**TO: House Health and Human Services Reform Committee**

**FROM: Nicole Erickson, Pease, MN 56363**

**RE: Support for HF 808, Early periodic screening, diagnosis, and treatment program allowed to cover Stiripentol.**

**DATE: March 6, 2017**

My name is Nicole Erickson, and I am the mother of Gabrael Erickson. Gabe was diagnosed with Dravet Syndrome at a year old and had his first seizure at 6 months old. He has tried several seizure medications including: phenobarbital, keppra, Depakote, Topamax, and onfi as well as several rescue medications. He continued to have prolonged seizures that didn’t stop with rescue medications. He almost always required intubation and transport by ground or air to the nearest PICU. His longest seizure lasted 5 plus hours and failed to stop after using all medications his neurologist recommended on his care plan. Before starting Stiripentol, Gabe was hospitalized several times a year. In 2014 he had six hospital stays. He started Stiripentol at the end of January 2015. He only had two hospital stays during 2015 and one in 2016. This was a huge improvement in the short amount of time he was on Stiripentol.

We are extremely grateful that Gabe’s seizures are now controlled at home and stop in under five minutes with the rescue medicine. The cost of Stiripentol is a major factor for many families. Without coverage from the State of Minnesota, we wouldn’t be able to afford Stiripentol for Gabe. Even though the cost of Stiripentol may seem high, if it helps as well as it does for Gabe, it probably saves money because of the fewer ambulance rides, helicopter rides, and hospital stays. It’s hard to say if Gabe would even be with us today if we hadn’t received approval of accessing Stiripentol through his insurance. It has greatly improved Gabe’s quality of life and letting others have this chance at success may also give them the quality of life they deserve.

Testimony on behalf of Amelia Weaver for inclusion of Stiripentol coverage

I am sharing my daughter’s experience today because it is important to me that other patients have access to Stiripentol, a medication that has helped my daughter Amelia. Amelia is ten years old. She has a rare and catastrophic form of epilepsy caused by a mutation of her Scn2a gene. Because of this mutation, Amelia has battled seizures since she was 18 months old. She has tried and failed over twenty anti-epileptic medications. Some days Amelia had nearly 100 seizures. Following the addition of Stiripentol to her medications, Amelia saw a significant decrease in her seizure frequency. In addition to an overall decrease, she experienced an almost complete elimination of the longer violent “grand mal” type seizures.

Amelia’s genetic mutation means she will always battle difficulties with her seizure control and health. Finding something that decreases her seizures is a significant improvement in quality of life for our daughter and our family. Denying desperate families and patients the chance to try this medicine is not right.

Thank you for your time.

* Angie Weaver

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