December 12, 2012

Immune Deficiency Foundation Comments
Silver State Health Insurance Exchange Board

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 Silver State Health Insurance Exchange Board 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 submit comments for the December 13, 2012 Regulation Workshop and Board Meeting.

Consumer protections in the Exchange are needed to promote 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 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 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 such anti-discrimination principles, at a minimum, prohibit plans from discriminating against a patient on the basis of the patient’s medical history, genetic information, evidence of insurability, 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 disease at risk. Universal coverage means nothing without access to treatments and specialists. In the case of patients with primary immunodeficiency disease, this means experts in immunology.

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 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 summaries 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,
Lawrence A. La Motte
Vice President, Public Policy