Quality of Care bill seeks safe access to life-saving therapies; Maple Grove resident testifies

(Created: Wednesday, April 8, 2009 10:37 AM CDT)

The Quality of Care bill (SF339) passed the Senate Health, Housing and Family security committee March, 27, following the passionate testimony of patients struggling with primary immunodeficiency disease and alpha-1 antitrypsin deficiency and their families.

One such patient was Maple Grove resident Lisa Akers. Akers described the impact the illness has on her family. Akers suffers from primary immunodeficiency disease. The disease leaves patients without a vital protein in their plasma that allows them to fight off infection. Left untreated, the disease can turn the common cold into severe pneumonia or bronchitis, leading to long periods of severe illness, hospitalization and even death.

"I felt as though I always had an infection of some kind, which really limited my ability to be a wife and mother, and to do my job," Akers said. "I was away from work a lot because of illness, and usually felt terrible. There were a lot of peaks and valleys in my energy level, which made it really hard to get much of anything done."

It took years of testing to discover the illness plaguing Akers. But after she found the right plasma protein therapy, her life changed dramatically. Her energy level returned, and once her treatment routine was in place, Akers finally felt that her life didn't revolve around her illness.

Unfortunately, Aker's daughter also suffers from the disease. At just 7 years old, she uses antibiotics throughout the winter to avoid infection. Although she does not need plasma treatments yet, doctors affirm that they will be needed eventually. She can play on the playground, swim in the pool and participate in Girl Scouts just like any other young girl.

Until recently, Akers' insurance covered the cost of her plasma protein therapy, which ran to more than $5,000 per month. The insurer is now forcing Akers to get a new determination of medical necessity for her treatments, leaving her very worried that her coverage will go away.

"I hate that my husband and I are trying to figure out how much equity there is in our house, in case we need to use it to pay for treatments," Akers said. "I can't live without these treatments, and while I understand that insurers have to make choices, I testified so that they know how taking the therapy away would impact my family. We need this bill to keep moving forward to protect the care we need."

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 Sen. Kathy Sheran of Mankato (SF 339) and Representative Kim Norton of Rochester (HF410).

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.

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 bill returned to the Senate floor for referral to the State and Local Government Committee this week. The House companion bill is currently with the Health Care and Human Services Policy and Oversight Committee.

For more information on primary immunodeficiency disease, visit www.primaryimmune.org.