December 13, 2012

Immune Deficiency Foundation Comments
Cover Oregon Individual and Employer Consumer Advisory Committee

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 Cover Oregon 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 December 14, 2012 Individual and Employer Consumer Advisory Committee 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.

Medical literature and the FDA agree that all forms of Ig therapy are clinically unique without generic equivalencies. Without strong consumer protection requirements regarding drug coverage, patients could be forced to switch from one form of Ig to another with the potential for serious adverse events. Experts in immunology determine the most appropriate Ig therapy product by assessing the individual clinical needs of a given patient as products are tolerated differently between individuals. Robust anti-discrimination standards for qualified health plans are needed to ensure that patients are not adversely affected or denied critical treatments through administrative limitations on treatment.

We recommend that anti-discrimination principles, at a minimum, prohibit plans from discriminating against a patient on the basis of the patient’s medical history, genetic information, disability, receipt of health care, or claims experience. Further, we recommend that QHPs be required to provide coverage that, at a minimum, complies with medically-established standards of care. 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 diseases at serious risk. Universal coverage means nothing without access to treatments and specialists.

A consumer-friendly approach is essential for effective use of the Exchange. 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 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. As mentioned above, plans with restrictive formularies for Ig therapies that force patients to switch from their current product can result in serious adverse reactions. Large patient 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. 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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