fairs and other locations, special promotion at sports events and media events.

Although there has been an increase in donations, there is still a shortage of viable organs and tissues necessary for transplant and restorative surgery. Data collected from the Behavioral Risk Factor Surveillance System survey provides guidance concerning the decision to become an organ and tissue donor in Pennsylvania. Public education activities focus on the need for organ donation, the eradication of myth, and encourage persons to sign a donor card to participate in PennDOT’s driver’s license program.

During the period FY 1994-95 through FY 2005-06, the DOH received a total of \$1,563,000 in state General Fund appropriations for the Organ Donation Awareness Program. (See Table 41.) As shown, the amount of the Department’s state appropriation has gradually declined between FY 1994-95 and FY 2005-06. Beginning with an appropriation of \$240,000 in FY 1994-95, the appropriation decreased to \$140,000 in fiscal years 1995-96 and 1996-97, followed by a decrease to \$120,000 for five consecutive fiscal years. After decreasing to \$116,000 in FY 2002-03, the appropriation remained at \$109,000 in fiscal years 2003-04, 2004-05, and 2005-06. DOH again received a state appropriation of \$109,000 for FY 2006-07.

Table 41

**State General Fund Appropriations to the
Department of Health for OTDA Purposes**
(FY 1994-95 Through FY 2005-06)

<u>Fiscal Year</u>	<u>Appropriation Amount</u>	<u>Fiscal Year</u>	<u>Appropriation Amount</u>
1994-95	\$ 240,000	2001-02	120,000
1995-96	140,000	2002-03	116,000
1996-97	140,000	2003-04	109,000
1997-98	120,000	2004-05	109,000
1998-99	120,000	2005-06	<u>109,000</u>
1999-00	120,000		
2000-01	120,000	Total.....	\$1,563,000

Source: Developed by LB&FC staff using information obtained from the Governor's Office of the Budget, Status of Appropriations documents.

Appropriations to PennDOT

In addition to receiving reimbursement from the Trust Fund for costs associated with the implementation of Act 102 provisions, PennDOT received a number of state appropriations for OTDAP program costs in five recent fiscal years. As shown on Table 42, PennDOT received \$503,000 in General Fund appropriations since program start-up, all during the period FY 2000-01 through FY 2004-05. PennDOT did not receive a state appropriation for OTDA purposes in FY 2005-06. A departmental review of reimbursement appropriations was conducted during preparation of the agency budget for FY 2005-06. The result of the review, according to PennDOT, "indicated that the organ donor program had been integrated into the highly automated photo license process and there was no longer a measurable ongoing cost."

Table 42

**State General Fund Appropriations to
PennDOT for OTDA Purposes**
(FY 2000-01 Through FY 2005-06)

<u>Fiscal Year</u>	<u>Appropriation Amount</u>
2000-01	\$100,000
2001-02	103,000
2002-03	102,000
2003-04	99,000
2004-05	99,000
2005-06	<u>0</u>
Total.....	\$503,000

Source: Developed by LB&FC staff using information obtained from the Governor's Office of the Budget, Status of Appropriations documents.

J. Program Planning, Budgeting, and Expenditures

Findings

J-1. The program lacks an overall, multi-year planning process and program spending priorities are formulated in the absence of an annual program plan or work statement with specific goals and objectives. The Advisory Committee has, on occasion, attempted to identify and formalize operational objectives for the program. For example, in 2002, the Committee held a planning session intended to identify and develop program and Committee goals. While this and a follow-up session were held, nothing was formalized in terms of a program or advisory committee planning process that could be tied to the budget. Planning of this type would, however, require more than the limited DOH staff resources currently available to the program.

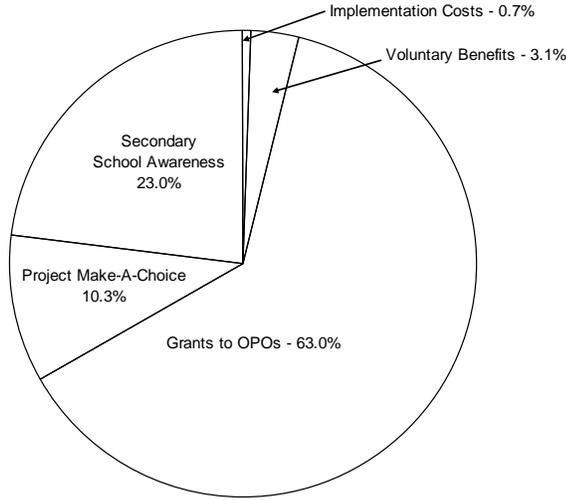
J-2. The Department of Health, with input from the Advisory Committee, develops expenditure priorities and two types of OTDAP budget requests: multiple separate requests for executive authorizations to expend monies from the Trust Fund and a request for a state General Fund appropriation for “organ donation awareness.” Program expenditures are made both from the Governor Robert P. Casey Memorial Organ and Tissue Donor Awareness Fund and the General Fund.

From the inception of the program in FY 1994-95 through June 30, 2006, expenditures for the Organ and Tissue Donor Awareness Program totaled \$6.2 million. Of this amount, \$4.5 million, or 72 percent, was funded from the Governor Robert P. Casey Memorial Organ and Tissue Donor Awareness Trust Fund; the remainder, \$1.7 million, was paid from the state General Fund.

J-3. Program expenditures are made primarily from the Trust Fund. These expenditures are to cover program implementation costs of the Departments of Health and Transportation and Revenue as well as the operating costs of the Organ Donation Advisory Committee. Following spending for these purposes, Trust Fund monies are used to cover the costs of voluntary benefits for donors and donor’s families, grants to OPOs, awareness programs for secondary school students, and a special project designated in Act 1994-102 as “Project Make-A-Choice.”

We attempted to document the amounts spent in each of these areas since the program began. Because detailed breakdowns by spending purpose were not available prior to FY 2000-01, we focused on spending data for the period FY 2000-01 through FY 2005-06. As shown below, grants to OPOs for statewide

public awareness campaigns have been the single largest expenditure category at about 63 percent of total spending during the period.



(FY 2000-01 Through FY 2005-06)

<u>Purpose</u>	<u>Amount</u>
Implementation Costs	\$ 20,796
Voluntary Benefits.....	93,871
Grants to OPOs	1,913,913
Project Make-A-Choice.....	313,937
School Awareness	<u>697,795</u>
Total	\$3,040,312

- J-4. While Project Make-A-Choice is listed in statute as a separate and distinct Trust Fund expenditure purpose, it is not separately identifiable as a distinct subprogram or activity within the OTDAP. DOH officials are not aware of any written guidelines defining Project Make-A-Choice and Advisory Committee members and OPO staff view it simply as supplemental funding to the OPOs for the statewide public awareness program. Expenditures for Project Make-A-Choice varied substantially between fiscal years 2000-01 and 2005-06, due mainly to the cycle of multi-year contracts with the state's OPOs.
- J-5. During the period FY 2000-01 through FY 2005-06, the OTDAP returned, or lapsed, \$187,257, or 27.4 percent of the total amount appropriated from the General Fund to the Department of Health for the program. These lapses occurred even though the total amount of the General Fund appropriation was reduced during this period from \$120,000 in FY 2000-01 to \$109,000 in FY 2005-06, and the Department used a portion of the General Fund appropriations to supplement Trust Fund monies granted to the OPOs.

OTDAP Budgeting and Planning

The Budget Process

Pursuant to the Commonwealth's program budgeting process, the budget request documents DOH submits annually to the Governor's Office of the Budget present organ and tissue donation awareness-related requests of two types: requests for executive authorizations to expend monies from the Trust Fund and a request for a state General Fund appropriation for organ donation awareness. Budget preparation for OTDAP is handled by the Department's Division of Budget within the Bureau of Administrative and Financial Services.

All expenditures from the Trust Fund are made on a continuing basis subject to the approval of the Governor. As such, monies are expended based on executive authorizations rather than appropriations from the General Assembly. In formulating the OTDAP budget, the Division of Budget considers the following:

- the projected OTDAP implementation costs of the Departments of Health, Transportation, and Revenue;
- the expenses of the Organ Donation Advisory Committee; and
- the four OTDAP spending purposes specified in law (i.e., voluntary benefits, grants to OPOs, awareness programs for secondary schools, and Project Make-A-Choice).

Recommendations for the expenditure of Trust Fund monies for the Department of Education's implementation of an organ donation awareness program in the state's secondary schools are formulated and submitted to the Governor's Office of the Budget by the Department of Education.

The Director of the Bureau of Health Promotion and Risk Reduction, in consultation with the Deputy Secretary for Health Promotion and Disease Prevention, develop the budget amounts to be requested for implementation costs of the Departments of Health, Transportation, and Revenue; for costs of the Organ Donation Advisory Committee; and under each Trust Fund expenditure purpose for remaining Trust Fund monies. Considered during this process are the priorities of the Governor and the Secretary of Health, the recommendations of the Organ Donation Advisory Committee, and the projected fiscal impact of proposed disbursements on the Trust Fund.¹

Often, when discussing activities and associated costs to be incurred from the Trust Fund, Advisory Committee members propose and consider motions which

¹According to DOH officials, their practice is to maintain an annual balance of no less than \$500,000 in the Trust Fund.

assign specific dollar amounts to activities. In some cases, Department of Health representatives have suggested that the Committee focus on priorities rather than specific funding amounts during Advisory Committee budget discussions. During past meetings, the Advisory Committee has also ranked identified priorities by importance.

While the larger Organ and Tissue Donation Awareness Program lacks an overall plan or annual and long-range performance goals and objectives, in the development of priorities for Trust Fund expenditures, program activities are often viewed through a multi-year framework. That is, while the Department must annually seek executive authorizations for the expenditure of Fund monies for each of the purposes specified in law, multi-year awareness initiatives may be considered in the formulation of requests to the Office of the Budget.

Examples of multi-year organ and tissue donation awareness initiatives among participating agencies include:

- Multi-year contracts and work plans with The Gift of Life Donor Program and CORE for the implementation of statewide organ and tissue donation public awareness campaigns (pursuant to Act 102's authorization of grants to OPOs for this purpose and for Project Make-A-Choice).
- Multi-year contracts and work plans executed by the Department of Education with the Lancaster-Lebanon Intermediate Unit (IU-13) for the implementation of organ and tissue donation awareness programs in the state's secondary schools.

The presence of contractual agreements among several of the state agencies engaged in responsibilities under Act 102 affects expenditure prioritization decision-making due to the desire to fund multi-year contracts and work plans, as well as to ensure continuity in the implementation of awareness activities.

State appropriations received by the Department of Health and PennDOT for implementation of OTDA program activities are not connected directly with the Trust Fund. However, there are appropriation needs that must be considered when planning and budgeting for current and future program initiatives and when calculating total costs for specific initiatives, as well as when analyzing the total cost of activities completed both by participant state agencies and the OTDA program generally.

Program Planning

The OTDAP budget is formulated in the absence of an annual program plan or work statement with specific goals and objectives. Planning of this type would,

however, require more than the limited DOH staff resources currently available to the program.

The Organ Donation Advisory Committee has, on occasion, attempted to identify and formalize operational objectives for the program. For example, at the June 2002 Advisory Committee meeting, the Project Director for the Lancaster-Lebanon Intermediate Unit (IU-13), responsible for implementation of the secondary school awareness campaign, led a planning session intended to identify and develop program and Committee goals. While this and a follow-up session were held, nothing was formalized in terms of a program or (advisory) committee planning process that could be tied to the budget.²

We found that the State of Delaware's Organ and Tissue Donor Awareness Program is developing a planning process that could serve as a useful model for Pennsylvania's program. The Delaware program is similar to Pennsylvania's and has a nine-member advisory board. The Delaware Department of Health and Social Service's Division of Public Health serves as the lead agency for the Delaware Organ and Tissue Donor Awareness Program. One full-time and one part-time staff member are responsible for administration of the program, each committing part of their obligated time for this purpose.

Working with a facilitator from the Delaware Department of Health and Social Services, the Organ and Tissue Donor Awareness Board convened a strategic planning session in September 2006. The primary purpose of the session was to identify goals and initiatives that, in the opinion of the Board, are of critical importance to move the program forward, including promotion of a driver's license online organ donor designation website.

The current strategic planning goals and objectives developed by the Delaware Board include four focus areas with corresponding goals and objectives. The current Plan has also integrated target dates, completion dates, and leaders corresponding to certain objectives.

This planning process is mandated in the Board's bylaws. The bylaws require that the Board develop a Donor Awareness Plan "to further donor awareness within the State of Delaware." The By-Laws prescribe that the Plan must include, at the minimum, the following:

- review of current and planned awareness programs;
- application and grant procedures leading to utilization of funds from the Organ and Tissue Donor Awareness Trust Fund;

²A "Committee Goals Update" session was scheduled for the December 11, 2002, Advisory Committee meeting, but the meeting was cancelled and a goal-setting and planning discussion was not conducted in subsequent meetings.

- contract procedures;
- provisions for appointing officers, and employees as well as obtaining of-
fice space and equipment;
- establish criteria for the allocation of funds from the Organ and Tissue
Donor Awareness Trust Fund; and
- provide for the application for grants and aid monies from other govern-
mental sources, local, state and federal.

The bylaws also prescribe that the Board must review and approve the plan every two years, and must make the plan available to the governor and state legislature.

While having a significantly broader scope of responsibilities and policy for-
mulation authority, both the U.S. Department of Health and Human Services Advi-
sory Committee on Organ Transplantation (ACOT) and the OPTN/UNOS organiza-
tions engage in program/strategic planning at the national level. The OPTN/UNOS
plan for 2006-2007 identifies six “challenges” with corresponding goals and action
steps. The six challenges are: (1) the donor shortage; (2) changing allocation prin-
ciples; (3) reduce variation in access to transplantation; (4) living donors: assessing
safety and program performance; (5) oversight of transplantation role of OPTN; and
(6) improvement of information technology systems.

