

Dear Senators and Representatives,

My name is Gia Sutermeister. I live in Ham Lake with my husband 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 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 MA-Tefra parental fees paralyzed us along with a new life-changing diagnosis for our daughter.

As Anneliese got older and her 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 Medicaid through MA-Tefra.

We are a family of 6. My husband works as a Research Engineer and I work in Clinical Research. It is a challenge to find before and after school care for Anneliese, so we stagger our work schedules to ensure we are home when she is home. In the summer, I am not able to work full-time due to a shortage of care providers for medically fragile children. We administer 4 medications multiple times per day, monitor for seizures, administer medical formula via syringe, transfer up and down stairs, in and out of her wheelchair, and ensure she is supervised at all times. We do all of this while also working to meet the various needs of our 3 other children.

Our monthly MA-Tefra fee 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 stopped contributing to our children's 529 College Savings accounts and borrowed money from our parents.. We have considered taking on additional work, but this additional work would further increase our MA-Tefra fee.

Having a child with medical needs is stressful financially and emotionally. The extra burden the MA-Tefra parental fee puts on families in this already challenging situation is unfortunate. I hope that you will support families like mine by eliminating the MA-Tefra Parental fee.

Best regards,
Gia Sutermeister
612-799-7772