Dear Chairman Kennedy,

RE: HB 8201, Testimony in support with amendment

The Immune Deficiency Foundation (IDF) is the national patient organization dedicated to improving the diagnosis, treatment and quality of life of persons with primary immunodeficiency diseases (PI) through advocacy, education and research. IDF supports with amendment HB 8201 to limit the out-of-pocket expenses for the medication patients with PI rely upon to live.

Patients with PI are born with malfunctioning or nonexistent immune systems. As a result, they are prone to infections and illnesses from any kind of virus, bacteria or fungi. Many of our patients are unable to produce antibodies necessary to fight disease. These patients require regular, lifelong treatments of immunoglobulin replacement (Ig) therapy to replace the antibodies their bodies do not naturally produce.

In recent years there has been a steady increase in the use of co-insurance cost-sharing with patients who need expensive specialty drugs such as immunoglobulin. We recognize that such policies are promoted to save payer costs. We do not have a problem at all with payers being efficient – as long as it does not endanger patients. The inability to afford medications is tantamount to a denial. Denial of this lifesaving medication is, in essence, endangerment.

Whereas current federal law establishes an annual out-of-pocket limit of $6,350 for an individual and $12,700 for a family -- which increases annually as health care costs rise -- many patients with life-threatening and chronic medical conditions such as PI, might be forced to pay nearly that much on a single prescription. HB 8201 would change this practice by capping the maximum or coinsurance for a single drug at $100 per month for each prescription drug and limiting the annual out-of-pocket expenditures for prescription drugs to no more than fifty percent of the Affordable Care Act annual limits.

While the intent of HB 8201 is to limit out-of-pocket costs for patients, the inclusion of all prescription drugs is overly broad. Specialty Prescription drugs on a plan’s specialty tier are those that create the most financial burden for patients in Rhode Island. These expensive specialty medications are subject to co-insurance of 20, 30 or even 40%, amounting to thousands of dollars in patient cost-sharing per treatment. We also fear that the legislation may have the unintended consequence of encouraging insurers to increase out-of-pocket costs for prescriptions in the non-specialty tiers by creating the $100 cap for these drugs that usually cost far below that amount. Rhode Island should amend this legislation and follow the lead of other states like Delaware and Maryland, which both passed legislation capping out-of-pocket costs for specialty drugs that fall under a specialty tier.
HB 8201 is very important for the hundreds of Rhode Island citizens who suffer from a PI, as patient financial responsibilities can mean the difference between receiving and not receiving needed medical treatments. For patients with PI who require Ig therapy, co-insurance costs can amount to thousands of dollars per month for this complex, biologic treatment. Most families cannot afford to pay such large costs and instead go without care.

Without treatment, patients with PI will be ill more often, utilizing the health care system constantly, and developing serious and severe co-morbidities and disabilities. The current situation encourages the unnecessary and burdensome use of the health care delivery system by allowing health insurance companies to isolate those with rare and chronic conditions who need expensive biologic therapies and making their cost of care unaffordable.

Thank you for your consideration of this critical issue. I urge a favorable report for HB 8201 with amendment to narrow the scope of the legislation to specialty drugs that fall under a specialty tier. Should you have any questions please contact Emily Hovermale at 443-632-2544 or at ehovermale@primaryimmune.org.

Sincerely,

[Signature]

Lawrence LaMotte
Vice President, Public Policy