OTDAP Expenditures

Total Program Expenditures

From the program’s inception in FY 1994-95 through the end of FY 2005-06,
OTDAP expenditures totaled \$6,207,293.³ (See Table 43.) Of this amount,
\$4,476,643, or 72 percent, was funded from the Governor Robert P. Casey Memorial
Organ and Tissue Donor Awareness Trust Fund and \$1,730,650 was paid from the
state General Fund.

As shown, the Department of Health spent a combined total of 65 percent of
OTDAP expenditures from both the Trust Fund and General Fund appropriations
during the period FY 1994-95 through FY 2005-06. PennDOT expended just under
22 percent during this period, and the Department of Education expended approxi-
mately 13 percent.

³This total represents total cash disbursements from the Trust Fund through the end of FY 2005-06 and total
General Fund expenditures through appropriations up to and including FY 2005-06. The Comptroller for Public
Health and Human Services approves contracts executed with the state’s OPOs and all vouchers for payment of
program costs.

Table 43

Total Expenditures Since Program Start-Up in 1994

<u>Agency</u>	<u>Trust Fund</u>	<u>General Fund</u>	<u>Total</u>
Department of Health	\$2,809,841	\$1,231,650	\$4,041,491
PennDOT.....	839,000	499,000	1,338,000
Department of Education...	<u>827,802</u>	<u>0</u>	<u>827,802</u>
Totals.....	\$4,476,643 (72.1%)	\$1,730,650 (27.9%)	\$6,207,293 (100.0%)

Source: Developed by LB&FC staff using information obtained from the PA Department of Health and the Governor's Office of the Budget, Status of Appropriations documents.

For the first two fiscal years of the program (FY 1994-95 and FY 1995-96), Department of Health expenditures from General Fund appropriations represented the only spending on the program. Beginning in FY 1996-97, a combination of Trust Fund monies and General Fund appropriations were used to fund program operations. Table 44 on the following page provides a further detailed breakdown of total OTDAP expenditures since the start of the program.

Expenditures From the Trust Fund

Program expenditures are made primarily from the Trust Fund. These expenditures are to cover program implementation costs of the Departments of Health and Transportation and Revenue⁴ as well as the operating costs of the Organ Donation Advisory Committee. Following spending for these purposes, Trust Fund monies are used to cover the costs of voluntary benefits for donors and donor's families, grants to OPOs, awareness programs for secondary school students, and a special project designated in Act 1994-102 as "Project Make-A-Choice."

We examined DOH fiscal records and appropriations reports compiled by the Governor's Office of the Budget in order to document the amounts spent by the program for each of the above-listed purposes. Because a detailed breakdown was not available for DOH expenditures prior to FY 2000-01 (i.e., only a lump sum DOH expenditure total is available), we focused this examination on spending data for the period FY 2000-01 through FY 2005-06. Table 45 provides expenditure amounts for each of the program purposes paid from the Trust Fund during this period.

⁴Act 1994-102 provides that the Department of Revenue is to receive compensation from the Trust Fund for "actual costs" related to implementation of its required OTDAP duties. The Department has not requested reimbursement from the Trust Fund for duties performed for the OTDAP program. The Department has also not received any General Fund monies for program-related activities. Department officials report that these duties, relating to the tax check-off option on state income tax returns, are incorporated in the overall tax processing system and separate costs are not identifiable.

Table 44

Total OTDAP Expenditures, by Fund and Agency
(FY 1994-95 Through FY 2005-06)

Trust Fund:	FY 94-95	FY 95-96	FY 96-97	FY 97-98	FY 98-99	FY 99-00	FY 00-01	FY 01-02	FY 02-03	FY 03-04	FY 04-05	FY 05-06
Education	\$ 0	\$ 0	\$ 0	\$ 0	\$120,694	\$ 9,313	\$ 93,781	\$129,661	\$ 39,353	\$ 90,000	\$150,000	\$195,000
Health.....	0	0	7,736	9,069	67,160	383,359	312,009	127,875	432,897	211,132	661,717	596,887
Impl. Costs.....	0	0	7,736	9,069	a	a	2,853	3,385	3,610	3,680	4,158	3,110
Vol. Benefits.....	0	0	0	0	a	a	0	2,717	17,633	28,241	24,327	20,953
Grants to OPOs	0	0	0	0	a	a	309,156	113,595	384,871	48,627	537,788	519,876
Project Make- A-Choice	0	0	0	0	a	a	0	8,178	26,783	130,584	95,444	52,948
Transportation.....	<u>0</u>	<u>0</u>	<u>70,000</u>	<u>230,000</u>	<u>0</u>	<u>539,000</u>	<u>0</u>	<u>0</u>	<u>0</u>	<u>0</u>	<u>0</u>	<u>0</u>
Subtotal.....	\$ 0	\$ 0	\$ 77,736	\$239,069	\$187,854	\$ 931,672	\$405,790	\$257,536	\$472,250	\$301,132	\$811,717	\$791,887
General Fund:												
Health.....	\$194,119	\$86,504	\$132,768	\$120,000	\$ 85,666	\$ 116,850	\$ 99,935	\$ 73,925	\$ 85,514	\$ 97,934	\$ 58,502	\$ 79,933
Transportation.....	<u>0</u>	<u>0</u>	<u>0</u>	<u>0</u>	<u>0</u>	<u>0</u>	<u>100,000</u>	<u>101,000</u>	<u>100,000</u>	<u>99,000</u>	<u>99,000</u>	<u>0</u>
Subtotal.....	\$194,119	\$86,504	\$132,768	\$120,000	\$ 85,666	\$ 116,850	\$199,935	\$174,925	\$185,514	\$196,934	\$157,502	\$ 79,933
Combined Funds:												
Education	\$ 0	\$ 0	\$ 0	\$ 0	\$120,694	\$ 9,313	\$ 93,781	\$129,661	\$ 39,353	\$ 90,000	\$150,000	\$195,000
Health.....	194,119	86,504	140,504	129,069	152,826	500,209	411,944	201,800	518,411	309,066	720,219	676,820
Transportation.....	<u>0</u>	<u>0</u>	<u>70,000</u>	<u>230,000</u>	<u>0</u>	<u>539,000</u>	<u>100,000</u>	<u>101,000</u>	<u>100,000</u>	<u>99,000</u>	<u>99,000</u>	<u>0</u>
OTDAP Totals.....	\$194,119	\$86,504	\$210,504	\$359,069	\$273,520	\$1,048,522	\$605,725	\$432,461	\$657,764	\$498,066	\$969,219	\$871,820

^aInformation is not available at this level of detail for this fiscal year.

Source: Developed by LB&FC staff using information obtained from the PA Department of Health and the Governor's Office of the Budget, Status of Appropriations documents.

Table 45

OTDAP Expenditures From the Trust Fund, by Purpose

(FY 2001-02 Through FY 2005-06)

Fiscal Year	Implementation Costs ^a	Voluntary Benefits	Grants To OPOs	Project Make-A-Choice	School Awareness	Total
2000-01	\$ 2,853	\$ 0	\$ 309,156	\$ 0	\$ 93,781	\$ 405,790
2001-02	3,385	2,717	113,595	8,178	129,661	257,536
2002-03	3,610	17,633	384,871	26,783	39,353	472,250
2003-04	3,680	28,241	48,627	130,584	90,000	301,132
2004-05	4,158	24,327	537,788	95,444	150,000	811,717
2005-06	<u>3,110</u>	<u>20,953</u>	<u>519,876</u>	<u>52,948</u>	<u>195,000</u>	<u>791,887</u>
Totals.....	\$20,796	\$93,871	\$1,913,913	\$313,937	\$697,795	\$3,040,312

^aIncludes Advisory Committee costs.

Source: Developed by LB&FC staff using information obtained from the PA Department of Health.

Implementation/Advisory Committee Costs. The first use of Trust Fund monies is for “actual costs” incurred by the Departments of Health, Transportation, and Revenue for program implementation and the costs of the Organ Donation Advisory Committee. Pursuant to statute, the Trust Fund distribution formula for remaining Fund monies then becomes effective following the payment of such costs.

During the period FY 2000-01 through FY 2005-06, only Advisory Committee costs were expended under this Fund purpose. These costs ranged from a low of \$2,853 to a high of \$4,158.

Voluntary Benefits. Following the payment of implementation and advisory committee costs, up to 10 percent of remaining Trust Fund monies may be expended annually by the Department of Health “for reasonable hospital and other medical expenses, funeral expenses, and incidental expenses incurred by the donor or donor’s family in connection with making a vital organ donation.” To date, the program has not paid for any hospital, medical, or funeral expenses. (See part E of this Section for further discussion of this issue.)

Under the “incidental expenses” provision of the statute, the DOH did institute a pilot program in 2002 under which organ donors and/or a donor’s family can receive reimbursement for meals and lodging expenses (up to \$300 per each donor or donor’s family). This benefit program is available to persons involved in the donation of a “vital organ”; tissue donors and their family members are not eligible to participate in the program under current law. During the period FY 2000-01

through FY 2005-06, a total of \$93,781 was expended for voluntary benefits to organ donors and their families.

Grants to OPOs. Act 1994-102 stipulates that up to 50 percent of remaining Trust Fund monies (following payment of implementation and advisory committee costs) “may be expended for grants to certified organ procurement organizations for the development and implementation of organ donation awareness programs in this Commonwealth.”

The Center for Organ Recovery and Education and the Gift of Life Donor Program, the state’s two federally-designated OPOs receive this funding to contract for a statewide public awareness program. The two OPOs receive identical budgets and work statements. According to Department of Health officials, this is done with the intention that the state’s two OPOs “work in concert to provide one organ and tissue donation awareness program throughout the Commonwealth.”

By virtue of being the two federally designated OPOs serving Pennsylvania, GLDP and CORE are essentially the guaranteed recipients of these monies as specified by Act 1994-102. Every three years, the Department of Health, along with GLDP and CORE, issue an RFP to solicit bids from firms desiring to operate the statewide public awareness campaign.

The amounts disbursed to the OPOs for this purpose varied significantly between FY 2000-01 and FY 2003-04. Much of this variation may be explained by the timeliness of contract execution. While FY 2003-04 was the first year of a new three-year contract, the contract was not formally approved for execution until almost mid-way through the fiscal year. As such, the actual expenditures for this purpose were the lowest of the six-year period. In fiscal years 2004-05 and 2005-06, years two and three of the multi-year contract, expenditures for this purpose remained above \$500,000 in each year. (Note: Annual figures represent a total of expenditures made by both OPOs.)

Project Make-A-Choice. Act 1994-102 authorizes up to 15 percent of remaining Trust Fund monies to be “expended by the Department of Health, in cooperation with certified organ procurement, organizations, for the Project Make-A-Choice program.” Regarding Project Make-A-Choice, the Act states that this “shall include information pamphlets designed by the Department of Health relating to organ donor awareness and the laws regarding organ donation, public information and public education about contributing to the fund when obtaining or renewing a driver’s license and when completing a state individual tax return form.”

Specifically, monies allocated for this purpose have been used to provide additional funding in the contracts executed with the state’s OPOs for the contracted statewide public awareness campaign. Therefore, expenditures for Project

Make-A-Choice varied between fiscal years 2000-01 and 2005-06 mainly due to the cycle of multi-year contracts with the state's OPOs.

As shown in Table 45, no expenditures were made for Project Make-A-Choice in FY 2000-01. Thereafter, spending rose to about \$8,200 in FY 2001-02 to a six-year high of \$130,584 in FY 2003-04. In fiscal years 2004-05 and 2005-06, the first two years of the three-year statewide public awareness contract, expenditures were \$95,444 and \$52,948, respectively.

Department of Education Secondary School Awareness. The statutory expenditure provisions further authorize that 25 percent of remaining Trust Fund monies are to be expended by the Department of Education (PDE) "for the implementation of organ donation awareness programs in the secondary schools in this Commonwealth." Act 1994-102 also stipulates that, upon availability of funding, and in cooperation with the Department of Health and the state's organ procurement organizations (OPOs), PDE is to establish a program that can be used for secondary education purposes, which is to include: (1) information about state law relating to anatomical gifts, including how to become an organ donor; and (2) general information about organ transplantation in the United States.

To implement this mandate, PDE has executed several multi-year contracts with the Lancaster-Lebanon Intermediate Unit (IU-13). (See part C of this Section for further information). Expenditures for this purpose varied from a low of \$39,353 in FY 2002-03 to a high of \$195,000 in FY 2005-06.

Expenditures From General Fund Appropriations

In addition to Trust Fund monies, the Departments of Health and Transportation have also expended monies from the state General Fund for OTDAP purposes. The amounts expended by these agencies between FY 2000-01 and FY 2005-06 are shown on Table 46.

Department of Health. General Fund monies appropriated to the Department of Health for OTDAP (through the "Organ Donation" appropriation) are generally used to cover the printing and postage costs of informational brochures, which are distributed by PennDOT in driver's license and vehicle registration renewal packets, in driver licensing centers, and to the public upon request. These materials are produced in support of the ongoing state awareness campaign entitled "Ordinary People, Extraordinary Power." This appropriation has also been partially used for organ and tissue donation awareness exhibits at local fairs and other locations, and special promotion at sports and media events. According to the Director of the Bureau of Health Promotion and Risk Reduction, it has been the policy of the Department of Health not to use Trust Fund monies for these purposes.

