Immune Deficiency Foundation Comments on the Illinois Navigator Program
Health Care Reform Implementation Council
July 24, 2012

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 Health Care Reform Implementation Council chooses to implement state-level Exchanges could have a critical impact on patients with rare and chronic diseases, such as those with primary immunodeficiency diseases (PIDD).

Communication with individuals regarding their rights and protections is critical for the successful implementation of the Exchanges. 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 access to life-saving intravenous immunoglobulin (IVIG) therapies on a monthly basis. All forms of IVIG are not the same, and without strong requirements regarding drug coverage, patients could be forced to switch from one form of IVIG to another, with the potential for serious adverse effects. In addition, such therapies are complex and expensive. Robust anti-discrimination standards are needed to ensure that patients are not adversely affected or denied critical treatments through administrative limitations on treatment. Patients of QHPs should not be limited in their choice of therapies under QHPs through formularies. It is important that IVIG not be included in any formulary because of the importance of PIDD patients accessing the product that best meets their individual clinical needs. Patients who are able to receive their immunoglobulin replacement treatment can live normal, healthy and productive lives. Without treatment, patients with primary immunodeficiency diseases will become increasingly sicker, utilized the health care system constantly and will develop serious and severe co-morbidities and disabilities.

It is essential that the navigators understand the unique needs of patients who suffer from rare and chronic conditions in order to provide them with appropriate information that reflects their rare and chronic condition to fully understand their quality health plan options. In addition, the navigators must have adequate training, be trusted sources of information, have no financial conflicts of interest and adequately represent the populations that are most likely to enroll in the Exchange. One size does not fit all!

Thank you for your consideration of this critical issue.