

November 4, 2020

To the health committee, Chairman Scott Lipps and Speaker Robert Cupp, thank you for taking the time to read our story.

On June 19<sup>th</sup>, 2020, while playing her favorite video game and almost completely out of nowhere, our daughter (Jolee Lombardo, 11 years old) started having motor and vocal tics. It started with shuddering, shaking her head back and forth, and making sounds like a high pitched bark. Over the next few days, her tics escalated quickly. She began having episodes of “tics” that kept her from walking normally, she would say her legs felt like noodles and she would collapse. Her speech would be interrupted by abrupt noises, or her words would become drawn out and slurred. I took videos and immediately got her in to see our pediatrician. During our visit, the doctor discussed Tourette’s syndrome as a possible diagnosis. However, I explained that this came on so suddenly and I felt like something else had triggered it. He ordered blood work and we went straight to the hospital to have it completed. By this point, even getting blood work was difficult due to my daughter’s jerky body movements but we managed to get enough blood drawn for the basic tests he had ordered. A few hours later, I got a phone call from the Pediatrician’s office saying that Jolee’s strep titers came back high and he suspected PANDAS disorder and to start an antibiotic (cefdinir) right away. Within a few days, Jolee experienced some relief. We completed the 10 day course of Cefdinir and hoped she would be cured. However, around day 12, new symptoms started surfacing... joint pain, repeating words over and over, hallucinations, and then terrible episodes at night that included rage, feeling terrified, feeling like she couldn’t breathe, many of her symptoms mimicked a panic disorder. I called our pediatrician and he ordered another round of antibiotics. In the meantime, I also was able to secure an appointment with a specialist in Columbus, Ohio. They suggested we add an ibuprofen protocol along with Jolee’s antibiotic to try to reduce the inflammation in her brain (autoimmune encephalitis). Again, this combo reduced Jolee’s symptoms but did not eliminate them. For the next six weeks we watched Jolee suffer through periods of what we eventually called “tic attacks” along with headaches, eye twitching, baby talk, OCD behaviors, irrational fears, separation anxiety, and more. For the sake of your time, I am trying to consolidate months of experiences into a brief synopsis. Jolee tried to attend school in August but was unable to focus; she would feel extremely frustrated and email me up to 42 times a day from school to be picked up. We started remote learning but any attempt at school work would send her into a “tic attack.” Desperate for help, we drove from Ohio to Washington DC to see a neurologist who treats PANDAS/PANS. On September 23<sup>rd</sup> and 24<sup>th</sup>, Jolee had high dose IVIG in Washington DC. Within one week of her treatment we saw her symptoms begin to go away. We are now six weeks out from her treatment. Jolee has successfully completed four weeks of in person learning at school, She is playing with friends, and playing sports again. She was able to catch up on all of her school work, earn A’s on her first 9 weeks report card, and says she LOVES school again. Her personality is back. She still has minor tics occasionally but the majority of her symptoms are gone.

This has been the scariest and hardest five months of my life. There have been moments and days when we literally felt like we lost our daughter. It cost us over \$16,000 to bring her back to health. I am incredibly thankful for the doctors we found who were

knowledgeable about PANDAS/PANS and autoimmune encephalitis. I am incredibly thankful for the IVIG treatment and that we were able to afford it. But, I cannot imagine the suffering of families who are unable to gain access to these doctors and treatments. It is imperative that we promote widespread understanding and treatment options for these conditions. Please help us make that a reality.

Kindly,

*Angela Lombardo*