Table 46

OTDAP Expenditures From the General Fund

(FY 2000-01 Through FY 2005-06)

Department of Health:

<u>Fiscal Year</u>	<u>Appropriation Amount</u>	<u>Amount Expended^{a,c}</u>	<u>Amount Lapsed^c</u>
2000-01	\$120,000	\$99,935	\$20,065
2001-02	120,000	73,925	46,075
2002-03	116,000	85,514	30,486
2003-04	109,000	97,934	11,066
2004-05	109,000	58,502	50,498
2005-06	109,000	79,933	29,067 ^d

Department of Transportation:

2000-01 ^b	\$100,000	\$100,000	\$0
2001-02	103,000	101,000	2,000
2002-03	102,000	100,000	2,000
2003-04	99,000	99,000	0
2004-05	99,000	99,000	0
2005-06	0	0	0

Total Combined:

2000-01	\$220,000	\$199,935	\$20,065
2001-02	223,000	174,925	48,075
2002-03	218,000	185,514	32,486
2003-04	208,000	196,934	11,066
2004-05	208,000	157,502	50,498
2005-06	109,000	79,933	29,067 ^d

^aDuring the period FY 1994-95 through FY 1999-00, the Department of Health's spending for OTDAP from the General Fund totaled \$735,907.

^bThis is the first fiscal year in which PennDOT received a direct state appropriation for OTDAP from the General Fund.

^cAmounts reflect state appropriations expended and lapsed, respectively, in actual and subsequent fiscal years.

^dAmount pending lapse as of February 2007.

Source: Developed by LB&FC staff using information obtained from the Governor's Office of the Budget, Status of Appropriations documents.

A portion of this appropriation has also been used to supplement contracts executed with the state's organ procurement organizations, CORE and the Gift of Life Donor Program, for implementation of Project Make-A-Choice and Act 102's provision of grants to the state's OPOs for the development and implementation of organ donation awareness programs in the Commonwealth. No portion of the General Fund appropriation is used to fund personnel expenses.

In fiscal years 2003-04 through 2005-06, CORE and the Gift of Life Donor Program each received \$30,000 in monies from this state appropriation (\$10,000 per fiscal year) pursuant to terms fulfilled in their respective contracts to implement a statewide organ and tissue donation awareness program.

In an OPO contract extension period, from July 1, 2006, through September 30, 2006, each OPO received an additional \$5,000 in state funds. Department of Health officials state that they plan to continue using a portion of their General Fund appropriation to supplement the OPO's statewide awareness campaigns as funding is available.

As shown in Table 46, the Department of Health has lapsed varying amounts of this state appropriation in the period FY 2000-01 through FY 2005-06. While the Department received an appropriation of \$120,000 in FY 2001-02, only \$73,925 was expended. In FY 2002-03, when the appropriation decreased to \$116,000, the Department expended \$85,514 and lapsed \$30,486. In FY 2003-04, expenditures were at a four-year high of \$97,934 as the appropriation dropped to \$109,000. By FY 2004-05, expenditures reached a four-year low of \$58,502.

In FY 2005-06, the Department of Health again received a state appropriation of \$109,000, of which \$79,933 was expended and \$29,067 was pending lapse as of February 2007. Table 47 presents expenditure detail for the FY 2005-06 Department of Health Organ Donation state appropriation. Expenditures were made under the Operational Expenses major object of expenditure.

As shown, almost 69 percent of the \$79,933 expended from the appropriation in FY 2005-06 was for the printing minor object of expenditure, followed by over 25 percent expended for advertising. Remaining expenditures in FY 2005-06 were for the graphic services and specialized services minor objects of expenditure.

Table 47

**Department of Health Organ Donation
General Fund Appropriation Detail
(FY 2005-06)**

<u>Minor Object of Expenditure</u>	<u>Amount Expended^a</u>
Specialized Services	\$ 167
Advertising.....	20,000
Printing	54,813
Graphic Services	5,012
Other Operational Expenses	<u>(59)</u>
Total.....	\$79,933

^aAmounts expended by minor object of expenditure are rounded to the nearest dollar.

Source: Developed by LB&FC staff using information obtained from the PA Department of Health.

PennDOT. General Fund appropriations to PennDOT in support of OTDAP have been for the costs of ongoing maintenance of equipment and computer systems in support of the collection of Trust Fund voluntary contributions (both at the time of driver’s license renewal and vehicle registration renewal). This has included maintenance costs for high-speed remittance processing equipment, mainframe data storage, financial reconciliation of collected funds, and vendor costs for data entry of the organ donor indicator on photo driver’s licenses and state identification cards.

PennDOT has received both General Fund and Trust Fund monies to cover OTDAP-related implementation costs. General Fund monies are requested for ongoing hardware and computer maintenance costs, while Trust Fund monies are requested to fund system development and implementation costs for new programs and enhancements to the existing program.

According to PennDOT officials, as these processes became integrated into PennDOT systems the need for General Fund monies was gradually reduced. A departmental review of reimbursement appropriations was conducted during preparation of the agency budget for FY 2005-06. The result of this review “indicated that the organ donor program had been integrated into the highly automated photo license process and there was no longer a measurable ongoing cost.”

For the receipt of Trust Fund monies, the Department of Health initiates contact with PennDOT when a proposed enhancement is identified for the improvement of the program. PennDOT then provides an estimate of a one-time implementation cost for such enhancement. Based on the estimate costs, the Department of Health then determines whether to proceed. If a decision is made to

proceed with the enhancements, PennDOT invoices the Department of Health for reimbursement upon completion of the enhancement.

As discussed previously, Act 1998-74 directed PennDOT to provide applicants for a renewal vehicle registration the opportunity to make a contribution of \$1 to the Trust Fund. Act 74 provided that the Trust Fund was to reimburse PennDOT for initial costs incurred in the development and implementation of the vehicle registration voluntary contribution. The General Fund was to reimburse PennDOT for the actual annual operating costs of administering this process up to a maximum of \$100,000 in the first fiscal year during which the pertinent provision of Act 74 was effective (FY 1999-00). Thereafter, PennDOT was authorized to receive a General fund reimbursement for actual operating costs of the program in an amount not to exceed the prior year's actual operating costs on a full fiscal year basis plus 3 percent.

While PennDOT did not receive this General Fund reimbursement in FY 1999-00, the Trust Fund reimbursed PennDOT \$539,000 in that year (See "Trust Fund Financial Statement" Section for further details). The Department received an appropriation of \$100,000 in FY 2000-01, of which it expended the entire appropriation. In FY 2001-02, the Department received a General Fund appropriation of \$103,000. Of this amount, PennDOT expended \$101,000 and lapsed \$2,000.

In FY 2002-03, PennDOT received an appropriation of \$102,000, expending \$100,000 and lapsing \$2,000. In both fiscal years 2004-05 and 2005-06, PennDOT expended its entire \$99,000 General Fund appropriation. PennDOT did not receive a state appropriation for Trust Fund collection costs in FY 2006-07.

In sum, the Department of Health and PennDOT received \$1,186,000 in General Fund appropriations related to OTDAP duties and responsibilities during the period FY 2000-01 through FY 2005-06. Of this amount, \$994,743 had been expended as of February 2007 and \$191,257 had lapsed.

Current Available (FY 2006-07) and Budgeted (FY 2007-08) Data

Trust Fund. In FY 2006-07, the Trust Fund incurred an implementation cost of \$30,000 to reimburse PennDOT for costs associated with the establishment and promotion of the online organ donor designation system, including reimbursement of services provided by contractors for this purpose.

These monies were disbursed for this purpose following a redirection of monies originally authorized in the amount of \$505,000 for Department of Health implementation costs in FY 2006-07. When initially authorized, \$5,000 was budgeted for Advisory Committee costs and \$500,000 for a performance evaluation of the Organ and Tissue Donor Awareness Program that was proposed to be completed by

a private contractor. This estimated cost for the proposed performance evaluation was reportedly based upon other previously completed contracted performance evaluations completed for the Department of Health. Concurrence of the permissibility of a performance evaluation as an implementation cost for the Department of Health was obtained from Department legal counsel prior to requesting the authorization for FY 2006-07.

The prospect of a performance evaluation of the program was considered and discussed by the Advisory Committee. At the September 7, 2005, Advisory Committee meeting, members discussed issuing a Request for Proposals (RFP) for a private contractor to conduct a performance evaluation of the Program. Some Committee members expressed concern over the potential cost of contracting for a performance evaluation, and the possibility of LB&FC completion of the evaluation was presented. A subcommittee was formed at this meeting, led by the Committee co-chair, to explore options for a “comprehensive evaluation.”

At the December 14, 2005, Advisory Committee meeting, a handout was provided to Committee members that provided background information on the LB&FC. A Committee member who is a state representative then explained the process whereby a resolution directing the LB&FC to complete a program evaluation could be introduced. A motion was then passed by the Committee which called for the setting of parameters regarding how the evaluation is to be completed and the corresponding resolution drafted, and affirming the decision to request that the LB&FC complete the evaluation.

House Resolution 698 of 2006, directing the LB&FC to conduct a performance evaluation of the Organ and Tissue Donor Awareness Program, was adopted on April 25, 2006. At the June 8, 2006, Advisory Committee meeting, a motion was passed that recommended the reallocation of the \$500,000 previously authorized as a Department of Health implementation cost for FY 2006-07 for the purpose of a performance evaluation of the Program; proposing \$30,000 to reimburse PennDOT for costs associated with establishing an online donor designation program and \$470,000 for promotion of the online designation program, to commence a grief counseling program, and for minority awareness programs in FY 2006-07.

In August 2006, the Department of Health’s Director of the Bureau of Health Promotion and Risk Reduction drafted a memo to the Director of the Department’s Bureau of Administrative and Financial Services recommending the following reallocation of the \$500,000 previously allocated for a program evaluation:

- \$30,000 to PennDOT reimbursement for costs incurred to establish the online organ donor designation website.
- \$440,000 for the marketing of the online organ donor designation website, and minority awareness initiatives, and \$30,000 for a pilot grief

counseling program. These monies were to be added to the FY 2006-07 authorization for grants to the state's OPOs as per Title 20, Pa.C.S. §8622(b).

A proposal for redirection of the \$500,000 was then submitted by the Bureau of Administrative and Financial Services to the Governor's Office of the Budget in late August, 2006. On September 22, 2006, an Expenditure Symbol Notification (ESN) was issued by the Governor's Office of the Budget, which authorized the proposed adjustment of Fund monies for FY 2006-07. (See Table 48.)

Table 48

Revised Executive Authorizations (FY 2006-07)		
	<u>Prior Authorization Amount</u>	<u>Revised Authorization</u>
To Department of Health:		
Implementation Costs	\$505,000	\$ 5,000
Grants to OPOs	425,000	895,000
To PennDOT:		
Implementation Costs	0	30,000 ^a

^aPennDOT indicated that the online designation system has been fully implemented, and that no additional features or adjustments are being planned.

Source: Developed by LB&FC staff using information obtained from the PA Department of Health

Following the reauthorization of Trust Fund monies in September 2006 supplementing FY 2006-07 grants to Pennsylvania's OPOs and the redirection of implementation cost monies to PennDOT, the revised FY 2006-07 funding levels became effective for the Trust Fund. (See Table 49.)

Table 49

Revised Trust Fund Expenditure Authorizations (FY 2006-07)	
<u>Trust Fund Expenditure Purpose</u>	<u>Revised Authorization Amount</u>
Department of Health Implementation and Advisory Committee Costs	\$ 5,000
PennDOT Implementation Costs	30,000
Voluntary Expense Benefits.....	60,000
Grants to OPOs	895,000
Project Make-A-Choice.....	90,000
Department of Education-Awareness.....	150,000

Source: Developed by LB&FC staff using information obtained from the PA Department of Health.

For FY 2007-08, both Department of Health and Department of Education have requested Trust Fund monies. Table 50 provides a breakdown of FY 2007-08 requests by Department. As shown, combined Trust Fund requests by the Department of Health and Department of Education total \$945,000 for FY 2007-08.

Table 50

Trust Fund Expenditure Requests By Department
(FY 2007-08)

Department of Health:

<u>Trust Fund Expenditure Purpose</u>	<u>Amount Requested</u>
Implementation and Advisory Committee Costs	\$105,000 ^a
Voluntary Expense Benefit	60,000
Grants to OPOs	465,000
Project Make-A-Choice.....	<u>90,000</u>
Total.....	\$720,000

Department of Education:

<u>Trust Fund Expenditure Purpose</u>	<u>Amount Requested</u>
Secondary School Awareness Program (OTDA Education Project)	<u>\$225,000</u>
Total.....	\$225,000

^aIncludes \$100,000 for a survey of Pennsylvania households on perceptions and positions on organ and tissue donation and \$5,000 Advisory Committee costs.

Source: Developed by LB&FC staff using information obtained from the PA Department of Health and the FY 2007-08 Governor's Executive Budget.

General Fund. In FY 2006-07, the Department of Health received a General Fund appropriation of \$109,000 in support of expenses associated with the Organ and Tissue Donor Awareness Program. As of February 2007, DOH expended \$30,058 from this appropriation. For FY 2007-08, DOH has again requested \$109,000 from the General Fund for expenses associated with the OTDAP.

PennDOT received no General Fund monies in FY 2006-07, nor has the Department requested General Fund monies for expenses related to the OTDAP in FY 2007-08.

