

Ohio House Bill 488

Chairman Lipps and House Speaker Cupp:

Kamron is now 12 and was born a typically developing child. He was extremely bright, met all his milestones early or on time, and he is my 4<sup>th</sup> child. He attended preschool and daycare with no concerns. I have preschool "report cards" stating how well Kamron was doing in preschool and his accomplishments. He was struck with severe, debilitating OCD, anxiety, and sensory issues in kindergarten. We thought he had sensory processing disorder and anxiety. We tried multiple medications, Physical and Occupational Therapy. We also tried expensive behavioral therapy and psychology. This was all private pay and through our insurance, and in addition to what our public school offered. At one time he had private therapies every night of the week, I was very invested in getting my child help.

About age 7, our occupational therapist said Kamron was her "most severe sensory processing patient". He developed severe rages, restrictions with who he played with or spoke to and how he played. He stopped playing with toys and started lining them up in patterns. He was not getting any better with medication or therapies. He became worse. I was left constantly wondering, "How did this happen to a child that was fine the first half of his life?" I am a RN and my background at the time was High Risk Community Case Manager, I have a professional medical and mental health background, so I was aware of the resources available and Kamron had access to all of the resources in my community.

As he continued to get worse, Kamron would no longer eat in the cafeteria of the school. He chose to eat alone in a classroom. He could no longer be in a "typical" classroom, due to harm to other students and teachers. Again, this is a child that attended a typical preschool and daycare without any concerns. Parents stopped letting their kids play with my son because of his behaviors. My once mild, mannered, calm, easy baby/toddler turned into the "Hulk" around age 7, just over pencils being tapped on a desk, babies crying, standing in line to go to another class, fears of natural disasters would kill his family, and fears of buzzing insects. He threw tables, chairs, and objects. He ran out of classrooms and away from teachers. He lost all safety awareness he had already had as a toddler and preschooler. At one point I paid a private, behavioral therapist to evaluate Kamron at school. It is documented that Kamron was dismissed earlier from other kids to walk in the halls with his hands over his ears, before other kids filled the hallways – the noise would put him into a rage. That same observation, Kamron "had to" ask the teacher multiple questions - about 1 question every 2-5 minutes, this went on the entire time of each class!! At age 7, Kamron also began stuttering. This was a kid that was very articulate from the age of 2.

Again, how does a typical child with no issues, suddenly become this way? No trauma in his life, we live in a middle class small town, he had access to all resources for help, and still continued to get worse.

Additionally, to add to our story, Kamron had frequent ears and sinus infections. I began to notice a trend after tracking his behaviors and illnesses– when he was sick, his behaviors would become extremely severe. He was sick CONSTANTLY with huge dark circles under his eyes. He appeared to have the look of a wild animal. He LOOKED sick, couldn't gain weight, fell asleep at school, especially after a rage. Yet doctor after doctor, treatments after treatments, nothing was found.

As a last straw, we started seeing a doctor who treated PANDAS. As a nurse, I had never heard of PANDAS, and I felt there was no way my child had this. Yet, there it was in blood work - high strep titers.

Today, Kamron's sensory issues have melted away. He has been eating in the cafeteria, standing in line, no more meltdowns or harmful behaviors for well over 2 years. He is clear minded and in control of himself. He is rebuilding trust of students and past friends— and it is NOT easy to rebuild trust among middle school kids. He is bright and recently tested at a “college ready level” on his schools reading tests. Even the school is AMAZED at how far Kamron has come and fully supports Kamron's journey. Because of this loss of time, there are things Kamron has missed out on. He used to love baseball and soccer, but could no longer play beginning in kindergarten due to fears of natural disasters and buzzing insects. His only birthday party invites are from family, he has never had a sleepover. We live in a development and kids don't want to play with Kamron because he considered “weird”. It's a very rare occurrence kids ring our doorbell asking to play with Kamron. Thankfully he has 1 good friend, who has stuck by Kamron's side.

