



2937 SW 27th Avenue, Suite 106
Miami, FL 33133



2937 SW 27th Avenue, Suite 302
Miami, FL 33133

ACTION ALERT – MINNESOTA'S STANDARDS OF CARE LEGISLATION SF 339 and HF 410

We are asking you to take action TODAY to help pass the Standards of Care legislation. This is very important legislation especially for plasma protein therapies users. This bill will ensure that treatment decisions are made by the patient and the physician, not the insurer.

The legislation specifically protects those with Alpha-1 – often called “genetic COPD” – as well as primary immunodeficiency diseases, and von Willebrand disease (a blood clotting disorder). People with these conditions often require biological plasma protein therapies to replace specific proteins that are missing or deficient in their blood.

The bill has been introduced in the Senate and the House but no action will be taken until after January 2010. We encourage you to take this opportunity to call and meet with your legislators to explain why this is very important to you.

HOW TO TAKE ACTION:

1. To find your legislators, please visit: <http://www.leg.state.mn.us/>.
2. Call your elected official in your district and ask for him/her to cosponsor SF 339/HF410.
3. **Make sure you tell him/her that:**
 - you are a constituent,
 - this issue is vital to you personally or to your community,
 - this issue is important to all Americans, and
 - you expect your elected official to take a stand in support of this legislation.

Talking Points for Quality of Care for Individuals Requiring Plasma Protein Therapies

- Senate File 339/House File 410 protects proper care for Minnesotans living with the rare genetic disorders alpha-1 antitrypsin deficiency, primary immunodeficiency diseases, and von Willebrand disease. *
- People living with these conditions lack or have defective proteins in their blood. Physicians prescribe plasma protein therapies to treat these disorders as these therapies are high impact, high value treatments that give life and improve quality of life to these individuals.
- Individuals now receiving care seek protection from insurance cost cutting decisions in the future. The proposed bill will not have a fiscal impact on the state or the private companies.
- The proposed bill will ensure that these individuals continue to receive the medically appropriate therapy.
- The proposed bill requires health plans to provide patients with the therapy that is medically appropriate for them because these therapies are not interchangeable. There are no generic or therapeutic equivalents.
- The proposed bill requires the Minnesota State Board of Pharmacy to develop rules for the provision of pharmacy services based on standards established by the medical advisory committees of the patient groups and professional societies representing these individuals.
- The proposed bill provides for a screening for von Willebrand disease in cases of excessive menstrual bleeding (Menorrhagia) prior to an invasive uterine procedure such as a hysterectomy to prevent this procedure when medically unnecessary. **

Please support a standard of care for plasma therapies and their recombinant alternatives.

Jan Petersen, Esq.
Alpha-1 Association
(320) 260-8316

Katherine Antilla, MAEd
Immune Deficiency Foundation
763-444-6840
kantilla@primaryimmune.org

Web site resources

www.alpha1.org
www.alphaone.org
<http://www.alphaone.org/healthcare/?c=03-ATSERS-Standards-PDFs>
www.primaryimmune.org
http://www.nhlbi.nih.gov/guidelines/vwd/1_frontmatter.htm

*2009 estimates suggest 475 Minnesotans are being treated in MN.

- 300 Primary Immune Deficiency – source: Immune Deficiency Foundation
- 100 Alpha 1 Antitrypsin Deficiency – source: Alpha 1 Foundation
- 75 von Willebrand disease – source: Centers for Disease Control and Prevention (CDC)

**CDC studies show that every year 30,000 women undergo hysterectomy for the diagnosis of abnormal uterine bleeding. Many of these women have an undiagnosed bleeding disorder and their condition could be managed medically. According to the CDC it takes a woman, on average, 16 years to get a diagnosis for VWD.