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RE: Written Testimony for SB475

February 14, 2020

I am writing in support of SB475, requiring the Maryland Medical Assistance Program to provide services for Pediatric Acute-onset Neuropsychiatric Syndrome (PANS) and Pediatric Autoimmune Neurologic Psychological Disorder Associated with Strep (PANDAS); requiring carriers to provide coverage for certain diagnosis, evaluation, and treatment of pediatric autoimmune neuropsychiatric disorders; applying the Act to all policies, contracts, and health benefit plans issued, delivered, or renewed in the State on or after January 1, 2021; etc. Currently, approximately one in every 200 children are diagnosed with PANS/PANDAS, yet most Maryland's insurance companies do not recognize this as a diagnosis and payment for treatment is often refused. If this bill were to be passed, doctors, parents, and caregivers could be educated on signs and symptoms, then treatment can begin immediately, before the inflammation of the brain becomes so severe it is debilitating, as it was in my son's case.

Three years ago, my son, Cameron, was a typical 10-year old boy who loved sports, friends, and X-box. He was not a sickly child, as he only had the occasional cold maybe once or twice a year. However, during the winter of 2016-17, he had swollen glands and ulcers in his mouth several times. He never had a fever or any other symptoms that made me think strep throat or anything serious enough to warrant a trip to the doctor's office. On January 21, 2017, Cameron had a severe panic attack while a friend of his was over. For no apparent reason, he curled up in a ball and began rocking for over an hour, unable to speak to anyone. After that, Cameron's personality was no longer like it was before. He was always angry, had emotional outbursts, he was kicking and slamming chairs into the table instead of pushing it in gently, and he was screaming and crying over the smallest things. If we asked him to do something, such as his homework, he would have a full-blown temper tantrum like he was 3 again. One day in February, he had another severe panic attack, where he kept screaming and crying hysterically, saying that everyone around him was going to get sick and die, including him. On March 7, he had another bout of swollen glands and the school nurse sent him home, even though he did not have a fever or white spots, with the recommendation that he be tested for strep as a precaution because it had been going around his school. I took him to his pediatrician and even though the rapid test came back negative, the swabbed culture came back as positive for strep and he was put on the normal 10-day course of antibiotics. I was not informed to look for other symptoms, or aware of PANDAS at this time. If I were aware then, I think the following could have been avoided.

Over the next few months, Cameron was getting worse and counselors and therapists were not helping. He was overly anxious, depressed, hard on himself, and kept insisting that he was fat. Then we noticed that his pickier than normal eating turned into a severe food restriction. He would eat an extremely small portion on his plate then throw it away before he thought anyone had noticed. We would see him look at his picture or in the mirror with disgust at his appearance. At his October 2017 well-child visit, just 7 months after his strep diagnosis, his doctor noted that he went from 80 lbs to 71 lbs, losing 9 pounds and was bordering on malnutrition. He also had 4 vaccines and a flu shot at this visit and within days, we began noticing a visible tic before he ate or when he had to put anything in or around his mouth. From

October to May, he got increasingly worse to point where it was so debilitating, we had to take him out of school. He developed severe OCD, his anxiety was 100 times worse, he added a vocal tic and the tics were no longer limited to when he ate but happened with other normal activities and were lasting 5 times as long. His social and motor functions began to rapidly decline: he had trouble dressing himself, he wet the bed, his handwriting got so small you would need a magnifying glass to see it, he was hallucinating and too scared to sleep alone in his own bed, he would put his shirt on, only to have to take it off and then again on again for another three times, he would try to wash his hands but had to keep going back to touch the faucet, he couldn't flush the toilet, and his aggression was to the point that all we could do is hold him to keep him from hurting himself or others. He could no longer do things for himself that he learned to do as a toddler.


Thankfully, in the early summer of 2018, my son received his diagnosis and began treatment for PANDAS. Cameron's case was so severe that antibiotics and steroids weren't decreasing the symptoms and was an ideal candidate for IVIG treatment and received his first treatment in August 2018. We saw drastic improvement after about two weeks approximately about 80% of his symptoms had vanished. Four weeks later, he received his second IVIG treatment in order to hopefully get him back to 100%. It was truly amazing, what the IVIG had done for our son. We had him back to normal for about a full month until someone at school had strep and Cameron's symptoms of anxiety and OCD had returned. He had his third IVIG treatment in November 2018. The average hospital stay was approximately \$15,000.00. Just the IVIG prescription alone was \$9,000.00 and initially denied by the insurance company. Thank goodness, after perseverance, they agreed to cover the costs.

After many tests, we found that Cameron was a strep carrier and had high strep titers so his neurologist referred us to an ENT specialist in DC. The doctor said he was an ideal candidate to have his tonsils and adenoids removed, which he did on February 1, 2019. His ENT doctor also recommended another course of IVIG following his surgery in order to flush the strep out of his body, which was done mid-February. The treatment did its magic and again, we were able to see our son return to about 95% normalcy where he stayed for a couple of months. During this time, his neurologist had moved his practice which, unfortunately for us and many other Maryland patients, was out of state and to add salt on an old wound, it was to a practice that did not accept health insurance... at all. Thinking back of all the hurdles and roadblocks from the insurance company that we were faced in order to treat Cameron, I can't say that I blame him. Cameron did eventually get another sore throat, but this time he did not have anyone to turn to for help or treatment. There is no one in Maryland familiar with PANDAS that is seeking new patients. I was forced to use old refills for antibiotics and steroids, following previously prescribed dosing instructions and luckily, this time it worked. We had caught it in time before the swelling was too bad and avoided everything that we went through a year before. However, we are now completely on our own and who knows what is going to happen when his immune system reacts to whatever is out there ready to infect him. Why should anyone have to drive out of state and pay out of pocket just to fight the insurance to hopefully get reimbursed perhaps only half of what was paid? Why should we have to file appeal after appeal to get our denied coverage for the IVIG treatments paid? Why should we as parents be forced to watch our children constantly be denied treatment for something that is very real and very treatable?

It is enough to have to deal with your child(ren) being ill without worrying about how to pay for their treatment, beyond the already expensive deductibles. My husband and I are both full-time working parents, we pay for our health insurance and are not asking for a free handout. We are asking for insurance to recognize and cover PANDAS as a diagnosable illness that my son has and to make it less controversial for a physician to learn how to better diagnose and treat this debilitating disease. Let's get these doctors, parents, and caregivers educated on signs and symptoms of PANDAS and PANS, then treatment can begin immediately, before the inflammation of the brain becomes so severe it is debilitating, as it was in my son's case.

Thank you in advance for your support.

Sincerely,

A handwritten signature in blue ink that reads "Melissa Cooke". The signature is written in a cursive, flowing style with a large initial 'M' and a long, sweeping underline.

Melissa Cooke