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 2533 to increase access to needed specialists and treatments for patients with PI.

PI represents a group of more than 200 related, rare genetic diseases. 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. Patients with PI are traditionally treated by immunologists, but as a result of symptoms and comorbidities also see a diversity of specialists including allergists, rheumatologists, otolaryngologists, pulmonologists, gastroenterologists, infectious disease specialists and hematology-oncologists. Treatments are diverse and can include regular infusions of immunoglobulin replacement therapy, prophylactic antibiotic therapy, bone marrow transplantation, enzyme replacement, interferon gamma and antifungals.

Recently, there has been a steady increase in out-of-network cost sharing. We recognize that such policies are promoted to incentivize patients to stay within their assigned network when choosing a care provider, however, PI patients often have limited options for care providers and sometimes must go out-of-network simply because a physician appropriate to their level of care is not included in network. 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 thereby discriminatory as well.

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 -- this limit applies only to in-network services. Patients who do not have available in-network care face costs that are even more daunting. AB 2533 would protect these patients’ access to medically necessary treatment.

This bill also requires an insurer reporting process for incidences of obstacles in access to treatment. This practice is innovative and progressive, empowering the patient and at the same time documenting the challenges found within healthcare policies in California.
AB 2533 is imperative 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. 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 2533. Should you have any questions please contact Emily Hovermale at 443-632-2544 or at ehovermale@primaryimmune.org.

Sincerely,

Lawrence LaMotte
Vice President, Public