K. Expenditure Management and Compliance With Statutory Spending Requirements

Findings

- K-1. The formula established by Act 1994-102 to govern the allocation of monies from the Trust Fund does not provide program administrators enough flexibility in program spending, and some authorized spending areas (for example, implementation costs and incidental expenses) are inadequately defined. Further, the manner in which the Fund has been administered, using separate restricted expenditure accounts or “silos,” for each of the four Act 102 statutory spending categories was cumbersome and made expenditure prioritization time-consuming and difficult.*
- K-2. During the course of this evaluation, the Department of Health and the Advisory Council, with concurrence from the Governor’s Office of the Budget, discontinued the “silo method” of Trust Fund management under which separate, continuing balances were maintained for each of the four “silos.” Under the new method, allocations of available funds continue according to the percentages specified in law, but all unexpended monies in each expenditure category (formerly “silo”) are returned to the Trust Fund balance at the end of each fiscal year for reallocation in the subsequent fiscal year. This change should give DOH and the Advisory Committee increased flexibility in managing the Trust Fund and reduce time-consuming administrative recordkeeping and explanations of and deliberations on silo balances at Advisory Committee meetings.*
- K-3. OTDAP spending has been fully in compliance with the statutory caps on program spending for voluntary benefits (10 percent), grants to OPOs (50 percent), Project Make-A-Choice (15 percent), and secondary school awareness (25 percent). In fact, the expenditures for most of the categories were significantly less than their spending cap in some or all of the years examined. As shown below, expenditures for each of the authorized Trust Fund spending purposes did not exceed their statutory spending caps at any time during the period FY 2001-02 through FY 2005-06.*

Fiscal Year	Expenditures as a % of Trust Fund Balance				
	Trust Fund Beginning Balance	Voluntary Benefits (10% Cap)	Grants To OPO (50% Cap)	Project Make-A-Choice (15% Cap)	Secondary School Awareness (25% Cap)
2001-02.....	\$ 964,139	0.3%	11.8%	0.9%	13.5%
2002-03.....	1,397,628	1.3	27.6	1.9	2.8
2003-04.....	1,628,958	1.7	3.0	8.0	5.5
2004-05.....	2,085,343	1.2	25.8	4.6	7.2
2005-06.....	2,048,496	1.0	25.4	2.6	9.5

Proportionally, the closest that any expenditure in this period came to the statutory spending cap was for “Grants to OPOs” in FY 2002-03, in which 27.6 percent of the beginning Trust Fund balance was expended. This expenditure amount also represented the highest proportion expended for any of the expenditure categories in the five fiscal years examined.

The figures also show that certain expenditures were significantly less than the statutory spending cap in some or all of the years examined. For example, the Voluntary Benefits expenditure amount never reached 2 percent of the total Fund beginning balance in any of the five years examined.

Trust Fund Management

Act 102 established the Organ Donation Awareness Trust Fund¹ as the central funding mechanism for organ and tissue donation awareness activities in the Commonwealth. This section documents the methods used by the Department of Health and the Organ Donation Advisory Committee to manage Trust Fund expenditures. It also evaluates compliance with the statutory Trust Fund expenditure provisions and formula set forth in Act 1994-102.

The Use of Expenditure Accounts or “Silos”

As previously discussed, Trust Fund expenditures are classified into five categories: “implementation costs” (including program-related costs of the Departments of Transportation, Health, and Revenue and the costs of the Organ Donation Advisory Committee); voluntary benefits; OPO grants; Project Make-A-Choice; and secondary school awareness programs.

These spending categories correspond to the statutory provisions of Act 1994-102 that provide for the disposition of monies deposited in the Governor Robert P. Casey Memorial Organ and Tissue Donation Awareness Trust Fund. The Act states that all moneys deposited in the Trust Fund, including interest which accrues from those funds, are first appropriated on a continuing basis subject to the approval of the Governor to compensate the Department of Transportation, the Department of Health, and the Department of Revenue for actual costs related to program implementation and to pay the costs of the Organ Donation Advisory Committee.

The law does not place any conditions or limits on the monies used to cover the implementation costs of these three state agencies or the advisory committee. Therefore, in theory, if the payment of agency implementation costs and the costs of the Organ Donation Advisory Committee required all of the monies in the Fund, the

¹Act 2000-120 changed the named of the Trust Fund to The Governor Robert P. Casey Memorial Organ and Tissue Donation Awareness Trust Fund.

law allows for the Fund to be depleted for these purposes. It is only following the appropriation of Fund monies for these purposes, that Act 102's distribution formula, prescribing the purposes and maximum percentage amounts of corresponding annual expenditure, becomes effective for remaining Fund monies, as follows:

- 10 percent of the total fund may be expended annually by the Department of Health for reasonable hospital and other medical expenses, funeral expenses, and incidental expenses incurred by the donor or donor's family in connection with making a vital organ donation;
- 50 percent may be expended for grants to certified organ procurement organizations for the development and implementation of organ donation awareness programs;
- 15 percent may be expended by the Department of Health, in cooperation with certified organ procurement organizations, for the Project Make-A-Choice program; and
- 25 percent may be expended by the Department of Education for the implementation of organ donation awareness programs in the Commonwealth's secondary schools.

The statutory percentages cited above for each of the four uses of remaining Fund monies represent a maximum level of expenditure, or cap, as a percentage of the "total fund." It is permissible, according to the law, to expend the entire remainder of the Fund balance according to the distribution formula. It is also permissible, according to the law, for no monies to be expended for these purposes. The expenditure of all Trust Fund monies, whether for implementation costs, costs of the Advisory Committee, or for the purposes prescribed for remaining funds remains discretionary and "subject to the approval of the Governor."

Moreover, since the percentage distribution formula exists in the law in the context of an annual expenditure, each expenditure cap regarding the amount of Fund monies that may be expended each year for each purpose is binding and revised each year. In other words, an annual exercise of discretion is permitted by law in the expenditure of "any remaining funds" for the four stated purposes in the distribution formula, not to exceed each of the stated percentage caps.

For much of the program's history, the Department of Health has used a system of expenditure accounts to manage and control Trust Fund spending. This approach preserved unexpended balances within each of the four purposes of the distribution formula from fiscal year to fiscal year rather than returning unexpended monies allocated within each of the four purposes to the Trust Fund balance at the end of each fiscal year. Department of Health officials referred to the account for

each of the four purposes set forth in the Trust Fund distribution formula as a “silo.”

Each year, following the subtraction of budgeted implementation costs, including Advisory Committee costs, the DOH, with input and involvement from the Organ Donation Advisory Committee, allocated “available funds” to each of the four expenditure categories according to the specified percentages. In this case, “available funds” were defined as the total amount of receipts deposited in the Trust Fund in the prior year, including interest, minus implementation and Advisory Committee costs. Thereafter, following actual expenditures for each of the four purposes, any unexpended monies would remain and accumulate in a “balance” for each silo. That is, each of the four Trust Fund expenditure purposes would, in practice, become sub-funds² with balances that could be used for each respective purpose in subsequent fiscal years, subject to the percentage caps prescribed in law and as authorized by the Governor. Table 51 demonstrates this practice as applied by the DOH and the Advisory Committee between FY 2001-02 and FY 2005-06.

The effect, in practice, of this method of financial management was the accumulation of a balance in each of the silos at the end of fiscal years, representing all unspent monies that had been allocated previously. In subsequent fiscal years, each silo (or purpose for the expenditure of remaining Fund monies) would then receive an annual executive authorization for a maximum level of expenditure.

To illustrate this practice, take, for example, the “Voluntary Benefits Silo”:

- As shown on Table 51, this “silo” had an ending balance of \$121,615 at the close of FY 2000-01.
- To this amount, the DOH added 10 percent of prior year (i.e., FY 2000-01) receipts credited to the Trust Fund, or \$64,079. This resulted in a beginning FY 2001-02 balance in the “Voluntary Benefits Silo” of \$185,694.
- Following expenditures of \$2,717 in FY 2001-02, the silo balance at the end of FY 2001-02 was \$182,977.
- This amount (\$182,977) when combined with 10 percent of the receipts deposited in the Trust Fund during FY 2001-02 (\$68,764) then became the beginning silo balance for voluntary benefits (\$251,741) for FY 2002-03. Table 52 illustrates how the balances in the four silos grew between FY 2000-01 and FY 2005-06 as a result of this practice.

²While silos did not appear in official Commonwealth financial records as subaccounts within the Trust Fund, DOH fiscal staff maintained an internal record of the cumulative balances in each silo. Unspent monies in the silos did not “lapse” or return to an unallocated status at the close of a fiscal year.

Table 51

Application of the “Silo” Method of Trust Fund Financial Management
(FY 2001-02 Through FY 2005-06)

	“Silos”			
	Voluntary Benefits (10%)	Grants to OPOs (50%)	Project- Make-A- Choice (15%)	Education Awareness (25%)
<u>FY 2001-02</u>				
Silo Balance at End of Prior Fiscal Year.....	\$121,615	\$ 56,426	\$ 65,059	\$ 80,251
Amount Distributed From Prior Year Receipts ^a	<u>64,079</u>	<u>320,394</u>	<u>96,118</u>	<u>160,196</u>
Beginning Silo Balance.....	\$185,694	\$376,820	\$161,177	\$240,447
Less Disbursements	<u>2,717</u>	<u>113,595</u>	<u>8,178</u>	<u>129,661</u>
Ending Silo Balance ^b	\$182,977	\$263,225	\$152,999	\$110,786
<u>FY 2002-03</u>				
Silo Balance at End of Prior Fiscal Year.....	\$182,977	\$263,225	\$152,999	\$110,786
Amount Distributed From Prior Year Receipts ^a	<u>68,764</u>	<u>343,821</u>	<u>103,146</u>	<u>171,910</u>
Beginning Silo Balance.....	\$251,741	\$607,046	\$256,145	\$282,696
Less Disbursements	<u>17,633</u>	<u>384,871</u>	<u>26,783</u>	<u>39,353</u>
Ending Silo Balance ^b	\$234,109	\$222,174	\$229,362	\$243,343
<u>FY 2003-04</u>				
Silo Balance at End of Prior Fiscal Year.....	\$234,109	\$222,174	\$229,362	\$243,343
Amount Distributed From Prior Year Receipts ^a	<u>69,997</u>	<u>349,986</u>	<u>104,995</u>	<u>174,992</u>
Beginning Silo Balance.....	\$304,106	\$572,160	\$334,357	\$418,335
Less Disbursements	<u>28,241</u>	<u>48,627</u>	<u>130,584</u>	<u>90,000</u>
Ending Silo Balance ^b	\$275,865	\$523,533	\$203,773	\$328,335
<u>FY 2004-05</u>				
Silo Balance at End of Prior Fiscal Year.....	\$275,865	\$523,533	\$203,773	\$328,335
Amount Distributed From Prior Year Receipts ^a	<u>75,384</u>	<u>376,918</u>	<u>113,075</u>	<u>188,460</u>
Beginning Silo Balance.....	\$351,249	\$900,451	\$316,848	\$516,795
Less Disbursements	<u>24,327</u>	<u>537,788</u>	<u>95,444</u>	<u>150,000</u>
Ending Silo Balance ^b	\$326,922	\$362,663	\$221,404	\$366,795

Table 51 (Continued)

FY 2005-06	"Silos"			
	Voluntary Benefits (10%)	Grants to OPOs (50%)	Project Make-A-Choice (15%)	Education Awareness (25%)
Silo Balance at End of Prior Fiscal Year.....	\$326,922	\$362,663	\$221,404	\$366,795
Amount Distributed From Prior Year Receipts ^a	<u>77,071</u>	<u>385,357</u>	<u>115,606</u>	<u>192,677</u>
Beginning Silo Balance.....	\$403,993	\$748,020	\$337,010	\$559,472
Less Disbursements	<u>20,953</u>	<u>519,876</u>	<u>52,948</u>	<u>195,000</u>
Ending Silo Balance ^b	\$383,040	\$228,144	\$284,062	\$364,472

^aImplementation Costs and the budgeted costs of the Organ Donation Advisory Committee are first subtracted from receipts prior to allocation to the four expenditure purposes according to percentages specified in law.

^bFigures for the ending balance may not equal the beginning balance minus disbursements due to rounding.

Source: Developed by LB&FC staff using information obtained from the PA Department of Health.

Table 52

Growth in the Size of the OTDAP “Silo” Balances

(June 30, 2001, Through June 30, 2006)

Ending FY Balance	“Silo”			
	Voluntary Benefits	Grants To OPOs	Project Make- A-Choice	Education Awareness
June 30, 2001.....	\$121,615	\$ 56,426	\$ 65,059	\$ 80,251
June 30, 2002.....	182,977	263,225	152,999	110,786
June 30, 2003.....	234,109	222,174	229,362	243,343
June 30, 2004.....	275,865	523,533	203,773	328,335
June 30, 2005.....	326,922	362,663	221,404	366,795
June 30, 2006.....	383,040	228,144	284,062	364,472

^aEnding silo balance represents the balance in each expenditure purpose, or category, following disbursements in each fiscal year.

Source: Developed by LB&FC staff using information obtained from the PA Department of Health.

Discontinuation of the “Silo” System

This method of managing the Trust Fund proved to be cumbersome and time-consuming both for DOH staff and members of the Organ Donation Advisory Committee. Recordkeeping, reporting, and related discussions at Advisory Committee meetings consumed valuable time and resources with little apparent return in terms of improved program administration. Rather, the use of the silo approach may, in some cases, have impeded or, at a minimum, made expenditure prioritization more difficult.

For example, one DOH official stated that the use of the silo system proved to be an impediment to efficient spending of Trust Fund monies. This was a reference to some “silos” accumulating a large balance due to monies not being expended while, at the same time, the balances on other silos were insufficient for intended activities and ongoing initiatives. Members of the Organ Donation Advisory Committee also, at times, expressed frustration with the silo system and its lack of flexibility. The minutes of Advisory Committee meetings we examined for the period 2000 through 2006 contain numerous references to the silo system, including discussion of whether it was necessary and the need to consider possible alternatives.

On several occasions, DOH officials discussed with the Advisory Committee the possibility of revising the method used to manage the Trust Fund. In late 2005, DOH requested that its Legal Counsel review the law to determine whether it provides for an alternative method of Trust Fund financial management.

The Office of Legal Counsel concluded that the silo method was not prescribed in law and was not necessary. Rather, the remaining balances for each of the expenditure purposes specified in law could be returned to the Trust Fund balance to be reallocated in subsequent fiscal years. The interpretation held, in part, that:

The law does not specifically set up separate categories of funds. The law merely sets spending limits on those funds and does so in a manner that only establishes the maximum amount that may be spent on any particular activity. It does not set up sub-funds within the fund that require a specific, permanent dedication to a particular activity.

Concerning the effect of the revised system on practical financial management of the Fund, the interpretation stated:

. . . a reallocation of the total fund balance, on a continuing basis, would distribute the funds over the years to the areas where they are needed most, to best provide the services that are required according to the Act. This reallocation on a recurring annual basis would allow for greater spending in areas where the most costs are incurred yet maintain reasonable and appropriate balances in other areas for expenditure when needed.

