

Hi, we live at 6425 SW. Bancroft S. Portland OR. 97221

At the beginning of the school year 2016, my son Charlie Williams had just entered freshman year at Edison High in Beaverton OR.

He was very excited to be starting school and participating in the theater program associated with Jesuit High School.

At the end of Sep 2016 he had a bronchial infection. I took him to his pediatrician at Kaiser Permanente NW Interstate where he had a flu shot and a general check-up.

Two days later we noticed he had developed a shrugging tic. I sent him to school that day and picked him up late, around 8 pm after theater practice. By the time I picked him up he had full blown motor tics. He was shrugging, flailing his arms, couldn't walk straight and had developed strange verbal tics. Needless to say my family was terrified, the onset was so sudden and bizarre.

We made an appointment for the next day with the pediatrician at Kaiser Permanente where they prescribed a first generation Antipsychotic drug, Haldol for Tic Disorder.

The tics continued and worsened and shortly thereafter he developed acute OCD, which we had never experienced before.

Several trips to OHSU emergency room followed with ever changing prescriptions for more antipsychotic meds. These were Clomiprimine, Risperdal, and Guanfacine. These meds seemed to dull the tics a bit but made my son very lethargic, dissociative, and he began to gain weight as a side effect.

Charlie still tried to attend school even though his symptoms included very strong physical and verbal tics, including Coprolalia, a cursing tic which was very disturbing to himself and his classmates.

At this point I was beginning to suspect PANS, although we saw a Pediatric Neurologist at Kaiser Permanente who assured us there was no such thing. We also saw a Neurologist in the emergency room at OHSU who took a quick look and diagnosed a tic disorder.

We then saw a Naturopath who diagnosed Charlie with PANS and began prescribing antibiotics and steroids. At this point his symptoms seemed to abate a very little.

He continued to try to attend school with the help of an anxiety therapist but it was tough going.

After about 3 months we were able to get an appointment with a Pediatric Psychiatrist at Kaiser Permanente. He unofficially diagnosed PANS but told us that Kaiser Permanente did not recognize PANS or PANDAS as an illness so we were not to expect any treatment other than for Tourettes Disorder.

By the next school year Charlie was barely able to make it into one or two classes, his OCD and anxiety were so bad. On advice from his therapist we had him entered into an inpatient clinic for teen Anxiety and OCD in Massachusetts. While there his symptoms flared and he had to withdraw.

Following his stay there I took Charlie to a PANS specialist in New Jersey. After testing and consultation and various medication trials, this doctor 's conclusion was that as no other treatment had worked Charlie needed IVIG. As our insurance would not cover IVIG our out of pocket cost would be about \$40,000 per treatment, due to Charlie's height and weight. He could need from 3 to 6 treatments. We are not able afford this amount.

At home his despair and depression worsened. We saw a psychiatrist at OHSU who tried to find a combination of meds that could help Charlie, even resorting to low dose Morphine at one point. Charlie's condition continued to worsen, he could not attend school. One day he confessed to me suicidal ideation and showed me where he had self harmed. He had burned large chunks of his forearm.

We decided to try another recommended teen OCD and Anxiety program in Wisconsin. He stayed there for about 3 months and his mood seemed to stabilize, although he still had the basic symptoms of tics, OCD, and Anxiety.

While he was there I pursued the treatment of IVIG for Charlie. I was told by the Pediatric Psychiatrist at Kaiser that it would never be approved. I was told by the doctor at OHSU that IVIG for PANS/PANDAS was "dead in the water".

The psychiatrist at the treatment program recommended a small supportive boarding school for Charlie. He entered that school last April and has done ok, although he has had several extreme flares where he could not speak, eat , drink or even stand, the school staff had to take him to the local emergency room. He will start Fall semester this week and we are simply crossing our fingers and praying that he will be able to function there.

This is a private school for which we are paying out of pocket, he is seeing a Naturopath there and a therapist, all of which we are paying for out of pocket. Not to mention all supplements, flights, hotels, etc. To say we are experiencing financial hardship would be an understatement.

The emotional and traumatic impact on our family and Charlie's sibling cannot be quantified. We have had no support other than family. We have seen other dismissive and disdainful doctors I chose not to describe in this story as they simply contributed nothing but negativity.

Still, we know that our only choice is to keep stepping forward, we tell Charlie that there is no problem that can't be solved!