September 10, 2018

Dear Representative Malstrom,

Prior to October 1, 2015 our son, George Swartz, was a typical seven-year-old boy. While he had some social anxiety, he enjoyed playing with friends, drawing, loving on his baby sister and cracking jokes. He had physical prowess and excelled at team sports. His smile was wide and contagious.

This all changed drastically overnight. After an illness of Group A Strep and Mycoplasma Pneumonia, George woke up on October 1, 2015 with an eye blinking tic. I found this peculiar but didn't think much of it. However, within hours his symptoms started to snowball. Our child became unrecognizable. He walked around constantly with his arms held out to his sides like there were balls in his armpits. His hands were held in a lobster-claw position. He could not enter rooms without tapping all the doorways first.

The next day at his soccer game, we learned he could not run anymore. Within a week, we received a call from his teacher at school informing us that his tics were so complex that he could no longer sit in a chair or write.

George presented with a sudden, encephalitic-like onset of symptoms following an infection. As time went on, he became depressed and angry, and cried and screamed seemingly over nothing, had acute movement issues and could no longer play sports. He could not control the movements his body demanded, and his obsessions and compulsions occupied 90% or more of his day.

The week of his symptom onset, we took George to his pediatrician, who shared that he didn't know enough about PANDAS to treat but ran blood work that showed active Group A Strep and Mycoplasma Pneumonia infections.

We also made an appointment with the child psychologist that George already saw for his social anxiety. She acknowledged that this was not a normal onset for Tourette's syndrome, and starting sharing George's case with multiple psychiatrists in her practice. Two of which said it sounded like PANDAS, he needed immediate treatment, but they did not know how to treat.

Next, we called the pediatric neurologists who refused to see George. The pediatric rheumatology clinic also refused. I called multiple pediatricians, to no avail. With many phone calls and emails, our pediatrician reluctantly submitted a referral to OHSU. We were approved for two assessment appointments with an intern. After the first appointment, the intern left, and we were unable to get back in.

Finally, George's psychologist called again. A third psychiatrist in her practice had not treated PANDAS before but was fascinated by the condition and agreed to treat following NIMH protocol until we could find an expert to take on his case. This doctor started George on antibiotics, and within a couple of days his symptoms receded.

Many children go years misdiagnosed and without treatment. We were lucky. We found someone to start treatment early. We still did not have an expert on board, but we found some temporary relief over the next year with the antibiotics prescribed.

In October 2016, George was having his second big flare. We started receiving communications from George's school regarding his aggressive behaviors and inability to engage in learning activities due to hyperactivity and OCD rituals. His teacher reported that he was unable to attend approximately 80% or more of the classroom lessons and work due to his medical symptoms. After several meetings to identify appropriate classroom accommodations and supports, we opted to have a special education assessment done with the intent to develop an Individual Education Plan (IEP.) This process unveiled just how impacting his medical symptoms are, and his inability to write and participate in class.

At this time, his lab work showed a positive Antinuclear Antibody with speckled and homogenous patterns, and an abnormal IFA Titer Serum of 1:1280. In January 2017, we followed up this test with Moleculera Labs Cunningham Panel, which showed borderline high and very elevated circulating levels of autoantibodies directed against Dopamine D1 Receptor (DRD1), Dopamine D2 Receptor (DRD2L) and Tubulin (TUB) neural antigens. Additionally, he had very elevated calcium/calmodulin-dependent protein Kinase II (CaM KII.) These results indicate a significant autoimmune neurological condition in which the patient's autoantibodies cross react and are directed against selected neuronal targets which are involved in normal neuropsychiatric and/or motor functions.

What was particularly heartbreaking with this situation is that George no longer separated himself from his illness. He no longer believed that these symptoms were a result of being sick, rather that his situation is because he was a bad person…and deserved it. He expressed wanting to die regularly. A 9-year-old child should not be forced to suffer and believe this about himself when a medical treatment can heal these symptoms.

At this point, it was clear that George met the criteria for the consideration of repeated dosing of IVIG for relapsing and remitting course of symptoms with frequent flares preceded by infections and a deteriorating baseline. Our son stopped responding to first line therapies of antibiotics and anti-inflammatories, and his symptoms became truly debilitating.

Through connections with other parents throughout Washington, we found an immunologist in Southwest Washington that would treat our son. This doctor immediately prescribed Intravenous Immunoglobulin (IVIG), knowing that the earlier a child is treated with immuno-therapy, the better the long-term outcomes.

Unfortunately, our insurance, Pacificsource, denied the preauthorization. We submitted an insurance appeal that was also denied. We had no choice but to move forward paying for IVIG out of pocket. We believed a delay in treatment could seriously jeopardize his life, overall health, and ability to regain maximum function.

In June of 2017, George received two days of high dose IVIG infusions, costing us $10,700. Before the infusion was complete, George's body was calm and still for the first time in almost two years. His tics disappeared. He was emotionally regulated. He experienced immediate relief of symptoms, including complete remission of:

- all verbal and motor tics
- all motor abnormalities
- Palilalia
- emotional lability
- irritability

- depression
- aggressive behavior
- oppositional behavior
- ADHD-like symptoms (hyperactivity and inability to focus or stop moving)
- irrational intrusive thoughts with severe fear
- frequent urination/enuresis/night-time bed wetting
- sleep disturbances
- joint pain

Additionally, he has had a drastic reduction in OCD behaviors and has returned to school a different kid. He attended school regularly, participated fully in the learning and completed all assigned work, including those involving handwriting. He met the annual goals on his Individualized Education Plan within the first week of school.

The treatment was an overwhelming success. However, shortly thereafter we received a letter from the immunologist saying that he would no longer treat PANDAS patients because every case ended in a timely and cost-prohibitive insurance appeal battle. He simply did not have the time with his busy practice. So here we are again, looking for expert care, and will likely have to fly out of state the next time George needs treatment.

After the overnight onset of George's illness, we have experienced the daily struggle of being an advocates and caregivers for our son as we have battled through diagnosis and treatment, finding providers, worked with the school system to provide the support he needs, and continue to fight to get the care that our team of medical experts have determined is the best path forward for George.

Additionally, the cost of treating these sick children becomes greater as the insurers deny treatment. Children with PANDAS/PANS will have to access a wide range of services throughout their lifetimes: special education, mental health and social services, and continual medical care, possibly including inpatient mental health treatment. This costs the insurer and/or the state much more money than the treatments insurance companies are fighting against.

IVIG is a well-researched and well documented treatment for Post-Infectious Autoimmune Encephalopathy (PANS/PANDAS) and there should be no controversy around this course of action. It's the right decision medically, financially, and morally.

From the bottom of our hearts, thank you for taking the time to learn about the terrible burden this disease places on children and families.

Sincerely,

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