



IMMUNE DEFICIENCY FOUNDATION

The National Patient Organization Dedicated to Advocacy, Education and Research for Primary Immunodeficiency Diseases

FOR IMMEDIATE RELEASE

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Contact: Lawrence A. LaMotte

443-632-2552

410-458-8336

NEW QUALITY OF CARE BILL PROTECTS MINNESOTANS WITH RARE, PLASMA PROTEIN DISORDERS

Legislation introduced in both the Senate and House would safeguard access to life saving therapies.

Towson, MD—February 5, 2009—Patients with rare, chronic diseases and disorders who rely on plasma protein therapies to control their disease would be ensured access to the lifesaving therapies they need to lead healthy, productive lives under legislation introduced by Senator Kathy Sheran of Mankato (SF 339) and Representative Kim Norton of Rochester (HF410).

Individuals suffering from primary immunodeficiency diseases, alpha-1 antitrypsin deficiency (hereditary emphysema) and von Willebrand disease (a blood clotting disorder) all require complex, biological plasma protein therapies in order to replace specific proteins that are missing or deficient in their blood.

The bills would require the Minnesota State Board of Pharmacy to develop rules for the provision of pharmacy services based on the standards established by patient group medical advisory committees and professional societies. Further, the proposed bill requires health plans to provide patients with the therapy that is the most medically appropriate. Plasma protein therapies are not interchangeable and no generics or therapeutic equivalents exist.

The goal of this legislation is to protect the proper care that these patients with rare, chronic conditions are receiving now from insurance cost-cutting decisions in the future and, as proposed, the legislation will not have a fiscal impact on the state.

As Marcia Boyle, President and Founder of the Immune Deficiency Foundation stated, “Without these proposed standards of care, patients suffering from these rare and chronic diseases are at risk of being deprived of their needed lifesaving treatments. That is unacceptable as it will result in not only severe debilitation and possibly death for these patients, but also increase health care costs for all Minnesotans.”

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 through advocacy, education and research.

Coalition partners, the Immune Deficiency Foundation and the Alpha-1 Association worked with Sen. Sheran and Representative Norton to bring this Quality of Care legislation forward.

Visit the Immune Deficiency Foundation at www.primaryimmune.org; visit the Alpha-1 Association at www.alpha1.org; visit the Alpha One Foundation at www.alphaone.org.

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