Following this interpretation, the Director of the DOH's Bureau of Health Promotion and Risk Reduction presented a proposal for an alternative approach to Trust Fund financial management to the Director of the Bureau of Administrative and Financial Services and to the co-chairs of the Organ Donation Advisory Committee. At the December 14, 2005, meeting of the Advisory Committee, the Office of Legal Counsel's interpretation and the proposal for the new system of Trust Fund financial management was presented to the full Committee.

Under this proposal, the practice of maintaining ongoing balances in each of the four silos would be discontinued. While allocations of available funds would continue according to the percentages specified in law, all unexpended monies in each expenditure category (formerly "silo") would be returned to the Trust Fund balance at the end of a fiscal year for reallocation in the subsequent fiscal year.

The Department then forwarded the proposed new system of Trust Fund financial management to the Governor's Office of the Budget for review and concurrence. The Office of the Budget concurred in the legal interpretation and the new system of financial management, and the Department of Health implemented the change beginning in FY 2006-07.

Table 53 provides a depiction of the new system of Trust Fund financial management using figures current as of the beginning of FY 2006-07. Modifications to requested authorization amounts are indicated in footnotes to the table.

At the beginning of FY 2006-07, the accumulated amounts in each of the expenditure categories were returned to the Trust Fund balance. The total Trust Fund balance, including Trust Fund receipts for FY 2005-06, was then distributed to each of the expenditure categories according to the percentages specified in law following the deduction of budgeted implementation costs and the budgeted costs of the Advisory Committee.

As can be seen in Table 53, the current system of Trust Fund financial management may permit increased Executive Authorizations for each of the four purposes for the expenditure of remaining Trust Fund monies based on trends of prior year actual disbursements. Similarly, monies not expended in one of the four purposes may, by virtue of being added to the Trust Fund balance at the end of each fiscal year, increase the allocation of purposes for which all authorized monies are spent. This is the case because allocations are made by the Department based upon the percentages specified in law; resulting in, by consequence, allocations increasing as the Fund balance increases.

The amounts requested for Executive Authorization for expenditure have been, in practice, well below the statutory maximum levels of expenditure (if all monies were to be expended). Under the current system of financial management, the amounts requested to the Office of the Budget then may be, accordingly, adjusted in subsequent fiscal years according to program activities in need of additional funding, the priorities of the Governor, Department of Health, or Advisory Committee, or changes in the amount of received and projected Fund receipts. Additionally, during the course of a fiscal year the Department may request additional Executive Authorizations for each of the four purposes if a program area of need is identified.

Department of Health program officials believe the new system has the potential to allow them in consultation with the Advisory Committee, to implement new awareness activities and provide greater flexibility and increased funding to areas in which it may be most needed.

Compliance With Statutory Spending Caps

As previously stated, following an allowance for implementation costs (including Advisory Committee costs), remaining Trust Fund revenues are to be expended in accordance with the statutory percentages specified in Act 102. These

Table 53

Illustration of the Current System of Trust Fund Financial Management
(FY 2006-07)

	<u>Expense Benefit</u> <u>Reimbursement</u> (10%)	<u>Grants to</u> <u>OPOs</u> (50%)	<u>Project</u> <u>Make-A-Choice</u> (15%)	<u>Education</u> <u>Awareness</u> (25%)	<u>Implementation</u> <u>Costs/Advisory</u> <u>Committee</u>	<u>Total</u>
7/1/06 Beginning Balance.....	\$ 0	\$ 0	\$ 0	\$ 0	\$ 0	\$2,167,820
Less: Budgeted Implementation						
Costs/Advisory Committee	0	0	0	0	505,000 ^a	505,000
Available Funding for Distribution	0	0	0	0	0	1,662,820
Allocation of Avail. Fund Bal.....	166,282	831,410	249,423	415,705	0	1,662,820
Less: Exec. Auth.....	<u>60,000</u>	<u>425,000^b</u>	<u>90,000</u>	<u>150,000</u>	<u>0</u>	<u>725,000</u>
Ending Balance ^{c, d}	\$106,282	\$ 406,410	\$159,423	\$265,705	\$ 0	\$ 937,820
Plus: Projected Revenue ^e						<u>911,000</u>
Revised Estimated Ending Balance (6/30/07)						\$1,848,820

^a\$500,000 originally budgeted as a Trust Fund implementation cost was subsequently reallocated to supplement grants to Pennsylvania's certified OPOs (\$470,000 total; comprised of \$440,000 for marketing of the online donor designation website and minority awareness initiatives, and \$30,000 for implementation of a pilot grief counseling program) and for implementation costs of PennDOT (\$30,000 for costs incurred to establish the online organ donor designation website in FY 2006-07). The \$5,000 budgeted for the costs of the Advisory Committee remained unchanged.

^bFollowing the revised authorization approved in FY 2006-07, the amount authorized for grants to Pennsylvania's certified OPOs was \$895,000.

^cEnding balances in each expenditure purpose are returned to the Trust Fund balance for reallocation in the following fiscal year.

^dEnding balances calculated using the assumption that the entire executive authorization is expended for each purpose.

^eProjected revenue is based on actual revenue received in FY 2005-06.

may be interpreted as representing an annual maximum level of expenditure, or cap, calculated as a percentage of the “total fund.”³

We examined OTDAP spending during the period FY 2000-01 through FY 2005-06 in order to determine if spending has been in compliance with the statutory caps. We conducted this analysis on the basis of the term “total fund” being defined as in the context of the previously discussed silo system of Trust Fund Management (i.e., the total funds available in the Trust Fund made up of the beginning balance, which includes prior fiscal year receipts, less budgeted implementation costs).

Table 54 presents the actual amount disbursed for each Trust Fund expenditure category and the corresponding percentage of the Trust Fund balance as of the beginning of each fiscal year (minus budgeted implementation and Advisory Committee costs of \$5,000 in each year) for FY 2001-02 through FY 2005-06. As can be seen, expenditures for each of the purposes for the use of remaining Trust Fund monies never exceeded the statutory caps during the period FY 2001-02 through FY 2005-06. Proportionally, the closest that any expenditure in this period came to the statutory spending cap was for Grants to OPOs in FY 2002-03, in which 27.6 percent of the beginning Fund balance was expended. This expenditure amount also represented the highest proportion expended for any of the expenditure categories in the five fiscal years examined.

Table 54 also shows that certain expenditures were significantly less than the statutory spending cap in some or all of the years examined. For example, the Voluntary Benefits expenditure amount never reached 2 percent of the total Fund beginning balance in any of the five years examined.

Significant variation from year to year was also noticed for some of the expenditure purposes. This is evidenced by expenditures for Grants to OPOs varying from 27.6 percent of the total Fund balance in FY 2002-03 to 3 percent in FY 2003-04, before rising again to above 25 percent in fiscal years 2004-05 and 2005-06. Similarly, expenditures for the Department of Education’s secondary school awareness programs ranged from 13.5 percent of the total Fund balance in FY 2001-02 to 2.8 percent in FY 2002-03. These variations were due primarily to delays that occurred in the processing and finalization of contracts with the OPOs and PDE Intermediate Unit 13.

³In Act 1994-102, only the initially listed expenditure purpose (i.e., donor/donor family expenses) actually uses the word “annually” in reference to its expenditure. The other three simply say “may be expended” without specifying “annually.” It is reasonable for the word “annually” to be read into the other three purposes. Similarly, only the initially-listed purpose states its percentage in terms “of the total fund.” The phrase “total fund” in this context likely should be read “total *remaining* fund” (i.e., after payment of implementation costs) since that is consistent with the context of this particular section. The rules of statutory construction state that we are to presume “that the General Assembly does not intend a result that is absurd, impossible of execution or unreasonable.” 1 Pa C.S.A. §1922(1).

Table 54

**Compliance With Statutory Spending
Caps, by Expenditure "Silo"**
(FY 2001-02 Through FY 2005-06)

Fiscal Year	Trust Fund Balance ^a	Expenditures as a % of Trust Fund Balance							
		Voluntary Benefits (10% Cap)	%	Grants To OPOs (50% Cap)	%	Project Make-A Choice (15% Cap)	%	Secondary School Awareness (25% Cap)	%
2001-02	\$ 964,139	\$ 2,717	0.3%	\$113,595	11.8%	\$8,178	0.9%	\$129,661	13.5%
2002-03	1,397,628	17,633	1.3	384,871	27.6	26,783	1.9	39,353	2.8
2003-04	1,628,958	28,241	1.7	48,627	3.0	130,584	8.0	90,000	5.5
2004-05	2,085,343	24,327	1.2	537,788	25.9	95,444	4.6	150,000	7.2
2005-06	2,048,496	20,953	1.0	519,876	25.4	52,948	2.6	195,000	9.5

^aBeginning balance includes budgeted implementation costs and Advisory Committee costs of \$5,000.

Source: Developed by LB&FC staff using information obtained from the PA Department of Health.

L. Trust Fund Financial Condition

Findings

- L-1. *The annual year-end balance in the Governor Robert P. Casey Memorial Organ and Tissue Donor Awareness Trust Fund has grown fairly steadily throughout the history of the program and reached a high of \$2.2 million at the end of FY 2005-06. However, a planned expansion of donor family benefits to include grief counseling and the need to address the issue of tissue donor eligibility and other pending initiatives could quickly deplete the available Fund balance.*

Fund Balance, As of June 30, 2006

As of June 30, 2006, the Governor Robert P. Casey Memorial Organ and Tissue Donation Awareness Trust Fund had an ending balance of \$2,167,820. (See Table 55.) In FY 2005-06, the program had an operating surplus (i.e., annual receipts exceeding annual expenditures) of \$119,324 and the fund balance increased by about 5.8 percent over the prior year.

Table 55

Governor Robert P. Casey Memorial Organ and Tissue Donation Awareness Trust Fund (Balance as of June 30, 2006)

	<u>FY 2005-06</u>
Beginning Balance	\$2,048,496
Receipts:	
Driver's License Applicants	\$ 291,168
Private Donations	2
State Income Tax Contribution.....	29,889
Vehicle Registration	448,960
Interest on Securities	<u>141,192</u>
Total Receipts	\$ 911,211
Total Funds Available.....	\$2,959,707
Disbursements:	
Education	\$ 195,000
Health	596,887
Implementation Costs	3,110
Voluntary Benefits	20,953
Grants to OPOs.....	519,876
Project Make-A-Choice	52,948
Transportation	<u>0</u>
Total Disbursements	\$ 791,887
Ending Balance	\$2,167,820

Source: Developed by LB&FC staff using information obtained from the PA Department of Health.

Table 56

Financial Statement for The Governor Robert P. Casey Memorial Organ and Tissue Donation Awareness Trust Fund
(FY 1994-95 Through FY 2005-06)

	FY 1994-95	FY 1995-96	FY 1996-97	FY 1997-98	FY 1998-99	FY 1999-00	FY 2000-01	FY 2001-02	FY 2002-03	FY 2003-04	FY 2004-05	FY 2005-06
Cash Balance, Beginning ...	\$ 0	\$ 13,660	\$591,505	\$ 798,757	\$ 843,937	\$1,012,786	\$ 726,288	\$ 964,139	\$1,397,628	\$1,628,958	\$2,085,343	\$2,048,496
Receipts:												
Transfer From General Fund.....	\$ 0	\$300,000	\$ 0	\$ 0	\$ 0	\$ 0	\$ 0	\$ 0	\$ 0	\$ 0	\$ 0	\$ 0
Driver's License Applicants	13,660	266,438	247,968	202,427	237,715	257,669	259,656	261,571	246,024	245,241	217,354	291,168
Private Donations	0	2,531	38	25	87	36	100	6	115	2	75	2
State Income Tax Contribution	0	0	0	36,641	69,614	57,273	45,049	37,152	50,360	42,128	42,673	29,889
Vehicle Registration	0	0	0	0	0	284,440	293,546	350,634	375,781	387,750	415,921	448,960
Interest on Securities	0	8,876	36,982	45,156	49,287	45,756	45,290	41,662	31,300	82,396	98,847	141,192
Total Receipts	\$13,660	\$577,845	\$284,988	\$ 284,249	\$ 356,703	\$ 645,174	\$ 643,641	\$ 691,025	\$ 703,580	\$ 757,517	\$ 774,870	\$ 911,211
Total Funds Available	\$13,660	\$591,505	\$876,493	\$1,083,006	\$1,200,640	\$1,657,960	\$1,369,929	\$1,655,164	\$2,101,208	\$2,386,475	\$2,860,213	\$2,959,707
Disbursements:												
Education	\$ 0	\$ 0	\$ 0	\$ 0	\$ 120,694	\$ 9,313	\$ 93,781	\$ 129,661	\$ 39,353	\$ 90,000	\$ 150,000	\$ 195,000
Health.....	0	0	7,736	9,069	67,160	383,359	312,009	127,875	432,897	211,132	661,717	596,887
Implementation Costs.....	0	0	7,736	9,069	a	a	2,853	3,385	3,610	3,680	4,158	3,110
Voluntary Benefits	0	0	0	0	a	a	0	2,717	17,633	28,241	24,327	20,953
Grants to OPOs.....	0	0	0	0	a	a	309,156	113,595	384,871	48,627	537,788	519,876
Project Make-A-Choice.....	0	0	0	0	a	a	0	8,178	26,783	130,584	95,444	52,948
Transportation	0	0	70,000	230,000	0	539,000	0	0	0	0	0	0
Total Disbursements	\$ 0	\$ 0	\$ 77,736	\$ 239,069	\$ 187,854	\$ 931,672	\$ 405,790	\$ 257,536	\$ 472,250	\$ 301,132	\$ 811,717	\$ 791,887
Cash Balance, Ending.....	\$13,660	\$591,505	\$798,757	\$ 843,937	\$1,012,786	\$ 726,288	\$ 964,139	\$1,397,628	\$1,628,958	\$2,085,343	\$2,048,496	\$2,167,820

^aInformation is not available at this level of detail for this fiscal year.

