March 26, 2013

The Honorable Donna M. Nesselbush
Senate of Rhode Island
Providence, RI

RE: S 754 - Support

Dear Senator Nesselbush,

The Immune Deficiency Foundation (IDF) thanks you for introducing S 754, which helps ensure that every Rhode Island resident has access to reasonable prescription drug benefits. S 754 would require health plans to establish a separate out-of-pocket limit for all prescription drugs equal to the maximum dollar amounts in effect under section 223(b)(2) of the Internal Revenue Code for self-only and family coverage.

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 PIDD are born with a malfunctioning or non-existent immune system and are thus vulnerable to multiple and numerous infections, viruses and fungi. 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.

S 754 is very important for the hundreds of Rhode Island citizens who suffer from a primary immunodeficiency disease as limits on patient financial responsibilities can mean the difference between receiving and not receiving their treatments. For our patients who need Ig replacement therapy, these costs can amount to thousands of dollars per month. Obviously, most families cannot afford to pay thousands of dollars a month and instead go without care. While the limits set forth in S 754 will benefit patients with primary immunodeficiency diseases, a large cost burden still falls disproportionately on these individuals with rare and chronic conditions as they will consistently pay the full out of pocket limit on a yearly basis. This financial burden keeps patients from seeking medical treatment and will force patients to be sick and constantly using more services of the health care system.

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 immunoglobulin therapy. Currently, insurers can increase out of pocket costs for patients unpredictably and arbitrarily, sometimes even in the middle of a plan year. Patients cannot anticipate and budget for health care costs or have informed discussions with their providers on containing their treatment cost. In essence health insurance companies and pharmacy benefits managers are pricing those with chronic and rare diseases out of the market, effectively denying care.
In many cases, medical plans & pharmacy benefit managers 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 pharmacy drugs, usually 20 to 33 percent for Tier 4 specialty pharmacy drugs. Some plans are even higher.
Without treatment, patients with primary immunodeficiency diseases will become increasingly more ill, utilizing the health care system constantly and developing serious and severe co-morbidities and disabilities. The current situation encourages the unnecessary use of and burden to the health care delivery system by allowing health insurance companies to isolate those with rare and chronic conditions who need expensive biologic therapies from their care by making the cost of care unaffordable.

Thank you again for introduction of S 754 and for your support of Rhode Island’s most vulnerable individuals. Should you have any questions please contact me at 410-632-2552 or at llamotte@primaryimmune.org.

Regards,

Larry LaMotte
Vice President, Public Policy