

November 3, 2020

Testimony of Vanessa Luckey

Re: HB 488

My life was difficult when I had a 4-year-old child who was not learning her letters like other children, and was struggling with sitting still, or staying on task.

My life became more difficult as my daughter progressed in age, and yet she lagged behind in all of her cognitive functions. Not terribly. You can't tell by looking at her. To look at her, you see a beautiful young lady. A little girl who people stop when we are out in public to tell her how beautiful she is. Who presents as "typical", and something underneath the surface was really wrong. And whatever was wrong, was getting worse. It was almost like she was "catching" slow-onset Autism.

We had all the testing that Cincinnati Childrens had to offer. No one had answers. Tens of thousands of dollars spent on genetics testing, MRI's, speech therapy, occupational therapy, Developmental Pediatrics, Neurology, Endocrinology, Psychology. We talked to everybody. Nobody had any explanations as to why we were seeing her struggle.

Everything changed on July 11, 2016. Everything.

On that day, my daughter went from being a child battling cognitive delays, speech delays and learning challenges, to now having severe facial tics, vocal tics, eye blinking tics, obsessive compulsive behaviors, oppositional defiant behaviors, severe anxiety, severe ADHD, urinary enuresis, sleep disturbance, and at times almost psychotic behavior.

On that day, she began to contort her face uncontrollably to the point where she had face and jaw pain and swelling that could be visibly seen.

On that day, my husband and I began switching off sleeping in her room with her nightly, because she would be up 5-8 times per night. If we were in her room with her, we had a chance that she would return to sleep. Sometimes that worked. We did that for more than 2 years.

On that day, my daughter began having accidents in public.

On that day, my daughter would no longer go to the bathroom unless we were standing outside the door where she could see us. She would no longer go in our basement or in our backyard alone. My daughter was 9 years old at the time.

She would obsess about certain foods and eat those only.

She would obsess about certain TV Shows and watch them endlessly.

She would go into 'pretend mode', acting as if she was in another world all together. Most times we could get her back. Occasionally we could not.

Her handwriting regressed to the point where she could not write at all. She could not learn to read. She could not learn math. She couldn't remember anything.

She would scream, all day long, for no reason. Sudden quick outbursts. Full on shouts. For. No. Reason.

She would go into full rages over the slightest things. I realized later, when she began to heal, that these rages caused me to have a level of Post-Traumatic Stress when I would ask her to do a simple task, and she would agree without an outburst. I braced myself for the rage for a long time. I still do.

Her pediatrician told me that this was a result of what was causing the cognitive delays and I needed to see a specialist to get her put on medication for the rest of her life. One for ADHD. One for OCD. One for ODD. One for tics. Who knows what else? They offered me no explanation for what was happening. They expected me to just medicate my child and move along.

In the time between July and November my research had turned up autoimmune condition that matched every symptom that my daughter had, including the sudden onset. It is called PANDAS; Pediatric Autoimmune Neuropsychiatric Disorder Associated with Streptococcus. We would later also be diagnosed with PANS, Pediatric Autoimmune Neuropsychiatric Syndrome, caused by many other types of pathogens.

What I did not have, to my knowledge, was evidence that my daughter had ever had a strep infection. No sore throat. No fever. No anything that would seem like she had ever had a Streptococcal infection.

It was on November 30, 2016 that I finally was able to get a doctor to run a blood test looking for strep. On that day we found it in her blood. She had never had a sore throat or a fever! Getting that positive blood test felt like Christmas!!!

That feeling was quickly dashed when the doctor refused to issue antibiotics for her because she “had no symptoms of a strep infection”, in spite of a blood test that showed elevated strep in her system.

No kidding, doc. I didn't ask you to test her because she was symptomatic for strep. I asked you to test her because every symptom she had matched PANDAS..

It would be months before I would find a doctor who would treat her, all that time her brain being altered by a condition that is completely curable when treated.