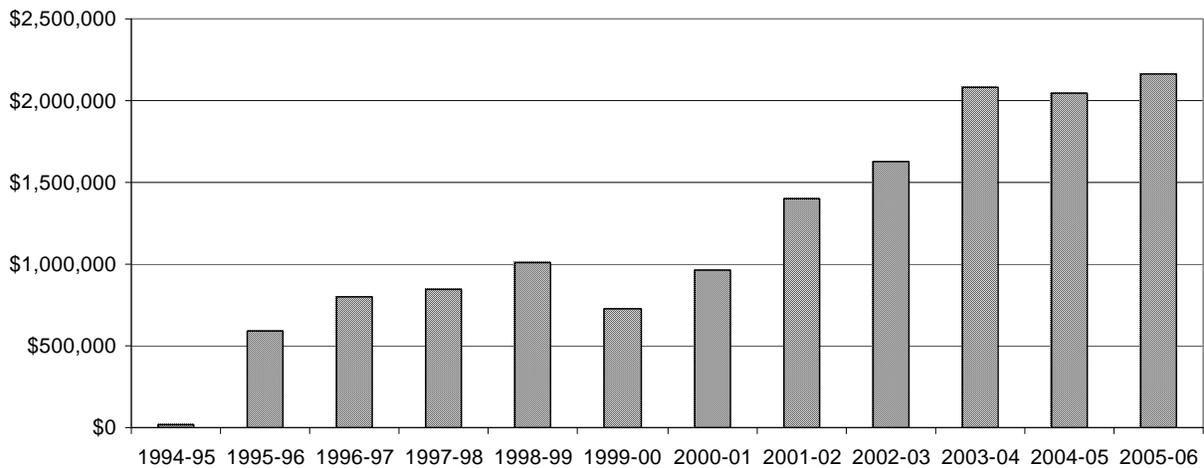
Source: Developed by LB&FC staff using fiscal information obtained from OTDAP fiscal records, PA Department of Health and from Commonwealth Status of Appropriations reports.

Historical Financial Statement

Using fiscal information obtained from the Department of Health and the Governor’s Office of the Budget Status of Appropriations reports, we developed a historical financial statement for the Trust Fund covering the program’s 12-year history through June 30, 2006. This section presents this financial statement and provides a year-by-year review and analysis of the Fund balance. As shown on Table 56 and Exhibit 15 below, this analysis indicates a fairly steady and consistent rise in the fund balance from \$13,660 at the close of FY 1994-95 to \$2,167,820 as of June 30, 2006.

Exhibit 15

Annual Growth in the Trust Fund Balance (FY 1994-95 Through FY 2005-06)



Source: Developed by LB&FC staff using information obtained from the PA Department of Health.

FY 1994-95. The section of Act 1994-102 that created the Trust Fund became effective on January 30, 1995. PennDOT commenced the \$1 voluntary contribution for individuals renewing their driver’s license or state identification cards in March 1995.¹ The \$13,660 collected through these contributions represented the only receipts, and the end-of-year cash balance, in FY 1994-95. No disbursements were made from the Trust Fund in FY 1994-95.

FY 1995-96. In FY 1995-96, the Trust Fund received \$266,438 in voluntary contributions from driver’s license and state identification card applicants. Also received in FY 1995-96 were private donation contributions of \$2,531 and a General Fund transfer of \$300,000. The purpose of this one-time transfer from the General Fund was to reimburse PennDOT for system development and implementation costs related to administration of the \$1 voluntary contribution at the time of

¹However, individuals renewing their driver’s license or state identification cards could have the “organ donor” designation added to their cards beginning December 6, 1994.

driver's license and state identification card renewals. Again, no disbursements were made from the fund, and at the end of FY 1995-96, the Trust Fund balance rose to almost \$600,000.

FY 1996-97. Disbursements were first made from the Trust Fund in FY 1996-97 in the amount of \$70,000, for purposes of the first reimbursement to PennDOT and \$7,736 in Advisory Committee costs to the Department of Health. Receipts from driver's license/state identification card applicants, private donations, and interest on securities were credited to the Fund in that year, resulting in total receipts of almost \$285,000. At the end of FY 1996-97, the Fund balance grew to just under \$800,000.

FY 1997-98. Fiscal year 1997-98 was the first in which state taxpayers had the option of contributing any amount of their state individual income tax refund to the Trust Fund. Nearly \$37,000 was generated from this source. However, there was an offsetting reduction of over \$45,000 in receipts from driver's license/state identification card applicants resulting in total receipts for FY 1997-98 of just under the amount received in FY 1996-97. Disbursements in FY 1997-98 included \$9,069 for Advisory Committee costs and \$230,000 reimbursement to PennDOT for system development and implementation costs. The Trust Fund ended the fiscal year with a balance of \$843,937.

FY 1998-99. During FY 1998-99, total receipts rose by 25 percent to \$356,703. Combined with a beginning balance of \$843,937, the fund had total funds available of \$1,200,640. On the expenditure side, FY 1998-99 was the first year in which Trust Fund disbursements (in the amount of \$120,694) were made to the Department of Education (PDE) for the implementation of secondary school awareness programs. Also in FY 1998-99, the Department of Health first contracted with the state's OPOs for implementation of a statewide organ and tissue donation awareness campaign. First year expenditures for this purpose were \$67,160, and the Fund ended the year with a balance of \$1,012,786.

FY 1999-00. In FY 1999-00, individuals renewing their vehicle registration had the option, for the first time, to contribute \$1 to the Trust Fund. In that year, \$284,440 was donated to the Fund from this source. Combined with other sources, primarily from driver's license applicants and state income tax contributions, revenues grew to \$645,174. PDE received just over \$9,000 for the continuance of secondary school awareness programs, and the Fund reimbursed PennDOT \$539,000 for system development and upgrades, and for the updating of forms and publications in connection with the initiation of the vehicle registration voluntary contribution. This was the last instance in which PennDOT received Trust Fund reimbursement in the period FY 1994-95 through FY 2005-06. The Department of Health continued to expend Trust Fund monies for Project Make-A-Choice and for grants to OPOs

totaling \$383,359. A substantial operating deficit resulted (receipts of \$645,174 versus disbursements of \$931,672) and the fund balance declined to \$726,288.

FY 2000-01. The fund returned to an operating surplus position with revenues of \$643,641 and expenditures of \$405,790. The major expenditure item in FY 2000-01 was contract payments to the OPOs totaling \$309,156. Revenues remained steady as donations through vehicle registration renewals increased to \$293,546, and the year-end fund balance increased to \$964,139.

FY 2001-02. Revenues again grew in this fiscal year (to \$691,025) led by a nearly 20 percent growth in revenues from contributions made by vehicle registration renewal applicants. Disbursements declined by about \$150,000 to \$257,536. In FY 2001-02, the Department of Health first expended Trust Fund monies for the voluntary benefits provisions of Act 1994-102 to reimburse organ donors and their families up to \$300 for the lodging and meal expenses related to making donations of vital organs. Also in this year, the Department made a separate disbursement for Project Make-A-Choice for the provision of additional monies to supplement a total of \$113,595 paid to the state OPOs. With increased revenues and reduced disbursements, the Fund balance rose to \$1,397,628.

FY 2002-03. As had been the pattern, revenues continued to exceed expenditures in this fiscal year. With continuing steady growth in donations at the time of vehicle registration renewal, revenues totaled \$703,580. When combined with the beginning fiscal year balance, revenues available to the program exceeded \$2.0 million for the first time. In terms of disbursements, the program continued to expend Trust Fund monies for the voluntary benefits pilot program, grants to OPOs, and Project Make-A-Choice, expending a total of \$432,897 for these purposes. PDE disbursements dropped over \$90,000 from the FY 2001-02 total to \$39,353 in FY 2002-03. The year-end balance in the Trust Fund was \$1,628,958.

FY 2003-04. Past revenue patterns continued and, overall, revenues increased by about 8 percent to \$757,517. Disbursements for the voluntary benefits pilot program increased to \$28,241 in FY 2003-04 while PDE disbursements returned to near prior-year levels at \$90,000. Overall, combined funding for grants to OPOs and Project Make-A-Choice decreased by \$232,443 between FY 2002-03 and FY 2003-04. The year-end balance exceeded \$2.0 million for the first time reaching \$2,085,343.

FY 2004-05. With a beginning balance of \$2,085,343 and revenues of \$774,870, funds available for OTDAP approached \$3.0 million. With this balance, the program returned, for just the second time, to an annual operating deficit portion (that is, annual expenditures exceeded annual revenues). In FY 2004-05, program expenditures were \$811,717 against revenues of \$774,870. In FY 2004-05, combined funding for grants to OPOs and Project Make-A-Choice totaled \$633,232,

representing the most expended for these combined purposes in the 12 fiscal years examined since the program began. Disbursements to PDE increased \$60,000 in that fiscal year to a total of \$150,000, while disbursements for the voluntary benefits pilot program decreased to \$24,327. The ending fund balance remained above \$2.0 million at \$2,048,496.

FY 2005-06. Although revenues from state income tax refund contributions dropped to an all-time low of \$29,889, revenues from voluntary donations made by donor's license and vehicle registration applicants remained strong with combined total receipts of \$740,128. With interest at \$141,192 on the strength of a growing fund balance, total revenues reached \$911,211 for the year. Disbursements for PDE, implementation costs, voluntary benefits, grants to OPOs, and Project Make-A-Choice totaled \$791,887. The Trust Fund balance rose to a new high of \$2,167,820 at June 30, 2006.

M. Review and Update of the State’s Anatomical Gift Act

Finding

M-1. Pennsylvania has not yet addressed or taken a formal position on the adoption of any or all of the proposed revisions contained in the updated Uniform Anatomical Gift Act (UAGA) which was adopted by the NCCUSL in 2006. While the revised UAGA makes changes in nine key areas of the act, Pennsylvania’s two OPOs do not believe there is a need for their wholesale incorporation into Pennsylvania law.

The Uniform Anatomical Gift Act

The National Conference of Commissioners on Uniform State Laws (NCCUSL) is a state governmental organization comprised of approximately 350 commissioners appointed by state governments. The NCCUSL mission is to provide states with non-partisan well-conceived, and well-drafted legislation that brings clarity and stability to critical areas of the law and to assume a primary role in the country for the improvement of state law. NCCUSL’s work supports the federal system and facilitates the movement of individuals and the business of organizations with rules that are consistent from state to state.

NCCUSL is the source of more than 250 uniform acts which seek to secure uniformity of state laws where diversity obstructs citizen interests. One of these acts is the Uniform Anatomical Gift Act. The NCCUSL issued its first Uniform Anatomical Gift Act in 1968. This original Act was amended in 1987 and a further revision was under consideration as of January 2007. This section discusses Pennsylvania’s adoption of the 1968 and 1987 versions of the Act and analyzes and compares the key areas of proposed change in the 2006 revision to current Pennsylvania law.

The 1968 UAGA

In 1968, the NCCUSL approved the UAGA. By 1972, the act had been adopted in every state. The UAGA provides the legal framework upon which human organs and tissues can be donated for transplantation by the execution of a document of gift authorizing an anatomical gift. The 1968 Act provided clarification of who had the right to exercise control over a dead body by recognizing an adult person’s right to exercise control of his or her own body upon death by preparing a document indicating intent to donate the body.¹ If a written document donating the

¹The UAGA authorized persons 18 years of age or older to make a gift of any part of their bodies, taking effect upon their death. This gift could not be rescinded by another party without the donor’s consent.

body was not prepared, then a priority list of relatives who may donate the body was set forth. The NCCUSL amended the UAGA in 1987.

The 1987 UAGA

The 1987 amendments retained the basic clarifications provided by the 1968 act, but modified the original law by providing for the following: (1) a simplified document of gift, eliminating the need for witnesses; (2) an explicit statement that medical attendants can rely upon a “document of gift,” with no other consent required; (3) a requirement that hospitals make a “required request” of incoming patients for organ donation²; (4) a provision that permits a person to execute a document that forbids the taking of all the body or specific organs, or that places other restrictions; and (5) a provision that forbids the sale of organs.

Under Pennsylvania’s law, anyone of “sound mind” age 18 or older may decide to be an organ and tissue donor. Parents and guardians must consent to that decision by anyone between the ages of 16 and 18, and must also make that decision for other minor donors. Any adult may complete and have properly witnessed an organ and tissue donor card and/or ask that the “Organ Donor” designation be placed on a new or renewed Pennsylvania Driver’s License or Photo ID Card at a photo license center. All three are considered to be legal documents for the purpose of organ and tissue donation. Additionally, proof of intent to be an organ donor may be evidenced through such a choice contained in a living will, durable power of attorney, or other documents of gift established by the Act. There are no fees or charges assessed to the donor’s estate or family for any procedures necessary for the donation of organs or tissues.

Pennsylvania adopted the 1968 UAGA and readopted it in 1994 pursuant to Act 1994-102. While Pennsylvania operates under the 1968 version of the UAGA, Act 1994-102 included additional provisions in Pennsylvania law that appear to address some of the changes of the 1987 UAGA.

The Proposed 2006 UAGA Revisions

In July 2006, a Revised Uniform Anatomical Gift Act (RUAGA) was promulgated by the NCCUSL to address in part the continuing critical organ shortage by providing additional ways for making organ, eye, and tissue donations. Non-uniformity among the states is an impediment to transplantation. Moreover, there also have been substantial improvements in the technology and practice of transplantation and therapy and the need for organs, eyes, and tissue for research and education has increased increasing the need for more donors.

²The federal Omnibus Budget Reconciliation Act of 1986, 42 U.S.C. §1320b-8, also requires all hospitals participating in Medicare or Medicaid to establish written protocols for the identification of potential organ donors. Pennsylvania includes a similar provision at 20 Pa C.S.A. §8617(d).

