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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