In between the time where we discovered Kamron had PANDAS and now, there is another chapter to the story. Kamron became so severe at one point I was worried he would need to be institutionalized. His rages and “unresponsive” episodes at home became extremely terrifying to our entire family. As he got older, he became stronger. He would have constant episodes where he would starting trying to fight people or objects with his eyes closed, not aware of anything happening to him, fall to the ground and become unresponsive while his eyes rolled back in his head. The first time this happened he was at a neighbor's house. We had to call 911 because he would not “wake up”. The hospital told me he must have “played hard and over did it”. These terrifying episodes started to increase. Kamron began to trip when walking, fall off his bike, reach for an object and not be able to grab it. He couldn't even catch a ball thrown close to him. He couldn't remember cousin's names, whom he played with on a regular basis. He couldn't go to school and I had to attempt to “homeschool” him while working full time. He couldn't write – he lost fine motor control – and would have meltdowns if asked to write or draw. One time, he attempted to jump out of his older brother's car while older brother was driving. He was 8! These are the darkest, scariest times in my LIFE. Watching my child go through this was scarier than anything I have ever witnessed as a nurse!

After seeing multiple specialists and trying different PANDAS treatments, our doctor decided to attempt IVIG based on the severity of how Kamron had become. Again, a whole extra chapter to our story. IVIG was not the first PANDA treatment we tried. It was requested at the beginning of January (2018). We did not get an official 3<sup>rd</sup> external denial, until around April (2018). While Kamron was had been having these extremely scary episodes, for 3 months, I had to argue with insurance on why my son needed these treatments, while I also had to work full time 8-5. The denial reasons were multiple variations. Nothing seemed to satisfy their version of “medical necessity”. The first doctor that reviewed our case was an adult urologist (doctor who specializes in the urinary system). The second was a pain management doctor. Peer to Peer, school records of decline, treatments we had tried, IVIG was still denied. We did get coverage about 8 months later, but again another stress that was placed on our family.

We fundraised half of the cost of IVIG and paid the rest out of our pocket. The first day Kamron had IVIG, he came home and colored for the first time in several years. Within a few weeks, Kamron was able to play catch with his dad and actually catch the ball! What a great feeling for him!! He began to regain his fine motor skills. I have before and after photos of writing samples that are simply astounding. His sensory issues melted away. He was able to go back to school in 4<sup>th</sup> grade and started off at a half day. He worked up to a full day by spring. 5<sup>th</sup> grade was his best year! He began making friends, became a

morning lunch announcer, and did presentations to the board of education. In the two and half years we spent on PT/OT that made no improvements, IVIG corrected his PT/OT needs in a matter of months!

I am here today as a parent and a nurse, to ask how are we allowing insurance companies to decide what treatments are “medically necessary” for our PANDAS kid? How can we let a medical provider with no knowledge of a “rare” disease decide when and if a child should receive treatment? Parents should not have to battle with appeals and denials while going through the awful experience of caring for a sick child with PANDAS. Again, I am a nurse with a solid background in navigating insurance, so I can’t imagine other parents without a healthcare background attempting to do this while managing a sick child. Why is OHIO so behind the rest of the world with treatment for PANDAS? There IS research through Yale, Harvard, Stanford, and many others on PANDAS. AS of 10/1/2020 PANDAS was added to the ICD10 diagnostic criteria under an already existing diagnosis. The Journal of Child and Adolescent Psychopharmacology has treatment guidelines for PANDAS. The Journal of Clinical Apheresis supports plasmapheresis as a Tier 2 treatment for PANDAS. The CDC now lists PANDAS as an ICD10 diagnostic code. Why are we not accepting and supporting these treatments for sick kids?

Lastly, I would like to add the amount of dollars that had been spent on Kamron’s PT/OT/psychology/behavior therapy in just one year far exceed the amount of IVIG treatments in 1 year, which wiped away all of these symptoms in just a very short time.