

Please Support House Bill 2390

My name is Maralee Wernz and I am an Oregon registered voter asking you to support House Bill 2390, to ensure insurance parity for Oregon children with PANDAS/PANS. My niece, a wonderful, smart, and spirited 11-year-old has only recently been formally diagnosed by a physician with PANDAS, a set of neuroimmune disorders resulting from infection (often from the very common streptococcus) which affects the basal ganglia region of the brain. These disorders can manifest themselves in psychological and neurological symptoms including but not limited to OCD, severe anxiety, sensory issues, tics, involuntary eating restrictions, rage and seemingly irrational behavior, urinary issues, sleep disturbances, and suicidal ideation.

In 2013, my sister and her husband began noticing my niece, age 4, developing atypical behavior for her age and for the personality they had come to know and love. She began exhibiting moments of extreme anxiety stemming from "minor" triggers such as transitioning between activities, leaving the house, or simply being asked to make a decision about a snack. She would worry excessive durations prior to any kind of outing, whether it be to the grocery store, museum, or visiting family. She began to show sensitivities to walking barefoot throughout the house due to changes of floor texture or the feel of some small piece of leaf or needle on her foot. An extreme sensitivity she developed was to any louder type of noise - whether it be a telephone ringing, a soundtrack on a movie, or people laughing and talking at the dinner table or in restaurants, for example, often to the point of covering her ears with her hands and bringing her to tears. She often lost her appetite and would lose weight rapidly. Anger and irrational responses would erupt at what would be considered the most unlikely triggers, such as conveying to her that it was time to ready for bed. She would have nightmares and daytime fears of her entire family being killed somehow, and her thoughts would dwell on this unbeknownst to anyone until she either woke up screaming or simply burst out crying.

Her parents had to pull her out of preschool because the teachers and staff could not manage these many disorders, and always attributed it to behavioral issues that would require psychiatric help. My sister had to leave her career to home school my niece as a result. Luckily, my sister has the intellectual and academic ability to dig into the root of the problem. She knew, inherently, that this child she saw changing before her eyes was not the child they had known for years prior. She also knew that the kind of changes she was seeing were completely out of sync with the type of nurturing home environment they had. Simply put, there was no correlation between the perceived behaviors and the family dynamic that had been established. My sister began to research and dove in headlong. Early on in their journey, she believed my niece to have either PANDAS or PANS, but no insurance would cover delving into it further, so she was left to her own devices of research and intelligence to find solutions to PANDAS/PANS to help my niece combat this "bully brain" as they call it. For 8 years my sister and my niece combatted this together - my niece having faith in Mom being mom and trusting that Mom's intelligence and perseverance would only help, not hurt. It was a challenging road for both. They worked together to identify potential triggers and my

niece often had to “check out” of family gatherings as a coping mechanism. This was, in truth, all too much for such a young person to have to tackle and come to terms with, but as I said before, she is wonderful, smart, and spirited.

It wasn't until this last fall, 2020, that my sister finally found a physician willing to look into the issue with her. Just prior to the appointment, my niece contracted a germ and had a major flare-up resulting in an almost fear-based resistance to eating, resulting in a huge weight loss, frightening everyone. My niece was diagnosed with PANDAS. My sister and her husband, and indeed the entire family, was relieved. Not just because my niece could now actually receive some type of structured treatment, but because my sister now knew that her time and energy paid off, that she had someone that now had her back. The looming consideration, however, is whether financially there might be some relief to address cost if states can recognize it as disorder under insurance codes.

Since the diagnosis and starting medical treatment, my niece has come full circle. My sister and her husband say that they have that pattern of behavior and personality that went missing when my niece was 4 years old. Her coping and decision-making have rebounded, her anxiety has decreased. What would likely have been misdiagnosed, and thus medically mistreated, as ADD, ADHD, or behavior/psychiatric issues, has been properly diagnosed and is being successfully treated.

Not every family has the resources that my sister had to be able to research on their own, spend the money on not only best-guess/researched treatments, much less the cost of formal testing and western medicine treatments. If caught early, the costs can be minimal because the impacts to the brain may be lessened. But if left too long, sometimes the brain cannot recover and the disorder symptoms become ingrained in daily life and may lead to more drastic behavior and issues. We need to have the insurance codes so that families can stop guessing - stop grasping at straws - get answers - and so that they can feel empowered to find doctors who can approach a correct diagnosis and treatment. The fact that this disorder affects children at their foremost developmental years should be alarming enough in and of itself to urge insurance coverage. Eight other states have passed legislation already ensuring that children in their state have access to this care. PANDAS/PANS affects 1 in 200 children, which is more than 4,000 children in Oregon alone. This is a frequency that we cannot afford to ignore. We need your support for these children.

Thank you for taking the time to read one family's story and consider supporting House Bill 2390.

Sincerely,

Maralee Wernz
(Auntie Maralee)