

Testimonies by Lisa Aker and Kathy Antilla to the Minnesota Senate Committee on Health, Housing and Family Security

Lisa Aker's Testimony

My name is Lisa Aker, and I'm a resident of Maple Grove, MN. Approx. 5 years ago, I was diagnosed with a primary immune disease, called Common Variable Immune Deficiency, or CVID. CVID is the inability to fight off routine illnesses, due to absent or improperly functioning proteins the immune system requires. It is a chronic disease, like diabetes, where there is no cure, only a method to manage it. For myself, and other PID patients, routine illnesses like the common cold routinely turn into more complicated infections like sinus and upper respiratory infections, and life threatening illnesses like pneumonia. My disease is managed by the plasma therapy considered in SF339.

In addition to myself, I also have a 7 year old daughter, Sophie, with Immunoglobulin G deficiency, which is very similar to my illness.

I have been undergoing plasma therapy since my diagnosis in 2002. The first 3 years were spent on IVIG, which is intravenous administration of immunoglobulin, which was administered every three weeks in a clinical setting. My transfusion sessions lasted about 5 hours. I quickly found different immunoglobulin products unique, there are no generics or therapeutic equivalents. We had to try a number of different products before we found one that worked best.

Some products we tried caused side effects, which in turn required additional drugs to treat the side effects. However, once on IVIG, I noticed the episodes of illness much less frequent and less severe.

While I was healthier, I was still missing a day of work every three weeks for my infusion appointment. I also struggled through peaks and valleys as my immunoglobulin levels dropped between infusions.

Approx. 2 years ago, my physician informed me about Vivaglobin, subcutaneous treatment (SCIG) that is self administered on a more routine basis than infusions. I started a quality of life clinical trial with Vivaglobin, and saw differences right away. My immunoglobulin levels were much more consistent and prevented more infections. I administer this drug at home with an infusion pump, much like diabetics.

This also significantly made my life more normal. I have the ability to travel with my family on vacation, and not have to schedule my life around infusion appointments and when I knew my immunoglobulin levels were at their peak. I have more energy, and less intense illness. I no longer miss work due to infusion appointments. Peace of mind and some normalcy has returned to my life.

Doctor visits have gone from 2 to 3 per week, to 2 to 3 per month. I've not had any inpatient hospital stays or ER visits since I started immunoglobulin treatment. Also, the treatment with Vivaglobin is less expensive than the transfusion therapy I was receiving.

Two weeks ago, I received an EOB from my insurance carrier, stating additional information was requested from my physician to determine if the treatment was medically necessary and if it was a covered benefit. Therefore, my claim for SCIG had been denied.

In following up with my insurance carrier, I discovered that:

A paper letter was sent via post to provider on March 2nd. I confirmed that my provider had not received the letter as of March 13th. When I requested a copy of the letter from the insurance to the provider, and I was told it would be faxed to me in 7 to 10 working days.

By this time, I was out of immunoglobulin, and had to receive a shipment on March 13th.

Because the prior claim was denied, it is likely that my claim for March 13th will be denied, as would any subsequent immunoglobulin treatments, because the first denial has not been resolved, any other doctor's visits or tests with the same diagnosis code may also be denied.

Right now, I have less than a four week supply of a life sustaining treatment, and no method to assist my provider or insurance company to resolve the denial.

This brings me to the proposed bill before this committee.

SF339, regarding preauthorization, would require that claim denial that I'm currently dealing with, would have to be resolved within 24 hours.

Also, we are all aware of the cost cutting decisions insurance companies are making these days. CVID is a rare disease. Patients getting immunoglobulin treatment is a very small population of about 300 patients in Minnesota. Since there are a number of unique immunoglobulin treatments within this population, there is no critical mass to manage or gain economies of scale from insurance formulary consolidation for immunoglobulin treatments. It simply cannot be managed the same way that more common chronic conditions can be like hypertension or low back pain, where there are tens of thousands of patients, and enough mass for insurance companies to leverage the volume.

The proposed bill ensures medically appropriate treatment for this small population and protects it from cost cutting measures such as the prior authorization I'm currently experiencing.

Kathy Antilla's Testimony

I would like to thank the Senate Committee on Health, Housing and Family Security for giving me the opportunity to encourage the passage of Standards of Care Legislation (SF 339) introduced by Senator Kathy Sheran. This legislation will protect the care of patients with rare, chronic diseases who rely on plasma protein therapies and enable them to continue to receive the life-saving therapy they need to lead healthy, productive lives.

My name is Katherine Antilla. I am the Director of Education and Volunteer Programs at the Immune Deficiency Foundation (IDF) which is a national patient organization dedicated to improving the diagnosis, treatment and quality of life of persons diagnosed with primary immunodeficiency diseases (PIDD) through advocacy, education and research. I am also the mother of a son diagnosed with a primary immunodeficiency disease.

Primary immunodeficiency diseases occur in persons born with an immune system that is either absent or hampered in its ability to function. These diseases are caused by hereditary or genetic defects and can affect anyone, regardless of age or sex. The World Health Organization recognizes more than 200 primary immunodeficiency diseases.

My son, Isaac, is 17 years old. He was diagnosed with common variable immunodeficiency disease at the age of five.

The first five years of his life consisted of a vicious cycle of infection (pneumonia, bronchitis, sinusitis and ear infections). Chronic coughing and vomiting, 100 doctor visits, numerous medical tests and prescription antibiotics (to the point of becoming allergic to half of them) were a part of this cycle. Isaac spent most of his days resting on the sofa fighting illness while his peers ran, played and enjoyed life.

Finally! Isaac received the diagnosis of CVID. The physician told us that life-long intravenous infusions of immune globulin (IVIG) would replace the antibodies that Isaac's body did not produce. IVIG would allow Isaac to live a normal life.

After the first infusion there was a sparkle in Isaac's eyes that we had never seen. Within a couple of months, Isaac could run and play! One summer day he announced, "Mom, look at me! I'm just like a normal kid now!" ...and today he continues to be a normal kid!

Isaac has had “zero” bouts of pneumonia since he started receiving IVIG. He is an excellent student who is looking forward to attending college and being a contributing member to society.

It is important to note that immune globulin is patient specific - There is no generic equivalent. The physician and patient determine which brand is the most medically appropriate for the patient. The brand is never changed without the physician’s prior approval due to the possibility of a life-threatening reaction. The physician and patient also determine the most appropriate site of care (medical setting or home) and mode of administration (intravenous or subcutaneous) which assures that the patient will receive this life-saving therapy.

In this time of cost-cutting decisions we need to assure that patients with PIDD have access to all brands of immune globulin (which is life-saving therapy) in all sites of care via all modes of administration. SF 339 assures that this will happen. This bill will NOT have a fiscal impact on the state.

In closing, I urge you to encourage the passage of Standards of Care Legislation (SF 339). Please help Minnesotans, like my son, to continue receiving medically appropriate therapy and living a normal life.