Dear Chairman Mike Gatto,

RE: Testimony in support of AB 1917

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 (PI) diseases through advocacy, education and research. IDF supports AB 1917 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.

Whereas current 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. AB 1917 would change this practice by capping the maximum or coinsurance for a single drug at 1/24th of the annual out of pocket limit.

AB 1917 is very important for the thousands of California 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, and I urge a favorable report for AB 1917. 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