The NCCUSL identifies nine key areas of change in the RUAGA. These are summarized and compared to current Pennsylvania law below.

- *Who May Make Anatomical Gift Before Donor's Death (Section 4)* – This section seeks to facilitate donations by expanding the list of those who may make an anatomical gift for another individual during that individual's lifetime to include health-care agents and, under certain circumstances, parents or guardians. The revised law would also empower a minor eligible that is eligible to apply for a driver's license as well as an emancipated minor to be donors. Pennsylvania law currently only allows the following persons to make an anatomical gift during the life of a donor: (1) an adult donor, (2) an agent acting under a power of attorney specifically authorizing the making of anatomical gifts, and (3) a minor 16 years old or older with parental consent.
- *Preclusive Effect of Anatomical Gift, Amendment, or Revocation (Section 8)* – The revised UAGA continues to honor the choice of an individual to be or not to be a donor and strengthens the language barring others from overriding a donor's decision to make an anatomical gift. Section 8 is designed to state firmly the rule that a donor's autonomous decision regarding the making of an anatomical gift is to be honored and implemented and is not subject to change by others and is restated in these amendments to take away from families the power, right, or authority to consent to, amend, or revoke donations made by donors during their lifetimes. This revised section more specifically addresses possible tension between a donor's autonomous decision to be a donor with the interest of surviving family members to make that decision. It addresses this tension by favoring the decision of the donor over the desires of the family and specifically strips family members of their right to make, amend, or revoke an anatomical gift. Pennsylvania law currently contains the general provisions that if there is a validly executed document of gift (including a driver's license designation), the consent of family members is not needed to make the anatomical gift valid and the anatomical gift cannot be revoked by the family members.
- *Who May Make Anatomical Gift of Decedent's Body or Part (Section 9)* – This section facilitates donations from a deceased individual who made no lifetime choice by expanding the list of persons who can make a gift of the deceased individual's body or parts by including the following persons: a power of attorney for healthcare at the time of death; adult grandchildren; and an adult who exhibited special care and concern for the decedent. The law would permit an anatomical gift by any member of a class where there is more than one person in the class so long as no objections by other class members are known and, if an objection is known, permits a majority of the members of the class who are "reasonably available" to make the gift without having to take account of a known objection by any class

member who is not “reasonably available.” The concept and definition of “reasonably available” is drawn from lessons learned in the drafting of the Uniform Health-Care Decisions Act and borrows language from that act. The term means that someone is able to be contacted without “undue effort and willing and able to act in a timely manner consistent with existing medical criteria necessary for the making of an anatomical gift.” Pennsylvania law currently only allows for anatomical gifts on behalf of a decedent to be made by (in order of priority) a spouse, adult children, parents, adult siblings, a guardian, or other person obligated to dispose of the body. These persons may make an anatomical gift on behalf of a decedent if persons in a prior class are not available and have not made a known objection.

- *Persons That May Receive Anatomical Gift; Purpose of Anatomical Gift (Section 11)* – This section of the revised UAGA would create numerous default rules for the interpretation of a document of gift that lacks specificity regarding either the persons to receive the gift or the purposes of the gift or both. For example, if a gift of a part is made to a named individual and it is later determined that the part cannot be transplanted into that individual, the law provides that the part passes to the organ procurement organization as custodian to allocate the organ in accordance with applicable organ allocation policies unless the person making the gift expressly provides to the contrary. In part, this section is designed to harmonize the UAGA with NOTA to facilitate the nationwide, equitable distribution of organs. This section creates a priority for transplantation or therapy over research or education and it specifies the person to whom a part passes when the document of gift merely expresses a “general intent” to be an organ donor. While Pennsylvania law contains provisions detailing who may receive anatomical gifts and for what purposes, it does not detail default rules or priority of use (except in tissue procurement) where such is not set forth in the document of gift.
- *Rights and Duties of Procurement Organizations and Others (Section 14)* – The revised UAGA would enable procurement organizations to gain access to documents of gifts in donor registries, medical records, and the records of a state motor vehicle department. (See also Section 20.) It seeks to resolve tension between a health-care directive requesting the withholding or withdrawal of life support systems and anatomical gifts by permitting measures necessary to ensure the medical suitability of organs for intended transplantation or therapy to be administered. (See also Section 21). Pennsylvania’s UAGA does not specifically address these matters.
- *Law Governing Validity; Choice of Law as to Execution of Document of Gift; Presumption of Validity (Section 19)* – This section recognizes anatomical gifts made under the laws of other jurisdictions. This is intended to assure that a document of gift is valid if it was valid either in the place

where executed or in the place where the person making the gift was domiciled, resided, or was a national. Moreover, a person can presume a document of gift to be valid unless the person has actual knowledge that it was not validly executed or was revoked. Such reciprocity is not specifically provided for under Pennsylvania's current UAGA.

- *Donor Registry (Section 20)* – Recognizing the development and use of registries, this section encourages and establishes standards for donor registries. Minimum requirements for a donor registry whether created by the state or not are that the registry: (1) provide an electronic database that allows persons to make an anatomical gift by use of a statement or symbol; (2) be accessible to all procurement organizations at or near the time of death of a donor or prospective donor to determine whether the donor or prospective donor made, amended, or revoked an anatomical gift; and (3) be operational on a seven day a week, twenty-four hour basis. Pennsylvania's current UAGA does not address detailed standards for the state's donor registry.
- *Cooperation Between Coroner/ME and Procurement Organization (Section 22) and Facilitation of Anatomical Gift From Decedent Whose Body is Under Jurisdiction of Coroner/ME.(Section 23)* - The revised UAGA would clarify and expand rules relating to cooperation and coordination between procurement organizations and coroners or medical examiners. Unlike prior law, this section does not empower coroners/medical examiners to make an anatomical gift of the body or parts of a decedent. Pennsylvania law does not speak to coordination of organ donor activities with coroners.
- *Relation to Electronic Signatures in Global and National Commerce Act (Section 25)* – The UAGA is updated to allow for electronic records and signatures. This is not addressed by Pennsylvania's current UAGA.

Analysis of Proposed Changes

Since approval of the Revised UAGA by the NCCUSL in July 2006, the proposed act has been adopted in three states, Idaho, Utah, and Virginia and has been introduced for adoption in eighteen other states³ as well as the District of Columbia and the U.S. Virgin Islands. Adoption of the Revised UAGA has been endorsed by the American Academy of Ophthalmology, the American Association of Tissue Banks, the American Society of Cataract and Refractive Surgery, the Association of Organ Procurement Organizations, the Cornea Society, the Eye Bank Association of America, the National Kidney Foundation, UNOS, and the American Medical Association.

³Arizona, Arkansas, California, Colorado, Indiana, Kansas, Minnesota, Missouri, Montana, Nevada, New Jersey, New Mexico, North Dakota, Rhode Island, South Dakota, Tennessee, Vermont, and Washington.

Pennsylvania’s two OPOs reviewed the proposed UAGA revisions and are of the opinion that given the success they have had working within the present context of Act 102, neither OPO is looking for a wholesale adoption of the 2006 UAGA in Pennsylvania. They think the language in Pennsylvania’s existing UAGA makes the process involved in organ donation much clearer than the revised UAGA. For example, routine referral is set forth in Act 102 but is still not included in the revised UAGA. Also, the revised UAGA does not mention who hospitals are to contact, but Act 102 speaks to a partnership between OPOs and the healthcare community. The OPOs identified what they viewed as positive aspects of the proposed revised UAGA, as follows:

- hospital life support must continue until an assessment can be made as to the viability of organs for donation;
- UAGA would now reference data on an organ donor registry as being the equivalent of a document of gift evidencing intent to make an organ donation; and
- the ability to make a donation under a healthcare power of attorney is expanded under the revised UAGA, while Pennsylvania law still requires “specific language” in the power of attorney to allow for organ donation.

When asked about the changes to the statutory list of persons capable of making a donation on behalf of a decedent, OPO representatives said they saw some value in discussing modifying the list somewhat but not to the extent of the proposed UAGA. When asked about the provisions in the proposed UAGA coordinating organ donation roles for medical examiners and coroners, the OPOs said that there is a potential need and that the OPOs would see advantages to having a coroner in attendance at the organ retrieval if the coroner is going to deny an organ donation, which is similar to how New Jersey handles it. When asked about the revised UAGA allowing minors who are eligible to obtain driver’s licenses to designate themselves to be donors without parental consent, OPO representatives said they were not certain they agreed with removing parental involvement from the decisions of such minors.

A state NCCUSL commissioner confirmed that the Pennsylvania delegation of commissioners⁴ to the NCCUSL is currently strategizing over the best way to have the revised law introduced in the state.

⁴Pennsylvania’s delegation of commissioners to the NCCUSL consists of ten persons from state government, academia, and private practice.

N. Compliance With Annual Reporting Requirements

Findings

- N-1. The Departments of Health and Education, the Organ Donation Advisory Committee, the state's organ procurement organizations, and tissue procurement providers are all required by statute to report periodically to the General Assembly. We found that these agencies and organizations compile one consolidated report and that the reports for the period 2000 through 2005 had been submitted and satisfied the statutory requirements. Transmittal of the 2006 report had not yet occurred as of mid-April 2007.*
- N-2. While program reports are provided to the Legislature, no annual OTDAP report is made available to the public stakeholders whose donations are the primary source of revenue for the program.*
-

Act 1994-102, in its amendment of 20 Pa.C.S. §8601 *et seq.*, created several annual reporting requirements to the General Assembly for the state agencies, OPOs, and tissue procurement providers involved in the implementation of the Act's provisions.

Title 20, §8622(d) mandates that the Department of Health (DOH) and the Pennsylvania Department of Education (PDE) are to submit an annual report to the General Assembly on expenditures of Trust Fund monies and to report on any progress made in reducing the number of potential donors who were not identified.

In cooperation with tissue procurement providers, OPOs are required to submit an annual report to the General Assembly as required by 20 Pa.C.S. §8617(e) which is to include:

1. the number of tissue donors;
2. the number of tissue procurements for transplantation; and
3. the number of tissue procurements recovered for research by each tissue procurement provider operating in Pennsylvania.

In addition, the Organ Donation Advisory Committee is to submit a report to the General Assembly within 30 days prior to the expiration of each legislative session concerning its activities and progress.

To satisfy these requirements, the Department of Health, in the name of the Organ Donation Advisory Committee, annually compiles required and supplementary information from each state agency of responsibility and the state's OPOs and

submits a report to the General Assembly to fulfill each of the annual reporting requirements specified by Act 102 and Title 20. We reviewed the annual reports in the period 2000 through 2005, and found that the reports satisfy each of the reporting requirements stated in law.

The annual reports consist of an introductory message from the chairs of the Advisory Committee which summarizes significant accomplishments, ongoing initiatives, and program milestones from the prior year; activity and progress reports for the Departments of Health, Education,¹ and Transportation (which fulfill all required departmental duties under Act 102 for each department), and include descriptions of ongoing awareness campaigns and bureaus of responsibility within each department; an end-of-fiscal-year Trust Fund financial statement; OPO service area information, including Pennsylvania counties served, population served, tissue and eye procurement providers within their service area, and statistics concerning organ, tissue, and eye donations; and a Pennsylvania county ranking of organ donor designations on driver's licenses and state identification cards, which provides the total drivers, designated organ donors, and the percentage of all drivers with the designation as of the end of the prior fiscal year.

¹Towards fulfillment of this mandate, the Lancaster-Lebanon Intermediate Unit (IU-13) updates PDE on activities completed on a quarterly basis, as per an executed contract. Annually, PDE completes an end-of-fiscal-year summary of activities completed and initiatives undertaken by IU-13 and PDE. This summary is then integrated into the Organ Donation Advisory Committee annual report to the General Assembly.

IV. Appendices

APPENDIX A

PRINTER'S NO. **3974**

THE GENERAL ASSEMBLY OF PENNSYLVANIA

HOUSE RESOLUTION

No. 698

Session of

2006

INTRODUCED BY PETRARCA, COHEN, TANGRETTI, BELARDI, BEBKO-JONES, BENNINGHOFF, BIANCUCCI, BLAUM, BUXTON, CALTAGIRONE, COSTA, DeLUCA, EACHUS, FABRIZIO, FRANKEL, FREEMAN, GABIG, GEORGE, GERBER, GERGELY, GRUCELA, HALUSKA, HANNA, HARRIS, HUTCHINSON, W. KELLER, LaGROTTA, LEACH, LEVDANSKY, MANN, MARKOSEK, McCALL, McNAUGHTON, MELIO, S. MILLER, MUNDY, PALLONE, PAYNE, PISTELLA, PRESTON, RAMALEY, READSHAW, SAINATO, SAMUELSON, SANTONI, SATHER, SAYLOR, SHAPIRO, SIPTROTH, SOLOBAY, STABACK, STETLER, STURLA, SURRA, TIGUE, VITALI, WALKO, WANSACZ, YEWIC AND YUDICHAK, APRIL 10, 2006

REFERRED TO COMMITTEE ON HEALTH AND HUMAN SERVICES, APRIL 10, 2006

A RESOLUTION

1 Directing the Legislative Budget and Finance Committee to
2 conduct a performance evaluation of the Commonwealth's organ
3 and tissue donor awareness program established under Act 102
4 of 1994.

