February 11, 2013

Immune Deficiency Foundation Comments  
Healthcare Reform Implementation Committee  
Communications Subcommittee

The Immune Deficiency Foundation, founded in 1980, is the national patient organization dedicated to improving the diagnosis, treatment and quality of life of persons with primary immunodeficiency diseases (PIDD) through advocacy, education and research. Primary immunodeficiency diseases are a rare and chronic genetic condition whereby patients are born with a malfunctioning or non-existent immune system and are thus vulnerable to multiple and numerous infections, viruses and fungi. The manner in which the District of Columbia chooses to implement state-level exchanges could have a critical impact on these patients as well as patients with other rare and chronic conditions. Thank you for the opportunity to submit comments for the February 13, 2013 HRIC Communications Subcommittee meeting.

Consumer protections in the Exchange are vital to continuity of care and maintenance of therapy, two considerations which are paramount to individuals living with rare and chronic conditions. Many patients with rare and chronic conditions rely on a regular treatment regimen, and disruptions in care can have devastating effects. Specifically, patients with PIDD require treatments of life-saving immunoglobulin replacement (Ig) therapies on a regular basis throughout their entire lives. Patients who are able to receive their needed Ig replacement treatment can live normal, healthy and productive lives. Without treatment, patients with PIDD will become increasingly more ill, utilizing the health care system constantly and developing serious and severe co-morbidities and disabilities.

Communication with individuals regarding their rights and protections is critical for the successful implementation of the Exchanges. The navigator should be non-biased and free of conflicts of interest in order to best serve as a resource for the consumers who will rely on it. It is imperative that the navigator include considerations for the unique needs of patients who suffer from rare and chronic conditions in order to provide them with appropriate information that reflects coverage for their condition, so they can fully understand their health plan options. It should be clear and transparent to these patients what the specific coverage and responsibility will entail for their Ig therapy. If this information is not included in the summaries on the navigator, insurers should at the least be required to inform patients upon inquiry of the plan’s benefits and detailed policies prior to a patient enrolling.

Large patient cost-sharing responsibilities for these expensive, biologic therapies can be equivalent to a denial of treatment for patients, particularly if the plan requires that the patient be responsible for a co-insurance percentage of their therapy’s cost. Patients need to be aware of these aspects of health plans in order to effectively choose a plan.

Please consider the needs of patients with rare and chronic conditions during your discussions of the navigator. Thank you and please contact me at llamotte@primaryimmune.org with any questions.

Sincerely,

Lawrence A. La Motte  
Vice President, Public Policy