

Diedre Moltere's Testimony given at MD Insurance Administration's PANDAS Work Group Mtg. 6/6/19

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Good Afternoon Ladies and Gentlemen,

My name is Diedre Moltere. I am a Frederick County MD resident. I only recently learned about House Bill 15 when my husband and I were driving home from taking our daughter and her friend roller skating a few weeks ago. I was scrolling through the radio channels when I heard discussion about PANDAS and the Bill. I was thrilled to learn of the Bill's existence but saddened to hear that it had not passed. As soon as I arrived home that evening, I pulled up information on the bill and got in touch with the MD PANDAS Facebook group.

I am here to talk to you today about our journey as a family, battling a little-known disorder at the time that would rapidly deteriorate our son's mental and physical health and well-being. My husband Teague and I have two children, a 16 year old son and a thirteen year old daughter.

In first and second grade, our son would clear his throat and exhibit nasal grunting off and on. Both eventually stopped. In September 2011, he was entering third grade and he was by all means a normal healthy, happy, active boy. He loved playing video games and soccer. He got good grades and was well-behaved in school and at home.

During the first few weeks back to school, we noticed nose crinkling and eye blinking that started to increase in prevalence. We gave him sinus rinses and allergy medicine. They did not help relieve his symptoms. By September 11, 2011, his blinking was constant and he was moving his eyes in all directions. We asked him to stop, but he said that he could not control it. I called our pediatrician group in Frederick and asked for an appointment that day. The soonest they could see him was two days later on 9/13. I was figuring we were facing a future with Tourette's syndrome. Our pediatrician, that day, Dr. Dodhi, was uncertain about Tourette's. She had his throat swabbed for strep and it came back negative. She then ordered bloodwork.

Four days after his erratic eye tics began, on 9/15 our son was now exhibiting full body tics. He had uncontrolled arm movements, shoulder shrugging, head tilting, and he was having trouble running on the soccer field, and so much so - that his coach stopped practice early that evening. He also went from being an independent third grader to following us around, being scared of the dark and insisting that the only way he could sleep was if it was in bed with us. Earlier that same day, our pediatrician called with the results. She told me he had high antibody levels for strep that could affect him neurologically, and that it could be a pediatric autoimmune disorder called PANDAS. She wanted to put him on antibiotics and see what happened.

I have never prayed as hard as I did those first few days of losing our son. As parents we felt helpless and powerless and wanted nothing more than to have our happy and healthy son back. That

evening we gave him amoxicillin, and I remember thinking to myself that there was no way a little liquid antibiotic was going to bring back our son, but I prayed to God that somehow it would.

When he awoke the next morning, he was back to normal mentally, and was tic free both physically and vocally with the exception of rapid blinking. By the end of his 10 days on antibiotics, all symptoms were gone.

One week later, his rapid blinking and eye movement returned. We went back to our pediatrician, and she recommended we see a pediatric neurologist at Hopkins or at Children's. I called Hopkins first, and I explained to the appointment scheduler that our son was having issues with tics. She asked me if I thought my son had PANDAS and informed me that they did not believe in PANDAS and that they would treat my son for his tic disorder. I told her I did not know if he had PANDAS but I wanted to see someone who believed in the possibility of PANDAS.

I then called Children's Hospital and within two days of seeing our pediatrician, we saw Dr. Lavenstein with Children's in Fairfax County. During his appointment, our son was exhibiting uncontrolled blinking and eye movement and was scared of being alone again. Dr. Lavenstein asked him if the eye movement bothered him, and he replied that his friends at school were making fun of him because of it. Dr. Lavenstein asked to study him via bloodwork every 30 days. He said with one round of bloodwork it would be difficult to see if he had PANDAS or a tic condition. He recommended the whole family be tested for strep.

The following day, we ended up back at the pediatrician's office, and our daughter tested positive for strep with a throat swab but he tested negative. They treated him this time with clindamycin knowing the situation, figuring she had just reinfected him. My husband and I tested positive as well. All four of us were treated with an antibiotic. By the end of the ten days, his eyes were normal again and he was back to being independent. On October 20, both children were re-checked and were strep free. Our doctor did not want to monitor him via routine bloodwork and only wanted to treat him if his symptoms returned. She did not want to put him through bloodwork because when he was ill the first time around, he was terrified of the throat swab and the needle. It took two people to get the throat swab and five people to hold him down and draw his blood due his escalated fears.

We made it over one year with no strep and no vocal or physical tics, and no odd mental issues, but on December 19, 2012, his blinking and uncontrolled eye movement was back, and he was now afraid of being alone again and convinced he was going to die. Again, his sister tested positive for strep the next day, and he tested negative. We saw a new doctor with our pediatric group and she prescribed amoxicillin. When they were both re-checked and still positive, his symptoms continued. She voiced frustration that we were abusing antibiotics and not trying to find out what the underlying cause was. She said just giving him antibiotics wasn't going to fix him. We then insisted on seeing Dr. Dodhi that treated him initially. She put him back on clindamycin on January 5, 2013.

That was our last battle with PANDAS and its grip on our son. Today, our son is an honor student and a high school and travel soccer goal keeper. He has a very bright future.

PANDAS wreaked havoc on our lives and we lived in fear that strep would somehow make its way back into our home only to take away our son again and so much so - that every day for over six years since he has gotten better, I have thanked God for two healthy children. I know that had we seen a different doctor that had never heard of PANDAS, we would likely have had a different outcome as many of the families here have faced and/or are facing. Think of yourself being one of these families fighting this devastating disorder. Imagine this being your son or daughter. Nothing can be worse than seeing your child's health decline and them not get the medical coverage they so desperately need. Please, I beg of you to support these families and their children by fighting for this bill to pass.

I would like to thank you for giving me the opportunity to speak in support of this bill today.