September 8, 2018

We were blessed with two wonderful children, Zadie and Alexander. Zadie is the older twin by one minute. When the twins turned 6, Zadie and Xander were in kindergarten and doing so well. Zadie was being evaluated for the Talented and Gifted (TAG) program at school, and even as a 5-year-old, she had practically taught herself to read.

She and her brother both came home with Strep throat and Coxsackie (Hand Foot and Mouth) disease in January 2016, and the week after we celebrated their 6th birthday in the first week of February, she had changed overnight. In fact, most PANS/PANDAS parents can identify the exact day their child changed, and we do as well. Our daughter was unable to get off the toilet for hours at a time and would cry and rage when we tried to convince her to do otherwise. After a night and part of a day with this concerning behavior, we took her to the urgent care. They suspected she may have a UTI, yet it was negative. She would wake up in the night, crying and hysterical, feeling the need to use the restroom with nothing coming out. We were so frightened for her. I came across a post online where someone had said their niece had a sensory processing disorder, which Zadie was also diagnosed with at age 3, and went through a time when she felt she had to go to the bathroom constantly, was “overwiping” and then went on an antibiotic and was “cleared” of this issue.

With further research based on this anecdote, I discovered the link to PANS/PANDAS:

> *The hallmark trait for PANDAS is sudden acute and debilitating onset of intense anxiety and mood lability accompanied by Obsessive Compulsive-like issues and/or Tics in association with a streptococcal-A (GABHS) infection that has occurred immediately prior to the symptoms. In some instances, the onset will be 4 to 6 months after a strep infection because the antibiotics did not fully eradicate the bacteria.*

and immediately presented the information to her pediatrician, Dr. Earl Lee, at Salem Clinic. While he had heard of this disorder, his immediate response was that it was “rare” and that he had never treated the disorder in any of his patients. Since we have been with him, he has already diagnosed at least one other pediatric patient with PANS/PANDAS, due to our presentation and health history. He had prescribed a 10-day course of Augmentin, which within 36-hours had reduced her night wakings, rages, and urinary urgency to nearly zero. He was skeptical to continue the Augmentin after the 10-day trial, due to concerns about antibiotic infection, and changed her prescription to Azithromycin, which made Zadie's flares of worry, night terror, and extreme crying resume. We stopped that prescription immediately and was given Augmentin again, which proved successful. However, as we worked to try to work on healing over the months of March, April and May, she was unable to continue with school, so I began to homeschool with her (She was ultimately homeschooled from kindergarten through first grade).

Zadie was on a 3-month course of Augmentin and doing better. We were able to travel to California and visit family, and she had no concerning issues. That summer, we researched and found a psychotherapist in Salem, whose daughter also has PANDAS, and she recommended a Naturopathic doctor in Portland, who had seen other PANDAS patients. She ran tests, including the Cunningham panel, which is the standard panel to recognize PANDAS/PANs, testing IgG-IgE levels immune deficiency levels. This test was approximately $900, and is not covered by insurance. We also paid for extensive supplements and vitamins to support Zadie's health and wellness, out-of-pocket, approximately $100 per visit, over 3 months. Tests that can give us so much information about how to identify the genetic markers and autoimmune triggers that are what create this neuropsychiatric autoimmune response in our children are not offered by pediatricians, and not covered by our medical insurance, which was Providence, and so we have put every test on a credit card. We were referred to Infectious Disease Specialists and Neurologists at Doernbecher and OHSU, and put on a year-long waiting list to see a Psychiatrist, and the referrals bounced around in the appeals department at OHSU as no one could determine if these referrals would be beneficial for my daughter or not. Zadie reported at the end of July 2016 to having a chronic stomach ache over several days. Her first tooth came out, which can cause increase bacteria and an autoimmune response. After continued reports of stomach ache, we took her to urgent care and she tested positive for Clostridium Difficile, which is a bacterium that can cause symptoms ranging from diarrhea to life-threatening inflammation of the colon and can be a result of long-term antibiotic use. She had to take Flagyl for 10 days and begin reducing her Augmentin course. She had two rounds of Clostridium Difficile, and we were advised to take her off Augmentin.

