December 11, 2012

Immune Deficiency Foundation Comments on the Proposed Advisory Task Force Guiding Principles
Minnesota Health Insurance Exchange Advisory Task Force

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 Minnesota Health Insurance Exchange Advisory Task Force 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. Thank you for the opportunity to comment on the Proposed Advisory Task Force Guiding Principles.

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 primary immunodeficiency diseases will become increasingly sicker, utilizing the health care system constantly and developing serious and severe co-morbidities and disabilities. Medical literature and the FDA agree that all forms of Ig therapy are clinically unique without generics, but without strong requirements regarding drug coverage, patients could be forced to switch from one form of Ig to another, with the potential for serious adverse effects. Physicians determine the most appropriate Ig therapy product for each patient by assessing the individual clinical needs of a given patient, as products are tolerated differently between individuals. Robust anti-discrimination standards are needed to ensure that patients are not adversely affected or denied critical treatments through administrative limitations on treatment. The Elimination of Health Disparities, as included in the Guiding Principles, must include the elimination of this type of administrative obstacle to care for patients with rare and chronic conditions. Patients who turn to the exchange for health coverage should not be limited in their choice of lifesaving therapies through restrictive formularies, which put patients like those with primary immunodeficiency disease at risk. Similarly, the Principle of Universal Coverage means nothing without access to not only treatments but also specialists. In the case of patients with primary immunodeficiency disease, this means experts in immunology.

Again with regard to the Proposed Principles, a Consumer-Friendly approach is essential. 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 their rare and chronic condition to fully understand their quality health plan options. It should be clear and transparent to these patients what their coverage and responsibility will entail for their Ig therapy. If this information is not included in the summary on the navigator, insurers should at the least be required to inform patients of the plan’s benefits prior to a patient enrolling. For patients with primary immunodeficiency disease, access to Ig therapies is the difference between health and serious illness.

Thank you for your consideration of this critical issue.

Sincerely,

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