

Hello everyone,

My name is Carrie Lough and this is my husband LaRance, and we are from Wellington Kansas. We are here today to tell you a little bit about what our experience has been raising a child with PANDAS—Pediatric Autoimmune Neuropsychiatric Disorder Associated With Strep.

I can't stand here today and tell you I personally know what it's like to have debilitating motor tics where I have an overwhelming urge that I'm unable to resist to throw my head and neck back a certain number of times until it feels "right" causing bruising and pain up and down my spine. Or snapping my wrists back and forth so hard that I have black and blue rings around them. I don't know what it feels like to have to scream at the top of my lungs during second grade class every few seconds while all my peers stare at me, and teachers openly ridicule me because I am supposed to be able to control my body like everyone else. I can't imagine being unable to stop myself from having overwhelming anxiety everytime my parents leave thinking that they might die or I might never see them again. And speaking of anxiety, I constantly wonder what it would be like to be unable to look someone in the eyes when they speak to me or when I am speaking. How would I feel if I had to hop a certain number of times when I walk or count numbers until I get to the "right one" or end every step on an even number in my head. If I was six years old how could I understand why the teachers were constantly yelling at me and giving me detentions and red sticks for listening to the things my brain was suddenly telling me I had to do. It was just like sneezing, unintentional and also unavoidable. But the teachers said I could stop. Why couldn't I just stop? And tests? Forget about it. Try taking a test while counting the even numbers in your head, blinking every few seconds, tapping the desk every third number in your head all while throwing your head and neck back. These are the realities that my six year old son faced every single day after a bout with strep throat and pneumonia left him forever changed.

I remember the very first time I noticed the change. Mason was six and had just gotten over a very nasty case of strep throat and pneumonia. He was playing outside in the sand (something he had previously loved) when I heard him start screaming and crying. He was upset that there was sand on his hands. From that point on he couldn't stand having his hands dirty. He was also suddenly glued to our sides afraid to go anywhere without us. This little boy had always been so independent and never met a stranger up until this point. It seemed like each day after this there were new symptoms. He was suddenly having terrifying night terrors where his eyes would be open and he would be screaming and talking but there was no way to wake him up. He began wetting the bed which had never been an issue before. And then came the tics. We didn't know that is what they were at the time of course. The first tics we noticed were sniffing and clearing his throat. We kept telling him to get a drink and get a tissue. He finally started crying one day and said "I just can't stop". We took him to our family doctor who couldn't find anything at all wrong. This began our very long journey of trying to find answers. We were referred to a neurologist the first time in Wichita. He told us that it was normal for boys to have tics and he would outgrow it. We asked about all the other symptoms and he said it was probably just a phase and also diagnosed him with migraines. Not to worry he said. We left feeling relieved but in the back of my mind I knew that it was something more. A kid doesn't just change like that overnight do they?

Listening to the doctor, we gave it some time. We watched silently as our baby got worse and worse. He started being oppositional and the tics and OCD kept getting worse and worse. Now I can't tell you how Mason felt but I can tell you as a mother how I felt. I don't know how many of you are parents out there, but as a mother it is my job to protect my children and heal them when they aren't well. It is a soul crushing feeling to watch your tiny child struggle and not be able to take that pain away. So one night after a particularly rough sleepless night due to more night terrors, we decided to ask for another specialist. The

next neurologist thought Mason might be having seizure activity. We had an EEG and many other tests until they eventually ruled that out. Mason was now struggling with school and wearing socks and shoes because they didn't "feel right". He was constantly getting into trouble at school for his "outbursts" which were actually vocal tics. We were so desperate to figure out what was going on with him. We went to see another highly recommended doctor in Wichita. I was watching this doctor watch my son--staring intensely. He went on to do his exam checking his ears, eyes, and throat. All normal. I was staring at my son sitting there happily swinging his legs on the exam table excited to have a break from school ticcing away blinking his eyes and shrugging his shoulders every few minutes. His tics had intensified and he was now also twisting his wrists in a way that left bruises around them. The doctor walked up to my husband after looking at my son, put his arm on his shoulder and said "Go home and find God. Only God can help this child". He proceeded to tell us that our son was possessed. My six year old son over there just smiling, ticcing, and swinging his tiny little legs off the exam table. We left that office in a hurry and never returned. Yet another neurologist we saw after that took one look at my son and said "He has multiple complex mental disorders the most severe being Tourette's Syndrome. Take him home, give him these antipsychotic drugs, and make accommodations with the schools. It is unrealistic to have high expectations for him."

This path continued for years. Searching for doctors and answers. Traveling farther and spending more each time. We saw Neurologists, Developmental Pediatricians, Psychologists, Family Doctors, Ear Nose Throat Doctors and never got any answers. That is until we found Dr. Kobayashi in Omaha Nebraska. It was no easy task getting into see the Dr. We had to fill out several medical timelines, questionnaires, records, and had to wait several months. The first time we saw him it was like a light had come on. He told us about PANDAS and all of the symptoms that went along with this disorder. NINE YEARS had passed by the time we found our miracle. NINE!!! Dr. Kobayashi started trying new treatments such as antibiotics, steroids, and different allergy medications with Mason and they were helping. For the first time ever, something was helping.

About a year later, Dr. Kobayashi informed us of a study with IVIG and thought Mason should apply. We did and we were very lucky to be accepted. We traveled back and forth from Southern Kansas to Omaha Nebraska, a six hour one way trip, every three weeks for six months of IVIG treatment for Mason. The first couple of treatments were rough for Mason making him not feel well and giving him headaches and nausea. But after that ALL of his symptoms disappeared for the rest of the time he was on IVIG. Nine years of symptoms suddenly gone. A couple of months after treatment had ended Mason had a flare up of his symptoms from being sick. It was extremely difficult for him when his motor tics and anxiety returned. At this point he begged us and his doctor for more treatments. Our insurance labeled the treatments as experimental and refused to pay. IVIG is extremely costly and unreachable for most without insurance coverage so we were unable to continue the treatments he needed. It took several months for Mason's flare to subside and at some points we wondered if it ever would. Dr. Kobayashi didn't give up on him though and tried many other treatments to help with Mason's symptoms. Eventually his symptoms leveled out and he noticed that at least eighty percent of his once incapacitating symptoms were gone. That was three years ago. Nearly all of his symptoms have stayed gone. He does still have mild to moderate motor tics that came back but he is healthy and happy now. I am proud to say Mason is a National Merit Scholar, Kansas Governor's Scholar, Kansas Board of Regents Scholar, graduated Suma Cum Laude, and earned a full ride scholarship to Oklahoma State University where he is currently studying biology on a pre-med track.

I want you to know that if we would have had doctors educated on PANS and PANDAS earlier in Mason's life he quite possibly wouldn't have had all of these lifelong symptoms. I want you to know that if he would have been able to continue his IVIG treatments his symptoms could have been gone for good. Despite

every single thing our son has been through, despite the doctors advice on my child being possessed and my child not being able to do much with his life, he has somehow beaten every single odd stacked like a mountain against him. I would never wish this nightmare on any parent or child. We need to do better. Primary doctors, pediatricians, neurologists, and psychologists should all be educated on this disease. There are real treatments out there that help these children. They need to be accessible to children like mine who may still be in the middle of the fire. We were lucky. But not every child and parent is. I shutter to think what our lives might be like if we would have never found our doctor in Omaha or worse listened to some of the uneducated doctors we saw and given up on him.