

Feb. 6, 2020

House Bill 447 Parent Testimony

Hi-

My name is Laura and I am a parent of a child diagnosed with PANDAS on October 10, 2018. It's a day I will never forget. My son was only 9 years old at the time. For many years we sought help from psychiatrists and psychologists. My son prior to October 10, 2018 was diagnosed as a child with ADHD, anxiety, sensory processing disorder, depression, bi-polar, and the list goes on and on. We were prescribed high/max doses of numerous medications such as Concerta, Depakote, Hydroxine, Vyvance, Ativan, Clonidine, Zoloft, Prozac, Diazepam, Buspirone, Lorazepam, just to name a few. My 9 year old son was taking all these drugs at high doses but NOTHING ever seemed to work.

So prior to October 10, 2018, my son was a suicidal, underweight, dilated eyes, pale, OCD thoughts, anxious, unexplainable separation anxiety, school refusal, unable to sleep in his own bed, angry, aggressive and violent. We were ready to commit him into a psych ward because we were so lost as to how to help our son. A part of his history that doctors refused to look at was that my son got strep throat quite often. We had strep June, August, and September in 2018, and many times before that. We were extremely desperate to help our son and after researching I found information about PANDAS-Pediatric Autoimmune Neuropsychiatric Disorder Associated with Strep (usually Group A) infection.

On October 10, 2018, I drove my suicidal, angry, OCD, aggressive child to our pediatrician. I begged for a strep throat test. At first, she hesitated because my son seemed to only be psychiatric in nature because he did not have any symptoms of strep throat. He did not have a fever, sore throat, headache, ear pain...he had nothing. But she ended up doing it anyways. While we waited for the strep test to show results, we discussed in-patient care for my son at a psych ward, which we already knew was an option, but as a parent it's so heartbreaking to think that your child has to go there.....it is so heartbreaking. When the doctor left the room and came back in she was crying. She looked at me and said "He's positive for strep throat." I'm crying, the doctor's crying and my son was freaking out. We now knew my son was not mental in nature but he has an autoimmune disorder and has had this the entire time we were treated by mental health professionals. Within 24 hours of my son taking the antibiotic, Keflex, he was happy, laughing, and my normal 9 year old son! It was like a miracle. But we still had a long way to go.

My son's symptoms were extremely severe because we were misdiagnosed for so many years that he may have permanent brain damage. We eventually found a doctor, that does not take insurance, and proceeded with aggressive treatment. My son was still unable to attend school, angry, OCD thoughts, huge anxiety and missed his entire fourth grade year of school. The doctor prescribed IVIG and so I knew my battle with the insurance company was going to be difficult.

But in fact, we had the opposite reaction from the insurance company. We got approval for a year's worth of monthly IVIG. Now, it didn't happen like magic. We, our doctor and I, spent

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numerous hours on the phone with the insurance company and pharmacy company. Many nights were extremely stressful not knowing if we'd get the approval and lots of tears were shed. But the moment we were told by the insurance company, "we will save your son" and got the approval, my heart sang with joy.

My son got the treatment that he needed and it has saved his life. So, my testimony is this.....please please please please stop the suffering of the children who are unable to get approval and being denied treatments that will help them, if not save their lives. We need this insurance mandate because we are the prime example, we are the study that we were never invited to participate in, we are the proof that this treatment works. The problem is we would have never been able to afford this treatment without insurance coverage and my son's outcome would be so very different. I freak out thinking about what would happen if we didn't get approval because I see other families continue to struggle. They are not receiving the proper treatment because they cannot afford it. It's sad. And I am worried that if we need continued treatment because we were misdiagnosed for so many years with possible brain damage, I am praying that we will still continue to get approval for IVIG coverage because I know this is what is working for my son. My son is able to attend school full time this year, his anxiety is non existent, he does not have anger or aggression, the OCD thoughts have disappeared, and best of all he is able to sleep in his own bed at night. The best part is my son does not take any MENTAL medications that were listed above. Going from max doses of some of those medications to not taking one single pill is a huge sign that a diagnosis, treatment for PANDAS, and insurance approval is what was needed all along.

Thank you for reading my testimony. We appreciate your time.. There is a national movement for coverage all over the country! Let's hope Maryland can join the states that already have insurance mandates for PANDAS/PANS coverage!! We really need hope for these kids and families and the legislators are the ones that can give us that hope we need.

Thank you,

***Laura Murdock***

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