This would begin my journey into the insane world of Autoimmune modulated neuropsychiatric disorders, and the system that refuses to believe they exist.

Because we were not able to find a doctor in Cincinnati that would treat our daughter, we had to travel to Columbus to receive treatment 2 hours away. There are 3 doctors in Columbus that are willing to treat PANDAS/PANS, but when I asked other mothers on PANS/PANDAS related Facebook groups who they recommended one particular Doctor was the overwhelming recommended doctor, especially if I was driving long distance. Dr. Allen Lewis. This man saved my daughter.

Dr. Lewis, however, had recently been forced to stop taking insurance because he found that he could not get reimbursement for treating this disease the way he saw fit.

If I were to take my daughter to see this expert, who is nationally and internationally renowned in treating this complex medical condition right here in Ohio, it would be an out of pocket.

That would cost us \$750, before any blood work was done or treatment plan was offered. We had thousands of dollars of blood tests ordered that day, almost none of which was covered by insurance. Yes, it was a lot of money, but that \$750 gave us a 3 hour, one on one visit, with a doctor highly recommended by The PANDAS Network. For the first time in over 5 years of seeking answers for my daughter, I finally found a doctor that knew the condition my child was fighting better than I did. Finally, we would have hope again! Finally, this thing would turn around!

Every time we took our daughter to see her treating medical doctor, it was thousands of dollars out of pocket between office visits and bloodwork. We went 3 times that year. Implementing his treatment plan was thousands of dollars out of pocket. We were fortunate that we did not need the more expensive treatments such as

plasmapheresis or IVIG. Had that been the case, it would never have been able to happen. Even the phlebotomist at Nationwide Childrens who we saw each time mentioned that Dr. Lewis' patients were always better when they returned for more bloodwork.

Beyond that, I had not been able to work for many years because of these ongoing and increasing challenges with my daughter. Our family of 4 have been living on about \$50,000 a year, while trying to pay for these doctor visits and treatments.

The only way that happened was because my mother passed away some years before, and I had an inheritance from her.

Dealing with my daughter's condition has cost me every bit of that \$120,000 inheritance from my mother. That does not include lost wages. We have also had to go into my husband's 401k many times to make ends meet. We estimate the total cost of lost wages and actual money spend to be well over \$350,000.

I wonder what might have happened had we not had 9 months pass from her date of onset, until we got before a doctor that would hear us, believe us, and treat my daughter? I wonder what life would be like if our pediatrician had understood this condition exists, or that the Developmental Pediatrician at Cincinnati Childrens would have understood that PANS/PANDAS kids often do not show signs of illness, such as fevers, because their immune system is not working properly? I wonder if doctors and hospitals might be more apt to take PANS/PANDAS more seriously if they knew that a diagnosis of this very real condition, would be covered by insurance?

I wonder how many children are out there, like many of our children here today, that have a treatable, curable autoimmune modulated neuropsychiatric disease, who are stuck on medications that treat symptoms, but offer no cure, because their doctors do not believe in PANS/PANDAS?

The plight of the child affected by PANS/PANDAS is a systemic failure of our medical community, and the insurance industry. Children that battle PANS/PANDAS can be cured and make a complete recovery when detected and treated early. As of this moment in Ohio, the insurance industry can refuse a curative treatment for our children.

You have an opportunity before you today to unlock that door for our children in Ohio. You have an opportunity to be on the cutting edge in this nation, as this disease continues to be acknowledged and taken seriously around the world, for Ohio to be a state that is a refuge for PANS/PANDAS families. You have an opportunity to SAVE families, insurance companies, medicaid, and hospitals hundreds of thousands of dollars, by allowing our children to be treated early, rather than spending hundreds of days in psychiatric wards, or getting so sick they need the most expensive treatments.

Today I am asking the legislature to hear our stories, look at our children, look at my daughter, and use that power that you have been given by the citizens of the state of Ohio, to give our kids access to the treatments that give them the best chance to overcome this curable disease.

Thank you.

