



**EASTERN PENNSYLVANIA CHAPTER**  
NATIONAL HEMOPHILIA FOUNDATION

Victoria Business Center, 1489 Baltimore Pike, Springfield, PA 19064 • 484-445-4282 *fax* 484-445-4284 • [www.hemophiliasupport.org](http://www.hemophiliasupport.org)

October 25, 2016

Senator Don White, Chair  
Senate Banking and Insurance Committee  
Commonwealth of Pennsylvania  
286 Main Capitol  
Harrisburg, PA 17120

CC: Members of the Banking and Insurance Committee  
**RE: Public Hearing on SB 841, October 25, 2016**

Dear Senator White and Members of the Banking and Insurance Committee:

As the Executive Director of the Eastern Pennsylvania Chapter of the National Hemophilia Foundation, I am writing on behalf of our more than 3,000 members in Pennsylvania affected by hemophilia, a rare bleeding disorder. I would like to provide comments to you regarding the impact of high patient cost sharing required by Pennsylvania insurers for drugs needed by some Pennsylvanians to manage complex health conditions, including those with hemophilia.

**HISTORY:**

*Senate Resolution 2013-70 and House Resolution 2013-348 directed the Legislative Budget & Finance Committee (LB&FC) to study prescription drug "specialty tiers" to determine their impact on access and patient care in the Commonwealth of Pennsylvania. The study completed and a report was issued by the LB&FC (dated September 2014), which included a Summary and Recommendations, as well as the results of a patient survey conducted by the LB&FC as part of the study. I reference my comments here to information provided in the "Prescription Drug Specialty Tiers in Pennsylvania" [The Report], *Legislative Budget & Finance Committee, September 2014.**

Specialty drugs are expensive medications that are used to treat a variety of serious medical conditions such as hemophilia, auto-immune disease, multiple sclerosis, hepatitis, cancer, arthritis, HIV-AIDS, and other complex health conditions. In general, specialty drugs do not have generic or lower cost therapeutic equivalents and include some of the most expensive medications available (page 14). They are often biologics, rather than traditional chemical drugs. Because many of these drugs are manufactured



in living organisms with high sensitivity to change in the manufacturing process, exact replication is almost impossible

Typically, specialty drugs are placed on Tier IV or V (or higher tier) of a drug plan's formulary and, require the insured to pay a portion of the actual cost of the drug each month (coinsurance or cost sharing) rather than a fixed amount (copayment). For some Pennsylvanians, cost sharing can amount to hundreds or even thousands of dollars each month for a single drug.

According to The Report, 98% of Pennsylvania health insurers have developed "specialty tiers" which require patient cost-sharing for specialty drugs.

Numerous studies and national data were analyzed by the LB&FC as part of the study process and are cited in the LB&FC Study Report.

*"The high cost of drugs in specialty tiers and their higher cost-sharing requirements can adversely impact those in need of such life sustaining medications.*

*Access to affordable, high quality prescription drug coverage is essential, in particular, for those with chronic health care needs, those with severe illnesses and those in need of life sustaining medications. Lack of access to such coverage can create significant economic hardships, in particular, for those with chronic health conditions and those with severe illnesses. In addition to economic hardship, absence of such access may reduce the likelihood of individuals going to a doctor, filling a prescription and adhering to the recommended treatment regime." (Page 26)*

Many Pennsylvania specialty drug consumers who responded to the LB&FC Survey reported that high cost sharing requirements for drugs on specialty tiers affected their access to needed care and/or created serious economic hardships:

*(page 29)*

- *over 40% delayed filling a prescription;*
- *over 40% reported skipping pills, injections or dosages;*
- *over 30% chose not to take a particular brand of medication because it was too expensive, even though their doctor thought it was the best medication for their condition;*
- *almost 30% delayed starting a new medication, and*



- ***20% indicated that they ceased taking the drug because they could no longer afford it.***

In addition, survey respondents reported that high drug cost sharing caused them to take on additional credit card debt, have problems affording food/groceries for themselves or their family, have difficulty making car payments and 10% (of survey respondents) reported having to declare bankruptcy. Other problems cited by survey respondents with high drug cost sharing included failure to pay income taxes, having to move in with parents and having to sell most personal property.

From national studies (Avalere and Milliman), we know high cost sharing for specialty drugs does not reduce unnecessary specialty drug use, but rather shifts the high cost of such drugs onto patients, reduces their adherence to treatment and creates serious economic hardships.

We believe that specialty tiers create an access barrier for people living with chronic disease, cause poor health outcomes, and create an added financial burden on those who need the most expensive medicines to sustain their lives. In many ways, specialty tiers can be seen as discriminatory against Pennsylvanians with chronic disease since individuals struggling with the most serious conditions are forced to pay higher amounts for drugs that may save their lives or slow the progression of their medical condition, reducing the overall costs of care.

The Report accurately gives voice to our concerns that specialty-tier pricing restricts access to medications for those unable to pay, disproportionately impacts the sickest patients and leads to worsening illnesses and non-compliance. As a matter of public policy, The Report, we believe, clearly outlined that high cost sharing negatively affects people with conditions that are typically treated with specialty drugs. ***"Often, patients with these conditions have no lower-cost options available to treat their disease and may be least able to afford their prescription drug(s) under a co-insurance."***

The Report goes on to say as a matter of public health, specialty-tier pricing ***"limits access to health care for vulnerable and at-risk populations. and the lack of treatment/management for communicable diseases results in increased transmission and higher infectivity in diseases like HIV/AIDS."***



**EASTERN PENNSYLVANIA CHAPTER**  
NATIONAL HEMOPHILIA FOUNDATION

Victoria Business Center, 1489 Baltimore Pike, Springfield, PA 19064 • 484-445-4282 *fax* 484-445-4284 • [www.hemophiliasupport.org](http://www.hemophiliasupport.org)

With appropriate treatment in patients with chronic, life-threatening and disabling conditions such as hemophilia, biologic drugs can prevent patients from becoming disabled or seriously ill, decreasing the overall costs of healthcare. With appropriate access to medicine, patients can maintain daily function, remain in the workforce, contribute to the tax base, and raise their families.

Today, I ask for your understanding of this important issue for patients in Pennsylvania and your support of *SB 841*. Thank you for your consideration.

Respectfully submitted,

Curt Krouse, Executive Director