

Chair Noor and the House Human Services Finance Committee,

My name is Gia Sutermeister. I live in Ham Lake with my husband Derek and our four children.

Our daughter, Anneliese, was diagnosed with a rare terminal neurological disorder in 2013, when she was 18 months old. We were told she would likely never walk, never talk, and that we could expect her to pass before age 5. She is now almost 11 years old.

Children with her disorder typically require a feeding tube, have debilitating seizures, and require continuous care including care at night due to sleep disturbances. Her disease affects all aspects of our family's life: practical, emotional, and financial.

We initially did not access many of the available services through the county and state. The overwhelming amount of information, meetings to attend, paperwork and monthly parental fees paralyzed us along with a new life-changing diagnosis for our daughter.

As Anneliese's needs continued to increase, primary insurance denied medical formula, a wheelchair, a walker, leg braces, therapies, and genetic testing. After receiving over \$50,000 in medical bills, we had no other choice but to start the process of accessing Medical Assistance through MA-Tefra. We are incredibly grateful for MA-Tefra and the services it provides for our daughter.

Our monthly MA-Tefra fee is higher than our mortgage and is paid in addition to our monthly premiums for primary insurance. In order to pay off medical bills and make the MA-Tefra payments feasible, we have considered taking on additional work, but this additional work would further increase our MA-Tefra fee.

Many working families like ours struggle to pay these fees. When I reviewed Parental Fee information released by DHS in October of 2018, I noticed there were 5023 past due accounts in collection at DHS and 2636 accounts in collection at the Department of Revenue at that time. We are also consistently behind in our payments because we must first pay our mortgage, increasing utilities costs, and daycare costs (to allow us to continue working). So far we have avoided being in collection, but that may not last much longer as we currently owe \$25K on our account and now also need a new adaptive vehicle in order to transport our daughter.

Having a child with medical needs is stressful financially and emotionally. The extra burden the parental fee puts on families in this already challenging situation is unfortunate. I am hopeful that you will support the bill to eliminate this parental fee for working families of disabled children.

Thank you.

Best regards,

Gia Sutermeister