July 27, 2011

The Honorable Mike Vereb
Pennsylvania House of Representatives
Republican Leadership Caucus Secretary
Room 146 Main Capitol
P.O. Box 202150
Harrisburg, PA 17120-2150

Dear Representative Vereb:

The Immune Deficiency Foundation thanks you for introducing HB 1609 which will assure that our patients with primary immunodeficiency diseases (PIDD) have the ability to obtain the prescription drugs that are recommended by their treating physicians by prohibiting health plans from creating multiple tiers within their formularies for non-preferred prescription medications. HB 1609 addresses a significant issue facing individuals with primary immunodeficiency diseases in the Commonwealth of Pennsylvania, as well as across the country.

The Immune Deficiency Foundation is the national patient organization dedicated to improving the diagnosis, treatment and quality of life of persons with primary immunodeficiency diseases through advocacy, education and research. Patients with PIDD have a genetic malfunctioning or non-existent immune system that does not allow them to create the antibodies necessary to fight viruses, fungi and bacteria. For most patients with PIDD, immunoglobulin (Ig) replacement therapy will allow patients to live relatively healthy, normal, productive and tax-paying lives. On average, a patient with PIDD will need to be infused with immunoglobulin once a month for the rest of his/her life.

High cost specialty drugs, like Ig, are generally classified in the highest and most expensive tiers (Tiers 3 and/or 4) of plans. As a result of this highest tier placement, patients with serious diseases such as primary immunodeficiency diseases, neuropathy, cancer, hemophilia, multiple sclerosis, and others that require specialty medications are being asked to pay thousands of dollars for prescribed medications.

Medical plans & Pharmacy Benefit Managers (PBM) are abandoning the traditional arrangement of patients paying a fixed amount, like $10, $20 or $30 co-pay for a prescription, and instead are charging patients a percentage of the cost of certain high-priced specialty drugs, usually 20 to 33 percent for Tier 4. Some plans are even higher. These costs can amount to thousands of dollars per month and economically limit access to vital, life-saving medications. Obviously most families cannot afford to pay thousands of dollars a month. Instead, patients go without care.

HB 1609 is very important for the nearly 2,500 Pennsylvanians who suffer from primary immunodeficiency diseases and are on Ig Replacement Therapy. In recent years IDF has received an increasing number of calls from patients informing us that their prescription drug benefit plan has suddenly increased their out-of-pocket costs to the point where they can no longer afford their life saving immunoglobulin replacement therapy. In essence health insurance companies and pharmacy benefits managers are pricing those with chronic and rare diseases out of the market, thus denying care.
This is a discriminatory practice against those with chronic illnesses and should be unlawful.

Let us be perfectly clear. Without Ig therapy, a patient is condemned to being sick nearly continuously, making many trips to their physician and emergency room, having several admissions to the hospital annually, probably having at least one stay in an ICU in any given year and continuously being on multiple antibiotics. Without appropriate care, these patients will develop serious and permanent disabilities and will die prematurely.

It is difficult to believe that Pennsylvania’s health policy is to promote illness and the unnecessary use of and burden to its health care delivery system by allowing health insurance companies and PBMs to isolate those with rare and chronic conditions and who need expensive pharmaceutical therapies, from their care by making the cost of care unaffordable. Passage of HB 1609 will certainly help allow people to receive their care.

Insurance is supposed to be a means by which health risk is spread across a pool of members. Yet when a child is born with a serious illness like X-Linked Agammaglobulinemia, one of the more than 150 recognized PIDDs, subscribers are often singled out for much higher out-of-pocket costs. This practice is appalling, discriminatory and negates the very reason they had been paying for insurance in the first place — to be protected from financial hardship should they or a family member becomes ill.

We thank you for introducing HB 1609 and urge the Insurance Committee members to support HB 1609. Should you have any questions please contact Larry La Motte, IDF’s Director of Public Policy at 443-632-2552 or ldamotte@primaryimmune.org.

Sincerely,

Marcia L. Boyle
President and Founder