SB 841 Testimony of Colleen Brock
Before
Banking and Insurance Committee
Senate of Pennsylvania
October 25, 2016

Good morning, my name is Colleen Brock and I appreciate you giving me the opportunity to speak to you today about the specialty tier issue and the impact SB 841 would have on my family's lives. I come here today representing both the Immune Deficiency Foundation, the national patient organization dedicated to improving the lives of the 250,000 persons nationwide living with primary immunodeficiency diseases, including my family. I have an immune disorder called Common Variable Immune Deficiency, also known as CVID, as do our children Emilee, age 17, and Adam, age 21. CVID is a disease where our bodies do not produce antibodies to germs or immunizations. That means we get very sick quite often because we have no protection against the germs we are exposed to. It means that the hospital is like a second home, you get bronchitis, pneumonia and a sinus infection all at the same time, you go to bed at night feeling good and wake up in the morning running a fever of 104 and are vomiting all day, and you live in constant fear that a food you eat may be contaminated causing possible death. Developing an autoimmune disease or cancer is another constant worry. It is for life, there is no cure, and there is only one medication that we can get that will help keep us alive.

Our son, Adam, was diagnosed at the age of six months when he aspirated his formula due to reflux. The pulmonologist, as a routine, did an immune profile and found that his immune system had never turned on as it should have by then. He spent the first year of his life in and out of hospitals and we actually planned his funeral his first Christmas because we did not think he would live much longer. He was very sick with a gastrointestinal bug called C-difficile and his immune system could not fight it off. Fortunately, he got better and we celebrated a great Christmas! Emilee was officially diagnosed at the age of eight, but we knew from birth that she, too, likely had a problem. I was diagnosed two years ago after going thru cancer treatments. The great thing is that even though we have all been diagnosed with this horrible disease, we lead as normal of lives as possible as long as we get our treatments. Adam has been swimming since he was eight and has swum on numerous swim teams. He is now a senior in college and will graduate in May with a computer science degree. Emilee is currently a senior in high school and has been swimming since she was four and has played volleyball for her high school team for the last four years. They are active and productive members of society. I also lead a very busy life. This is possible for all of us because of the medication we receive and the protections, like frequent hand washing, that we take!

Since we have little natural protection against germs, we need a medication made from donated plasma called immunoglobulin, also known as Ig or gammaglobulin. This is the only medication available to keep us alive. We each receive our treatments every three weeks, it takes several hours to administer, and costs approximately $10,000 a month for each of us. Yes, there are different companies that produce this medication, but there is no generic or biosimilar available as an alternative. Even though the medication is the same, they are all manufactured differently and not all patients can tolerate the same product. This is extremely important to understand. Each medication has a different additive mixture and concentrations. Thus no one medication can be taken by all patients with primary immunodeficiency. We had a very close call when Adam was about a year old. There was a shortage of gammaglobulin and the hospital had to use a different product than the one Adam had been getting and he had an anaphylactic reaction. Shortly after his infusion started, he spiked a high fever, his blood pressure plummeted, and he got very sick. They stopped his treatment and were getting ready to move him to the pediatric intensive care unit when he finally stabilized. I was told by his immunologist and pediatrician to make sure he never got that product again. Each patient needs to have the ability to discuss with their physician which product would be best for them to take based on what is wrong with their immune system. It should not be up to the insurance company to dictate what product our patients must take.

The issue of specialty tiers and co-insurance scares me to death! If insurance companies are allowed to charge an extra fee for certain medications, how and where do I come up with the money to stay alive? Creating another co-pay or co-insurance for medications in this specialty tier that insurance companies have created spells disaster for so many families. Ours included. A representation of how this specialty tier could directly affect us would look something like this: If the insurance company says we must pay $100 per month for the gammaglobulin then we would have to dole out $300 per month for 10 months and $600 for two months because we receive our med every 3 weeks. That equates to $4,200 per year for our treatments alone, on top of our $4,000 deductible, and our insurance premiums because we are a small business and pay for our own insurance. Specialty tiers are usually set up requiring co-insurance where the patient must pay a percentage of the cost of treatment. Some plans require co-insurance as high as 40 and 50% per month. We can't pay $4,000 or $5,000 per month time times three ($48,000 or $60,000 per year) in our family. We would have to choose between bankruptcy or death.

Autoimmune disorders are also very common for patients with CVID, and I myself have developed severe rheumatoid arthritis and have had cancer. If any of the other 17 medications that I take fall in this category, I would have to pay an additional $1,200 or more each year on top of the money we would have to pay for our gammaglobulin treatments. There are thousands of patients just like me, so this example would be the same for other people with primary immunodeficiency diseases. We just don't have that kind of money and would quickly become financially bankrupt. This specialty tier is a disaster in the making for so many families and is so wrong! It penalizes me because my children and I have a rare and chronic disease.

In closing, I would like to say that I realize the medication we are discussing is very expensive, and I don't take that lightly. However, I ask you, could you stop taking your medicine so that your children live yet they would no longer have a mother or father? Or worse yet, could you decide which of your children dies first and pick out their casket because you don't have the money to buy their medications?

I urge you to pass SB 841.

Thank you,

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