Good morning. Senate Resolution 2013-70 and House Resolution 2013-348 directed the Legislative Budget & Finance Committee to study prescription drug plan “specialty tiers” to determine their impact on access and patient care. Typically, drugs placed on the specialty tier in a plan’s list of covered drugs (i.e., its formulary) are used to treat chronic and life-threatening conditions, such as hemophilia, multiple sclerosis, hepatitis, and cancers. They are often biologics rather than traditional chemical drugs. Because such drugs are manufactured in living organisms, exact replication is almost impossible; and they currently have no generic equivalents. Specialty tier drugs also tend to be very expensive, with some costing $100,000 per treatment episode.

As a result of placement on a drug plan’s formulary specialty tier, specialty drugs often require individuals to pay a percentage of the drug’s cost (i.e., a coinsurance), rather than a fixed dollar amount (i.e., copayment) when obtaining a prescription. Typical out-of-pocket costs for a specialty drug with 20 percent cost sharing is in the range of $1,500 to $3,000 per prescription, according to one major pharmacy benefit manager.
The use of specialty drug tiers became more widespread with the start of Medicare’s voluntary outpatient prescription drug program known as Medicare Part D. Over 90 percent of Part D plans now have “specialty tiers,” with beneficiaries responsible for between 25 to 30 percent (or more) of the specialty drug’s cost. Specialty tiers are not as prevalent in employer-sponsored health plans as they are in Part D plans. By 2014, however, 23 percent of workers were in employer plans with specialty tiers, up from just 3 percent ten years earlier. Typically, workers in such plans are responsible for 32 percent of the specialty drug’s cost when filling a prescription.

We reviewed the cost of specialty drugs for the average Pennsylvania household (with a median income just over $50,000) and found that the average Pennsylvania household would spend more than 20 percent of its annual income for almost two-thirds of the most common specialty drugs.

While most employees are in plans with annual out-of-pocket maximums, out-of-pocket costs for prescription drugs are not always counted toward these caps. According to a 2013 national sample of employer health plans 84 percent of those in preferred provider organization plans (PPOs) were in plans that did not count prescription drug cost sharing toward the annual out-of-pocket maximum.
As part of this study, we received surveys from 375 Pennsylvanians who use specialty drugs. Almost half (47 percent) of those responding to our survey reported their insurance coverage did not limit their annual out-of-pocket prescription drug costs. Only 12 percent reported their out-of-pocket costs were capped on a per prescription basis.

Consumers responding to our survey also underscored the economic burden households can experience when one of their members must rely on specialty drugs. Almost all of those responding to our survey had health insurance coverage for prescription drugs. However, even with prescription drug coverage, roughly 40 percent reported having to take on additional credit card debt and experienced problems with purchasing such necessities as food and groceries and 10 percent reported they had had to declare bankruptcy. Others reported failing to pay income taxes, having to move in with parents, and having to sell most personal property.

In response to our survey questions concerning access to care, over 40 percent noted they had delayed filling prescriptions and had skipped pills, injections, or dosages. Over 30 percent reported they had chosen not to take a particular medication because it was too expensive, even though their doctors thought it the best medication for their condition. Twenty percent reported they had ceased taking their specialty tier drug because they could no longer afford it.
National studies demonstrate that high cost sharing for specialty drugs reduces adherence to treatment. One study, for example, found that when cost sharing for an oral cancer drug prescription is greater than $500, the patient is four times more likely to abandon oral cancer therapy than when cost sharing is $100 or less; and when cost sharing for drugs to treat multiple sclerosis is greater than $200, the patient is 25 percent more likely to abandon the multiple sclerosis drug than when cost sharing is $100 or less.

Some public and private programs help those with limited incomes with the high out-of-pocket costs of specialty drugs. The Medicare Part D program, for example, provides assistance through its Low Income Subsidy (LIS) program for those with incomes below 150 percent of the federal poverty level (i.e., $17,505 for an individual) and limited resources (i.e., $13,300 for an individual).

Pennsylvania has several programs that can also assist with the high out-of-pocket costs of specialty drugs. In particular, the PACE/PACENET program provides considerable assistance to cardholders who require specialty drugs through its Medicare wrap around program. The program assists elderly Pennsylvania residents with incomes as high as 200 percent ($23,500) of the federal poverty level. It pays for almost all of a cardholder's specialty drug out-of-pocket costs under his/her Medicare Part D plan, with the cardholder only responsible for the PACE program's
small copayments (e.g., $9 for a brand name drug for a PACE cardholder and $15 for a PACENET cardholder).

In 2013, PACE and PACENET had over 3,200 cardholders (i.e., 1 percent of total cardholders) with over 15,000 specialty drug claims totaling about $42 million paid on their behalf. Cardholders paid less than 1 percent of such costs, the state 25 percent, and third parties, such as prescription drug plans, paid the remainder.

PACE also operates a Patient Assistance Program and Clearinghouse (PA-PAP) that helps all adult Pennsylvania residents regardless of age or income gain access to pharmaceutical manufacturers' pharmacy assistance programs. In 2013, over 14,000 persons received almost 50,000 medications through the program.

Several proposals have been offered to help assure access to specialty tier drugs, including proposals at the federal level, where key decisions about pharmaceutical drugs and drug plan benefit designs are often made. One provision of the Affordable Health Care Act (ACA), for example, placed caps on out-of-pocket costs for essential services, including prescription drugs. Implementation of this provision, however, has been delayed. When and if this provision if eventually implemented, it should provide some relief for people who are dependent on specialty tier drugs.
In the meantime, several states have acted to improve access and affordability of drugs on specialty tiers. Maine and Vermont, for example, now require prescription drug plans to have annual caps on out-of-pocket costs, and Delaware and Maryland recently adopted out-of-pocket caps for certain specialty drugs on a per prescription, rather than an annual, basis.

We recommend that the Commonwealth advocate at the federal level for change in federal policy to help assure access to affordable life sustaining specialty drugs, and that Commonwealth agencies continue to undertake steps to educate consumers about PACE’s Medicare Part D wrap around and its Patient Assistance and Clearinghouse programs. In particular, the PACE program may wish to engage the PA Medical Society to acquaint physicians with the assistance available through these state programs.

We also recommend the General Assembly consider “stop gap” measures until such time as the Affordable Health Care Act’s provisions on out-of-pocket caps are fully implemented. Such measures could include those that have been adopted in other states to limit out-of-pocket costs for certain specialty-tier drugs. The impact of such a measure may be limited, however, as it would not apply to many employer benefit plans that are overseen at the federal level (e.g., ERISA).
We thank the many associations that assisted with our consumer survey, in particular the Pennsylvania Medical Society and the National Hemophilia Foundation’s Delaware Valley Chapter. We also thank Tom Snedden, the Executive Director of the PACE/PACENET Program and his key staff for their valuable assistance throughout the study.