We then saw a naturopath who works primarily with children who are autistic and does not take insurance. Over the course of 3 visits, we were charged $1500 for office visits, in addition to approximately $750 in tests not addressed by our insurance company, including the Organic Acids Test, which provides important markers to determine how infections and bacterias are affecting the gastrointestinal system.

It was determined she had tested positive for a genetic mutation called MTHFR which means that she cannot correctly methylate B vitamins or foods with folic acids. It also has a great impact on the T-cells which serves the immune system. This disruption has depleted her nutritional intake and immune system response. MTHFR also had an impact on her need for removal of an abscessed tooth and cavities that needed to be filled, as the dentist we had under Providence refused to perform our extraction because I requested she be sedated without Nitrous Oxide, the use of which could result in increased homocysteine levels, increased oxidative stress, and activated NMDA glutamate receptors. All of these could contribute to inflammation; additionally, nitrous oxide also might cause hematologic problems, neuropathy, and neurotoxic effects on patients with MTHFR. We found a specialized dental clinic in Portland, which works primarily with children with special needs and who contracts with an anesthesiologist, providing in-office sedation, with a care-plan tailored to the child’s medical conditions. However, this provider does not take insurance and we had to pay for the extractions and the anesthesia services out-of-pocket, totaling over $1400.

We were able to raise Zadie’s health to a baseline, where she was able to begin attending school (with a flexible schedule based on her needs) for her second-grade year. However, this disorder ebbs and flows, based on environmental factors, exposure to others who are actively ill or even “carrying” inactive illnesses (such as strep buried inside the tonsils) and even such things as whether she has a loose tooth, which causes bacteria and an autoimmune response to the bacteria, increasing her symptoms.

It is now September 2018, and we have yet to find a permanent solution for Zadie’s health and healing. Our next option is to consider other homeopathic and naturopathic treatments, functional medical doctors, craniosacral treatments and other alternative medical treatments, generally not covered by insurance providers and another out-of-pocket expense, as the “conventional” next approach in PANS/PANDAS treatment would be plasma exchange or Intravenous Immunoglobulin. IVIG has been shown to be helpful with the harmful inflammation caused by autoimmune illnesses but the exact causative actions are not clear yet. Donor antibodies may “retrain” the abnormal antibodies in the patient or the large amounts administered may simply overwhelm the harmful antibodies – thereby removing them from the PANDAS patient. Several studies have shown the efficacy of this treatment for PANS/PANDAS patients, and yet it is largely denied by insurance companies. The cost for this treatment is upwards of $13,000 per day, with required 2-day infusions. Many families are willing to pay out-of-pocket for this treatment, due to the horror and helplessness they feel while their children try to battle this disorder, without the support of the medical or insurance communities. Yet, most families are struggling to care for the most basic needs of their children and cannot afford to even consider the out-of-pocket expense for this treatment. And if the disorder continues untreated, the child could have irreparable physical and psychological damage.

We are a one-income household, as this disease is too unpredictable for both parents to work outside of the home, especially during cold and flu season. We were able to qualify for OHP as a secondary health insurance, some years ago, which helped immeasurably with urgent care and medical co-pays which are frequent especially during cold and flu season with constant strep swabs ($50), co-pays and coverage for mental health and therapeutic treatments ($50), and prescription coverage. As of June 2018, we were discharged from Oregon Health Plan coverage, seemingly arbitrarily, as our income has not changed, and our daughter's physical and mental health challenges related to PANS/PANDAS continue.

We thank you for your consideration in addressing hows PANS/PANDAS affects families in Oregon. It is time for all medical and insurance providers to begin to take this disease seriously.

We are extremely thankful for the support of the Salem/Keizer school district. There are a number of students within the district and even in my daughter's school who have PANS/PANDAS. I want to commend the faculty and staff of Yoshikai School and Principal Zan Payne, for helping my daughter to pursue academic success, despite her health challenges.

On behalf of children in Oregon with PANS/PANDAS and the families who love them, we thank you for your leadership and foresight in recognition of this issue.

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