

**Proponent Testimony: HB 189
May 11, 2022**

Chairman Lipps, Vice Chair Holmes, Ranking Member Liston and members of the Ohio House Health Care committee:

Last week my 15-year-old daughter sent me a text that said “Um, mom, I think I have a choir concert tonight.” It was 5 pm. She needed to be at the school by 6:15, and I wasn’t arriving home until 6 pm. I texted back telling her to get something to eat and get ready and I’ll be there by 6 to get you there. When I arrived, she was fed, dressed and ready. Why am I telling you this? Because my daughter is recovering from PANDAS.

Two years ago, the same scenario would have ended with my child unable to function as her brain would have been constantly looping the obsessive thought that “she was stupid”; her body would be convulsing with physical tics; and she would be curled up in a ball on the floor alternating between crying and screaming. Two years ago, we would have never made it to the concert.

My daughter was diagnosed in 2017 with PANDAS after 10 months and visiting multiple doctors until we found one who could help her. By the time she was seen, my then 11-year-old was depressed and having suicidal thoughts.

The doctor who diagnosed her immediately put her on an antibiotic. They helped and she got better, but not 100%. Then in May 2019 she was exposed to strep on top of having seasonal allergies, and she went downhill fast. Her obsessive thoughts were off the chart. She would yell and scream that “she wanted it to end.” She would hit and thrash in episodes of rage that she doesn’t remember. All the progress we made was gone and she was back to where she started with obsessive thoughts of hurting herself, rages, verbal tics, depression, and anxiety.

In June 2019, she had her first IVIG treatment and by Fall 2019, our daughter started to reemerge as her fun, loving self. She gained back her confidence and put aside obsessive thoughts. She started to thrive again. Until summer 2020, when one Tuesday she started to develop physical tics, and by that Friday she was having full body tics from the moment she got up in the morning until she went to sleep. This time her mind didn’t leave her or send her on an OCD loop, but her body did. She was frustrated and exhausted from the constant movement of her limbs.

A few weeks later she had her second IVIG treatment to stop the tics. Within a month, they were gone. Since then, she is thriving and acting like a normal teen with the expected attitude us parents endure from our teens, but also all the great stuff like coming home and sharing about her day, or a new show that just dropped on Netflix, or shopping for homecoming dresses, and performing in choir concerts.

IVIG saved my daughter’s life and gave her back her childhood. Unfortunately, the cost of IVIG is out of reach for many families – it was almost out of reach for mine. After being denied by insurance, we paid more than \$10K out of pocket for the first round to save her life because we couldn’t wait. Her life depended on it. The second round, we asked for a physician’s peer-to-peer review after being denied, and it was approved because the physician was impressed with how well she responded to IVIG. The research is out there – IVIG works for PANDAS/PANS kids. It needs to be accessible for all children with this horrible disease.

I appreciate your time and I request that you support HB 189, so that all Ohio families and children faced with this disease have all the options available to them. Thank you.

Valerie Wolford
1738 Fairway Drive
Uniontown, OH 44685