

Chair Wiklund and Members of the Senate Health and Human Services Committee,

Thank you for the opportunity to provide written testimony. My name is Anne St Martin and I live in Inver Grove Heights with my husband and two sons. I am asking you, **PLEASE INCLUDE SF 1029, INCREASED ACCESS FOR RARE DISEASE PATIENTS**, in your Omnibus bill. **My family has personally dealt with insurance barriers and had limited access to the proper services my son has needed over the years.**

My son Leo is 6 years old and has a rare genetic disease called Pompe Disease. Pompe Disease affects 1 in 40,000 people. Leo was born on May 17, 2016. In all senses it was a normal pregnancy and delivery. As Leo turned 3 months, he developed feeding issues. Those issues progressed and we knew Leo needed help. We knew we needed to see a specialist.

Our pediatrician recommended that we go see a pediatric neurologist. First we needed to wait for prior authorization from our insurance. **As I sat there and watched my beautiful baby get weaker and weaker I knew I could not wait the 3 to 6 weeks they said it could take for insurance to approve the appointment. On top of that there are limited numbers of specialist appointments available to you. So, even after you get the prior authorization, you then can wait 8 more weeks to even get into see a doctor.**

I called the specialist office and told them we would pay out of pocket for the visit. They told me it could cost up to \$5000 or more for the visit. They then told me the next available appointment was in 4 weeks. I told them I would not stand for that. Luckily a pediatric neurologist appointment had opened up the next day. We took that appointment and prayed. The next morning we checked in at our neurology appointment. I gave my credit card to the receptionist and we waited. I remember thinking this was it. We were going to get the answers we needed. It would be worth the cost and Leo would be ok. Instead the PA came into the room, looked him over, listened to his heart, and then told us she was calling an ambulance and checking us into the hospital. When we got to the hospital they did an EKG and saw that Leo was in heart failure. At 4 months old Leo's heart was so large it was crushing his left lung and he was in the beginnings stages of respiratory failure.

Leo was rushed into emergency surgery the first night in the hospital where they stabilized his heart, put in a G-tube for feeding, and later a trach for him to breathe...then we just waited. Two weeks later still in the hospital the results of the expensive genetic labs (that we paid out of pocket for) finally came back and we were given the official diagnosis of Pompe disease. **It took 6 weeks for insurance to approve the recommended dose of medicine while in the hospital.** We were in the hospital for a total of 4 months until Leo was strong enough to come home.

I know today that WE are one of the lucky rare disease families out there. We had good private insurance when we entered that hospital. We had the ability to afford thousands of dollars of out of pocket expenses to be seen quickly which literally saved Leo's life. We were told by the doctors that if we would have waited for a prior auth to get that initial neurologist appointment Leo would have died of heart failure at home. Can you imagine waking up to your dead child in his crib because you were waiting on a stranger to review a piece of paper recommending they see a specialty doctor...? **But you know who was not luckyLeo. Those 4 to 6 months we waited for appointments, diagnosis, medicine, and insurance approvals for treatments the glycogen continued to build up in his outer skeletal muscles taking away his ability to walk.**

As a parent and a citizen I am asking you to **PLEASE INCLUDE SF 1029** in your Omnibus bill. I want all the rare disease children who come after Leo to have access to a provider that is knowledgeable about their disease. **I don't want the financial standing of a family to determine how long they have to wait to save their sick child. I want the medical community to understand that time is essential to treating these rare diseases and not feel the pressure to wait for insurance approval before they do. And most importantly I want insurance companies to not stand in the way of a child's life or future because it needs a prior authorization.**

Thank you for your time and your support of children like Leo.