

Madame Chair and Members of the Health Finance and Policy Committee,

I am a part of a group of parents who share the bond of being mom's to children with medical complexities in the state of Minnesota. These children rely on Durable Medical Equipment (DME) and home care to lead their best lives and participate in their communities. The cost cutting measures that were proposed by the Minnesota Blue Ribbon Commission and included in the Health Finance and Policy Committee's Omnibus bill regarding DME rate reform, will limit access to vital resources needed for our children.

First, I will share a bit about my journey with Sophia

**Varsha**  
&  
**Sophia**



Sophia was born with a mass in her abdomen that was pushing on her heart and lungs. While the mass was removed, she started having seizures at 5 months old, and at one point was up to 20 or more seizures each day. After seeing numerous doctors Sophia was eventually diagnosed with Potocki-Shaffer syndrome, which causes organ systems to encounter multiple problems as a result of their inability to communicate. At the time, she was only the 11th known case in the world.

Today, Sophia is now 14 years old, is living a wonderful life at home with her dad, sister and me. She fills her days with some of her favorite things including swinging, going to school, reading books with her sister and parents, and watching her favorite shows.

Now that you know a little more about Sophia, we'd like to share some of our concerns around the rate reform provision in the omnibus bill.

**'Rate Reform'** moves all DME rates to the Medicare fee schedule and will reduce access to the medically necessary equipment and supplies that are specific to caring for children with medical complexity. It could also have the impact of sending complex pediatric children, like Sophia, to live in the hospital due to lack of available equipment that meets her unique needs at home.

It's important to call out that Medicare is designed for stable aging Americans, not children with complex disabilities. The overwhelming majority of DME products on the Medicaid fee schedule are currently reimbursed at the Medicare level. The Medicaid program has worked hard to create as much efficiency as possible to find the lowest cost solutions where possible. The products that do not align with the Medicare fee schedule are highly specialized, medically necessary items designed for the complex pediatric population. I'm talking about items such as custom trach tubes for smaller airways, gastrostomy tubes, and specialized enteral nutrition that you can't buy from the store. Sophia relied on a gastrostomy tube and specialized nutrition in her healthcare journey.

I am asking for protection on the reimbursement for these specialized DME products. They are essential to allowing our children the freedom to live life at home and participate within our communities. If these products were reduced to Medicare reimbursement levels, suppliers would not be able to afford

to provide them at such a significant loss. As a result, my child and others would be forced to use products designed for a completely different population. This would result in risks to their health and negative impact to our whole family's quality of life.

As parents and citizens, we would like to see the DME rate reform provision removed from the Health Finance and Policy Committee Omnibus bill. This provision will limit access to care, increase costs by sending patients into the hospital due to lack of access to supplies necessary for their unique needs. I am available to meet with you virtually along with Sophia and further explain why these recommendations will hurt the access to healthcare and the quality of life for children like Sophia.

Thank you for your time and attention to this matter.



Sincerely,

Varsha Leiseth | 612-227-8801

Concerned Parents of Children with Medical Complexities