

My son, Kamden, was born a very happy healthy boy. His grandpa would always say "You always have a smile for grandpa don't you". Kamden had the most contagious laugh. It came straight from his belly. And a smile that would light up a room.

This all changed for us in the summer of 2011. The sweet two year old who gave me baby fever on a daily basis was a fading memory. Kamden began throwing violent tantrums to which we now call episodes. Even at just over two years old he was so strong that it was hard to restrain him during these episodes.

Four months later Kamden was at my mothers while I was working. My phone rang with my mother in tears on the other end asking me to come to her house because something was happening to Kam. His entire body would lock up when trying to talk. This followed with a stutter and soon after we started to notice facial and voice ticks. We were sent to a neurologist who diagnosed Kam with tourettes and said that we shouldn't have to come back to see him and that Kam would likely grow out of it.

To gain support for our family we took Kam and our two other boys to a therapist. We were told that he was a bad kid because he was behaving badly. I left in tears with no help for our family. His rage episodes were getting worse and our family was suffering.

As time went by a number of symptoms began to appear. He was shutting down at school and bolting from the classroom. I was called to his small private school where he had locked himself in the supply room and was frantic and non verbal. This was the point where I knew that something major was happening to my son.

In the next few years he was diagnosed with ADHD plus sensory issues, OCD, ODD tendencies and extreme anxiety. To which we were told was all under the umbrella of his tourettes diagnosis. He was put on one medicine after another. His symptoms would seem to get better for a week, maybe two before it all came crashing back down worse than before.

December of 2016

Kamden began having rage attacks that were extremely violent. He was beyond volatile. I was afraid to be home alone with my 7 year old son and I was afraid for the safety of his brothers. Doctors could not understand why no medicines were helping. I got a call from his school, the first call of many. There had been an incident where Kamden had pushed a classmate down and started punching him. This is something that, to this day he can not recall doing. "Why would I punch Forest? Hes my friend". This was just the beginning of Kamden's loss of memory during his episodes. Our new reality was his older brother taking their younger brother into his bedroom and locking the door during these episodes. Kamden would black out, pupils completely dilated, no one was home. This was no longer my son. Kam will throw anything that he can get his hands on. He will grab knives and try to stab you. When restrained he will kick, punch, bite, pinch, headbutt...anything to get lose so that he can grab the next thing to hit you with. Our life was a living nightmare. We had no quality of life.

Kamden went from being a star student to being placed into the special ed room full time. He began speaking like a baby and crawling around on the floor. He would crawl more than he would walk. He began hallucinating that all of the teachers were stuffed animals and he was in a candy world. He bolted from the classroom and was found down the hall, on his back unresponsive, legs twitching. We believe that this was a seizure though doctors can not give us any answers. Why is our son having episodes of crawling and baby talking to the point that he is non verbal for hours??? It's his tourettes and all of the disorders that go along with it is what we were told. His pupils are dilated because he is in fight or flight we were told. When you see the look of pure terror on your child's face for no given reason you know that these answers are not fact. The fact is that something is happening to my son and no one is willing to look outside of the box. No one is willing to dig deeper and find answers.

We were a family in crisis grabbing for straws. A friend told me about a functional neurologist that she taken her son to who was wonderful and really looked at the what was causing the symptoms not just giving them a label and sending them home with a new prescription. Of course this doctor was not covered by our insurance. We knew that something had to be done. We paid \$1000 out of pocket to be seen and evaluated. After hearing all of the ugly truth about Kamden's transformation he asked us if we have ever heard of something called PANDAS. He explained that it is when a child's immune system attacks the brain and causes the onset of a number of psychiatric symptoms linked to a strep infection. He ran a number of tests and found that Kamden's brain was not functioning correctly. He suggested that we get a Cunningham Panel done to rule out PANDAS. After 4 appointments and \$3000 out of pocket later we decided to try to find a doctor to order the Cunningham Panel who was covered by our insurance. The Panel was \$1000 and we were grasping at ways to pay for it. I was told by two doctors that it was unethical for them to take his blood and run these tests because PANDAS was not a true diagnosis and no treatment has proven to help with this fictional diagnosis. I was livid to say the least. We decided to pay for the test any way that we could.

I will never forget the day that we got the call with the results. It was the week before Halloween 2017. The Panel came back and Kamden had a diagnosis. PANDAS. I was shedding tears of relief and happiness. My boy had a diagnosis. He would be treated and get his life back. I wish I could say it was that easy.

We were not able to find any doctors local who specialized in the treatment of PANDAS. We knew that Amy Joy Smith was very successful at treating PANDAS but she was in California and our funds were exhausted. Kamden's symptoms grew with intensity. I was constantly covered in bruises and bite marks. I was called to the school on a daily basis to help support Kamden. He began having such anxiety about school that he could not even finish his shortened day of 2.5 hours a day without incident. We decided that Kamden and our family had suffered enough and we put Kamden onto the wait list with Amy Joy Smith. Three months later we got the call that they had an opening. We had a phone consult and were on a plane to California the next week.

Amy Joy Smith ran numerous tests. Labs showed that his weakened immune system was not able to fight off many things. He had MRSA in his sinuses, bartonella and h pylori to name a few. Kamden told her that his whole body itched, something that he never told us because it was his normal. Itching all over was his baseline. His gut was extremely backed up. As Amy put it "his entire body was toxic". Surprisingly we found no strep. Our boy had PANS which is caused by an unknown factor. We believe that the MRSA, to which Amy believes he had for a very long time, is the trigger. He began having terrible allergies just before the onset of his symptoms. His sinuses were constantly inflamed. We began a number of herbal as well as prescription medications. Insurance would only cover the Rx meds. They would not cover any of the appointments to see Amy nor would they cover any of the herbal meds. We have paid thousands out of pocket. After months of working with Amy she recommended IVIG treatment for Kamden based on the fact that he had been suffering for so long and because his symptoms are so extreme. While working on clearing up all of Kams underlying infections and bacteria we submitted the request for IVIG to insurance. The first request was denied. The appeal was sent in. The appeal was denied. Our hearts are broken and hopeless at this point. An external appeal is our only chance at getting an approval to save our sons quality of life.

The great news is that kamden is now free of all underlying infections and bacteria. We are at the point that we could try a steroid burst. We put all of our eggs in this basket. This had to work. I am happy to say that Kamden showed some small improvement with the steroid burst. The fact of the matter is that his only chance at healing the inflammation that has been raging on his brain for 7.5 years is to be approved for IVIG through our insurance.

I can not tell you how PANS has impacted our entire family. We have contemplated splitting up the family to keep his brothers safe. Kamdens older brother suffers from anxiety and depression from the trauma that he has been through. We fear that Kam will never be able to function in society as an adult. We feel that we have never met our son. Since Two and a half this has consumed our boy. Families need to be able to get the required treatment for their children. Lives have been lost from PANS/PANDAS. No one should have to watch their child suffer because of a lack of coverage issue. Our children are sick.

This is literally our last hope for treatment. I pray that you are able to shed light on this issue and gain support for our children.

Thank you,  
Deborah Miller and Family  
Kamden 9  
Broden 11  
Aasen 6  
Scappoose, OR 97056