April 2, 2013

The Honorable Robert Mensch, Vice Chair
Senate Committee on Public Health & Welfare
Harrisburg, PA

RE: SR 70 - Support

Dear Senator Mensch,

The Immune Deficiency Foundation (IDF) thanks you for introducing SR 70, a resolution directing the Legislative Budget and Finance Committee to study the issue of specialty tier prescription drug pricing in Pennsylvania to determine the impact on access and patient care.

Founded in 1980, IDF 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 primary immunodeficiency diseases are born with a malfunctioning or non-existent immune system and are thus vulnerable to multiple and numerous infections, viruses and fungi. Many patients with primary immunodeficiency diseases require regular, lifelong treatments of immunoglobulin replacement (Ig) therapy to replenish the antibodies necessary to fight disease and stay healthy and productive.

SR 70 is very important for the hundreds of Pennsylvanians who live with a primary immunodeficiency disease as this study will help the population understand that large patient cost responsibilities for treatments can mean the difference between receiving and not receiving their specialty medications. Ig therapy is a complex biologic medication derived from pooled human blood plasma. Costs for Ig replacement therapy medication can amount to thousands of dollars per month. If patients are forced to pay a percentage of this cost, many will not be able to afford their treatments and instead will go without care. Without treatment, patients with primary immunodeficiency diseases will suffer additional illnesses and infections, utilizing the health care system constantly and developing serious and severe co-morbidities and disabilities.

In recent years, IDF has received an increasing number of calls from concerned patients as insurers have begun shifting the costs of biologics like Ig therapy onto patients through higher deductibles, copayments and coinsurance, making it increasingly difficult for patients with primary immunodeficiency diseases to continue receiving their lifesaving Ig therapy. In essence health insurance companies and pharmacy benefits managers are pricing those with chronic and rare diseases out of the market while encouraging the unnecessary use of and burden to the health care delivery system.

Thank you again for introduction of SR 70 and for your support of Pennsylvania’s most vulnerable individuals. Should you have any questions please contact me at 410-632-2552 or at llamotte@primaryimmune.org.

Regards,

Lawrence A LaMotte
Vice President, Public Policy