5 WHEREAS, The Commonwealth's organ and tissue donor program is
6 a joint responsibility of the Department of Health, the
7 Department of Transportation, the Department of Education, the
8 Department of Revenue and the two Pennsylvania organ procurement
9 organizations that meet the requirements of section 371 of the
10 Public Health Service Act (58 Stat. 682, 42 U.S.C. § 273); and

11 WHEREAS, Each department is responsible for developing and
12 administering portions of the program designed to increase organ
13 and tissue donation and awareness in Pennsylvania; and

14 WHEREAS, Pennsylvania's two organ procurement organizations

Appendix A (Continued)

1 are responsible for developing and administering portions of the
2 program designed to increase organ and tissue donation awareness
3 in Pennsylvania; and

4 WHEREAS, These programs are funded by the generosity of
5 concerned Pennsylvanians through voluntary donations to the
6 Robert P. Casey Memorial Organ and Tissue Donation Awareness
7 Trust Fund; and

8 WHEREAS, Since the enactment of Act 102 of 1994 there has
9 been a significant increase in the number of Pennsylvanians
10 placing the organ donor designation on their driver's license
11 and in other ways indicating their willingness to be an organ
12 and tissue donor; and

13 WHEREAS, Since the enactment of Act 102 of 1994 there has
14 been a significant increase in actual organ and tissue donations
15 in Pennsylvania, and thousands of people have received
16 lifesaving organ and tissue transplants; and

17 WHEREAS, More than 6,500 Pennsylvanians remain on the organ
18 donation waiting list, and thousands more are in need of tissue
19 transplants; therefore be it

20 RESOLVED, That the House of Representatives direct the
21 Legislative Budget and Finance Committee to conduct a
22 performance evaluation of the Commonwealth's organ and tissue
23 donor awareness program established under Act 102 of 1994; and
24 be it further

25 RESOLVED, That the committee make a report, with
26 recommendations as appropriate, which shall be submitted to the
27 Speaker and the Minority Leader of the House of Representatives
28 by November 30, 2006.

APPENDIX B

A Summary of Act 2006-65, The Pennsylvania Organ and Bone Marrow Donor Act

Act 2006-65 created the Organ and Bone Marrow Donor Act. The Act authorizes every business firm providing paid leaves of absences to employees for the specific purpose of organ or bone marrow donation to qualify for a tax credit.¹ A covered “paid leave of absence” is not to exceed five working days (or the hourly equivalent) per employee and does not include periods of annual or sick leave that an employee is given. The tax credit would be equal to the amount of employee compensation paid during the leave of absence, costs of any temporary replacement help, and other miscellaneous expenses provided for by Department regulation incurred in connection with the leave of absence.² Unused credits may be carried over for three taxable years but may neither be carried back against preceding years nor refunded. The Act applies to taxable years beginning on or after January 1, 2006 through taxable years beginning in 2010. Carryover credits may be used after 2010.

Under the Act, the Department of Revenue is responsible for promulgating implementing regulations, publishing necessary forms, as well as providing an annual report to the General Assembly as to tax credits granted.³ Applications for tax credits must be filed with the Department by the 15th day of the fourth month after close of a business’s taxable year. An application must include (1) the signature of an authorized business representative, (2) the individual or entity’s name, (3) identifying numbers, (4) address, and (5) sufficient proof of the length and purpose of the donor’s leave and the amount of the employee’s compensation as well as the need for and the costs associated with temporary replacement help.⁴ The Department is to notify businesses that have applied for tax credit regarding the authorization of the tax credit, including the amount of the credit available and may return incomplete applications for needed information.

As of this report, the Department informed the LB&FC that the Department is preparing regulations implementing the tax credit. Pa Schedule OC and corresponding instructions have been updated for the PA-40, PA-41, and PA-20S/PA-65 to incorporate the new tax credit. Moreover, the Department is preparing application forms. Department officials said that the Department will track applicants, review documentation received and award the credits as appropriate and will discuss the credit and updated forms with tax professionals in the Department’s Fall Tax Seminars.

¹The credit may be applied by businesses against taxes due under Article III (personal income tax), IV (corporate net income tax), VI (capital stock franchise tax), VII (bank and trust company shares tax), VIII (title insurance companies shares tax), IX (insurance premiums tax) or XV (mutual thrift institutions tax) of the Tax Reform Code of 1971 but may not be applied against taxes withheld by an employer from an employee under Article III (personal income tax) of the Tax Reform Code of 1971.

²Credits calculated for a business firm subject to tax in another state are apportioned to the Commonwealth pursuant to regulation. Also, a tax credit relating to employees of pass-through entities (partnerships or Pennsylvania S corporations) is calculated in proportion to the member’s or shareholder’s portion of the pass-through entity’s income.

³The annual report is to be given within five months after the close of any calendar year in which tax credits given under the Act were used.

⁴The Department may require such proof at its discretion, which proof may include written verification by a physician or similar documentation regarding the length and purpose of the donor’s leave.

APPENDIX C

Responses to This Report

Commonwealth of Pennsylvania



DEPARTMENT OF HEALTH

HARRISBURG

THE SECRETARY

June 8, 2007

Philip R. Durgin, Executive Director
Legislative Budget and Finance Committee
Room 400
Finance Building
Harrisburg, Pennsylvania 17105-8737

Dear Mr. Durgin:

I am responding to your letter of May 16, 2007, in which you provided a draft report of a performance evaluation of the Organ and Tissue Donor Awareness (OTDA) Program, and an opportunity to provide comments.

The Department believes that the recommendation to develop a multi year strategic plan for the OTDA Program (#19) will be helpful in organizing and guiding the future direction of this program. Similar strategic planning activities have been implemented by other programs in the Department with a great deal of success. Also, the adoption of bylaws, enhanced documentation and the tracking of Advisory Committee actions, proposals etc. could help the Committee to operate more effectively.

With regard to options for action by the General Assembly, the Department of Health (Department) agrees that amendment of the Anatomical Gift Act, in the fashion recommended by the LBFC, could aid in the implementation of other recommendations of the report (3, 11, 13, 14, 18, 21, 23, 24, and 25). The designation of the Department as the lead state agency for administering and coordinating this program will help to clarify relationships among the four (4) state agencies involved with this program, and would give OTDA greater structure and organization. The Department will work with the General Assembly should they choose to pursue legislative changes to the OTDA Program.

As noted by the LBFC, the staff person currently assigned to manage the OTDA Program also serves as the lead Public Health Educator for multiple statewide chronic disease prevention and education programs and worksite health promotion. The Department will use the recommendations of the LBFC Report to examine ways to provide staff support to the OTDA Program in the future.

Funding is another area that received thorough review by your staff. The Department will use the LBFC recommendations as a guide in future reviews of funding allocation methodology. Since certain components of some recommendations for funding (i.e. #3(b), #20) are not contingent upon changes in legislation, the Advisory Committee will consider them as part of a strategic planning exercise included under Recommendation #19 which will be undertaken in the upcoming fiscal year.

The Department appreciates the thoughtfulness and expansiveness of the suggested actions to improve the Program implementation and management, listed in the Report as #4, 5, 6, 7, 8, 10, 12, 15, 16, 17, 19, 22, and 26. The Department will review each of these recommendations, as well as opportunities to improve the funding and deliverables included in the grants to the Organ Procurement Organizations, with the Advisory Committee as part of the proposed planning process.

I wish to thank you and your staff for a most thorough review of this Program. The recommendations contained in the report give the Department, the Advisory Committee and the General Assembly much to consider as we continue our significant progress in our work to increase organ and tissue donation across Pennsylvania.

Sincerely,



Calvin Johnson, M.D., M.P.H.
Secretary of Health

RECEIVED JUN 08 2007



COMMONWEALTH OF PENNSYLVANIA
DEPARTMENT OF EDUCATION
333 MARKET STREET
HARRISBURG, PA 17126-0333
www.pde.state.pa.us

June 8, 2007

The Department of Education welcomes the opportunity to provide a response to the Legislative Budget and Finance Committee report, "A Performance Evaluation of Pennsylvania's Organ and Tissue Donor Awareness Program. The Department will be responding to the recommendations pertaining to "The OTDA Education Project: Secondary School Awareness Activities" on pages S-28 - S-31.

The Committee has made five recommendations pertaining to the program. Prior to addressing the individual recommendations, the Department would like to take this opportunity to clarify the relationship of some of the various entities, e.g. Advisory Council, Department of Education, Intermediate Unit (IU) 13, noted within the report draft. The Department of Education is responsible for the OTDA Education Project. Intermediate Unit 13 is the statewide OTDA Education contractor that has been selected by the Department. Recommendations regarding the OTDA Education project should be addressed to the Department of Education, and the Department will then, in turn, oversee the implementation of issues with the selected contractor in partnership with the Advisory Council as recommended in the report.

Recommendation 5, S-28: PDE and IU 13 have reviewed the five "By The Numbers" recommendations and are in the process of incorporating them into the 2007-2008 work plan and contract. The "quick start guide" was developed as part of the 2007 "Classroom Toolkit" update. PDE does not support the recommendation to cover the cost of substitutes for teachers attending the OTDA Education Institute as the OTDA Education project does not have sufficient funds to cover this cost while maintaining the current level of activities.

Recommendation 6, S-28: The development of a DVD that is designed to gain the attention of school superintendents in secondary schools is designated as a deliverable for the 2007-2008 statewide OTDA Education contract.

Recommendation 7, S-29: PDE looks forward to collaborating with the Organ Donation Advisory Committee as part of its multi-year strategic planning process. Below, we respond to each component of Recommendation 7:

Recommendation 7a, S-29: PDE currently has a link to the OTDA Education Project website on the welcome page of the Health and Physical Education website. A link will be established on the Driver and Safety Education website. PDE staff will research the viability of placing a link on the PDE homepage in order to increase the exposure of the OTDA Education Project.

Recommendation 7b, S-29: Annual goals and objectives are currently a component of the work plan that is utilized in the statewide OTDA Education Project contract that is implemented by IU 13. The Department looks forward to ongoing collaboration with the Advisory Committee to set the best possible annual goals and objectives.

Recommendation 7c, S-29: PDE recommends that the survey questions be incorporated into a student survey that is already in place. PDE staff will discuss the possibility of adding questions to the PAYS (Pennsylvania Adolescent Youth Survey) survey that is currently administered to Pennsylvania school-age children with the appropriate interagency contacts. PDE believes this to be the most efficient way to gather the valuable data needed for the OTDA Education project, as administration of this survey has already proven successful.

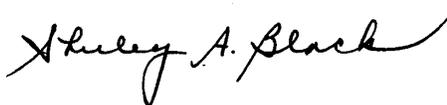
Recommendation 7d, S-29: This recommendation can be addressed within the statewide OTDA Education Project contract. PDE supports the implementation of a sustainability assessment. Discussion, regarding potential data needs, has occurred and is ongoing with the statewide OTDA Education contractor, IU 13.

Recommendation 7e, S-29: PDE understands the intent and value of expanding organ and tissue donation education to universities within the Pennsylvania's State System of Higher Education. PDE will include its Office of Post Secondary and Higher Education in the discussions regarding program expansion to ensure a strategic approach to this expansion.

Recommendation 8, S-29: PDE and the State Board of Education have no objections to the Advisory Committee participating in the regulation process with the State Board of Education. All groups and organizations are welcome to participate in the Board's regulatory review process. As long as the group understands that there are no commitments by the Board to do anything until proposed regulations are developed.

Recommendation 9, S-30: PDE wants to note that this will incur increased costs for LEAS in terms of training and curriculum development.

Sincerely,



Shirley A. Black
Health & Physical Education Advisor/
OTDA Education Project Director

RECEIVED JUN 08 2007



June 8, 2007

Mr. Philip R. Durgin
Executive Director
Legislative Budget and Finance Committee
Room 400, Finance Building
Harrisburg, PA 17105

Dear Mr. Durgin:

Gift of Life Donor Program and the Center for Organ Recovery and Education (CORE) gratefully acknowledge and commend John Rowe and the staff of the Legislative Budget and Finance Committee for their commitment and thorough evaluation of Pennsylvania's Organ and Tissue Donor Awareness Program. We would also like to acknowledge the Departments of Health, Transportation and Education for their ongoing commitment and coordination of the various programs that are highlighted in this report. We would also like to recognize the extraordinary compassion of Pennsylvanians who have supported donation and enriched the lives of so many others.

This report highlights how critical it is to have a statutory framework regarding donation on a public level as well as a professional level. Over the last 10 years, this collaborative efforts between the state's two organ procurement organizations ("OPOs") and the various state departments has dramatically impacted the lives of Pennsylvanians who have been waiting for a life-saving transplant. This successful collaboration and the generosity of Pennsylvanians have contributed to the Commonwealth being a national leader in donation and transplantation.

While this report has focused primarily on donation for transplantation, donation for research has also provided families with an opportunity to support medical and scientific advancements through work with organizations such as NDRI, IIAM, and the Commonwealth's academic medical centers. In this area as well, CORE and Gift of Life have worked with families and served as national leaders.

Both CORE and Gift of Life generally agree with the findings as determined by the Legislative Budget and Finance Committee, specifically the endorsement of amendments to Act 102 to reflect and incorporate certain provisions of the UAGA 2006 as well as advancements in clinical practice. Additionally, CORE and Gift of Life agree

that the standards regarding tissue recovery and ensuring qualified personnel participate in the process should be updated; that the voluntary organ donor awareness check - off provision by the General Assembly be reinstated; that legislative support to mandate organ donation be included in secondary school curriculum be provided; and a dedicated full-time position in the Department of Health to administer OTDAP and coordinate the activities of the Organ Donation Advisory Committee be considered.

CORE and Gift of Life do support continued and expanded collaboration opportunities and strongly advocate that the two agencies serve as the point of contact for funding of programs that might apply for sub grants through the Trust Fund to ensure that the campaign messaging is accurate and consistent.

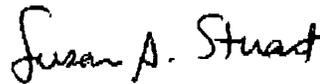
In addition, both CORE and Gift of Life continue to see a critical need for a funeral expense benefit for donor families as passed in the original legislation on a pilot basis. We believe that this benefit falls within the federal guidelines and would once again enable Pennsylvania to lead the nation in providing service to donor families.

We welcome the opportunity to work in partnership with the General Assembly and the various state agencies to discuss and implement the findings of this report.

Sincerely,



Howard M. Nathan
President and CEO
Gift of Life Donor Program



Susan A. Stuart
President and CEO
CORE