

March 18,2024

Dear Chairman and member of the House Insurance Committee,

My name is Carrie Lough and my family is from Wellington, Kansas. I would like to let you know 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, uncontrollable urge 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 a black and blue ring 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 every time my parents leave, thinking that they might die or I might never see them again.

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 every sequence of steps on an even number in my head. If I were six years old, how could I understand why the teachers were constantly yelling at me and giving me detentions for listening to what my brain was suddenly telling me I had to do when it felt just like sneezing, unintentional and also unavoidable.

Tests? Forget about it. Do me a favor for one moment. Put yourselves in my sons's shoes. Close your eyes and picture this with me. Try counting by even numbers in your head while blinking every few seconds. Then tap the desk every third number all while throwing your head and neck back every fifteen seconds while taking a timed test. You can't. It's literally impossible. These are the realities that my six-year-old son faced every single day, year after year, 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 suddenly had 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. Crippling anxiety over something different each day. 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 childhood 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 more severe. He would have night terrors every other night.

Now I can't tell you how Mason felt during all of this, 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 helplessly for days—turned into months and months—turned into years. We saw doctor after doctor, specialist after specialist. The very last one we met before Dr. Kobayashi said to us, "Take him home, give him these antipsychotic drugs, and make accommodations with the schools. It is unrealistic to have high expectations for him." The one before that told us he was possessed—a sweet little boy was possessed!

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. NINE YEARS had passed by the time we found our miracle. NINE!!! My child's entire childhood was stolen out from under him. Dr. Kobayashi started trying new treatments with Mason and they were helping. For the first time ever, something was helping. Eventually, when Mason was a sophomore in high school, we were chosen to participate in an IVIG study for six IVIG treatments.

ALL of his symptoms disappeared the whole time he was on IVIG. Nine years of symptoms suddenly gone. I have attached the medical journal with positive findings in favor of ivig treatment for PANS/PANDAS that my son participated in for your review. A couple of months after treatment had ended Mason had a flare up of his symptoms from being sick (getting a normal every day virus that triggered his autoimmune symptoms to return). 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 costly so we were unable to continue the treatments he needed. It took several months for Mason's flare to somewhat subside. 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 seven years ago. Most of his debilitating 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 so extremely proud to say Mason went on to become a National Merit Scholar, Kansas Governor's Scholar, Kansas Board of Regents Scholar, graduated Summa Cum Laude, and earned a full ride scholarship to Oklahoma State University where he is currently graduating in May with his degree in zoology/ecology. He has been invited as a teaching assistant to continue on at Oklahoma State to get his Master's degree in his field, and is looking forward to continuing on towards his PHD.

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 lifelong symptoms. I want you to know that if he would have been able to continue his IVIG treatments his symptoms also could quite possibly be gone for good. Despite every single thing our son has been through, despite the doctor's 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. The State of Kansas needs 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. Many other autoimmune diseases use IVIG treatments, so what we are asking for is not at all outlandish and should be approved. Insurance companies should be held responsible for not allowing these tiny warriors to receive the medical treatments that have been proven effective to treat them. They need to be accessible to children like mine who may still be in the middle of the fire. We were fortunate to finally find an educated doctor and to be accepted into a life-changing study. But not every child and parent are. I shudder 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. Where would Mason be right now? Mason's ENTIRE childhood was stolen by this disease. Please don't let other Kansas Children see the same fate that my son had to experience.

Thank you,

Larance and Carrie Lough

Proud parents of a PANDAS warrior