

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:

We at the Immune Deficiency Foundation appreciate the opportunity to provide written testimony on **SB 841** which we enthusiastically support. This bill allows individuals living with primary immunodeficiencies (PI) and other chronic diseases in Pennsylvania access to lifesaving treatments that they otherwise could not afford.

The Immune Deficiency Foundation (IDF) is the national patient organization dedicated to improving the diagnosis, treatment and quality of life of persons with PI through advocacy, education and research. People with a PI are born with a malfunctioning or non-existent immune system which leads to recurring illnesses because of their inability to produce antibodies necessary to fight viruses, bacteria and fungi. You may recall the “boy in the bubble” who had virtually no immune system - the severest form of a primary immunodeficiency disease. The good news is that for many of our patients there is a treatment that when taken for the **rest of their life**, they can live normal, healthy and productive lives. This treatment option, the only viable one available to patients with PI, is immunoglobulin (Ig), a blood plasma product that acts as a temporary immune system for the patient. Immunoglobulin replacement therapy is lifesaving and requires life-long infusions. It is also expensive, costing on average of \$7,500 to \$10,000 per month.

People who rely on expensive specialty drugs, such as Ig replacement therapy, to treat chronic conditions face incredible out-of-pocket expenses that often cost more than their mortgage, forcing many to go without treatment because they simply cannot afford it. This often occurs because health plans are structuring their pricing using a specialty tier co-insurance model that in many cases forces patients to pay 30 to 50 percent or more of the cost of treatment instead of a fixed co-pay. In recent years, there has been a steady increase in the use of this co-insurance cost-sharing with patients who require expensive specialty drugs. This financial burden on patients and families increases the likelihood that the most vulnerable among us will forego care. In fact, according to IDF’s 2014 Health Insurance Survey of patients with PI, approximately one-third (1/3) of

patients reported that they had skipped treatments because they could not afford the out-of-pocket (OOP) costs required by payers. They literally put their lives at risk because of they couldn't afford the high cost of their treatment.

The Legislative Budget and Finance Committee Report on this topic explored the adverse effects that the high cost of drugs in specialty tiers and their high cost-sharing requirements has on those that require these medications. Within the report, the Committee came to many of the same conclusions arrived at by IDF and other patient advocacy organizations regarding the negative impact that high cost prescription drug specialty tiers have on access and patient care in Pennsylvania, exemplifying the necessity of SB 841.

Numerous studies have demonstrated that patients who forego treatment create ***significantly more costs to the health care system than if they would have received their original treatment.*** Non-adherence to medication regimens not only have a direct impact on health and disease progression – it contributes direct annual costs of \$100 billion to the US health care system. Indirect costs exceed \$1.5 billion annually in lost patient earnings and \$50 billion in lost productivity¹.

Many medicines used to treat chronic diseases are breakthrough treatments that often prevent disability, save and improve lives, and allow patients to function and remain in the workforce. Unfortunately, certain insurer practices threaten to put medications financially out of reach for many Pennsylvania residents as they shift astonishing costs to consumers. These practices go against the basic premise of insurance and are causing commercially insured patients to underutilize treatments or go without their treatments entirely.

This is simply not acceptable for the thousands of Pennsylvania residents suffering from chronic diseases including PI. **We urge you to pass SB 841 to protect patients from disproportionately high medication cost-sharing.**

For further information or questions, please contact Lynn Albizo, Director of Public Policy, Immune Deficiency Foundation at 443-632-2544 or labizo@primaryimmune.org.

Respectfully submitted,



Lawrence A. (Larry) LaMotte
Vice President, Public Policy

¹ Goldman D.P., et al. (2004). Pharmacy benefits and the use of drugs by the chronically ill. JAMA., 291(19): 2344-2350