



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

PATIENTS WITH RARE, LIFE-THREATENING DISEASES TESTIFY AT THE CAPITOL TODAY

Patients to advocate for passage of Standards of Care (SF 339) Legislation

ST. PAUL, MN—March 18, 2009—Today, individuals with primary immunodeficiency diseases (PIDD) and alpha-1 antitrypsin deficiency (genetic chronic obstructive pulmonary disease) will testify at a hearing of the Senate Committee on Health, Housing and Family Security to press for the passage of legislation that will ensure them access to their life-saving therapies. Patients with rare, chronic diseases whose lives depend on plasma protein therapies would be assured access to the therapies they need to lead healthy, productive lives under legislation introduced by Senator Kathy Sheran of Mankato (SF 339). Identical legislation has been introduced in the House by Representative Kim Norton of Rochester (HF 410).

“Access to these life-saving therapies is critical for people living with primary immuno deficiency,” said Kathy Antilla, Director of Education and Volunteer Development with the Immune Deficiency Foundation and the mother of a Minnesota teenager who is living with the condition. “I am so glad to have the opportunity today to speak with lawmakers in my home state today to discuss the unique nature of primary immunodeficiency disease, and the need to assure that immune globulin treatment is available to our community.”

Patients with PIDD lack a vital protein in their plasma to fight infection, placing them at increased risk of developing pneumonia, bronchitis, respiratory infections and viral infections that, left untreated by intravenous immunoglobulin (IVIG) therapy, can lead to long periods of severe illness, hospitalization and even death.

The bill requires 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. As proposed, there will not be a fiscal impact on the state.

“Passing Senator Sheran’s bill will make Minnesota a leader in ensuring that people living with these conditions have access to the treatments they need to live healthy and productive lives” says President and Founder of the Immune Deficiency Foundation, Marcia Boyle.



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

The Committee on Health, Housing and Family Security will hear SF 339 on Wednesday, March 18, 2009 at 5:30 p.m. in Room 15 of the Capitol.

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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