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Ohio Health Committee

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On January 9th, 2018, I drove our 11-year-old daughter, Lily, to Columbus, OH, from our home in Cincinnati. Lily did NOT want to go; she'd been up half the night feeling sick to her stomach and insisted the trip would be miserable. I pleaded with her, and reminded her that getting her to a specialist was vital to helping her recover... After much coaxing, she finally agreed to make the trip. I bundled her up with her stuffed unicorn and her American Girl doll, and we got on the road, only 50 minutes late. The first hour on I-71 N was quiet - Lily sat in the back seat and gave me a thumbs-up in the rear-view mirror when I asked how she was doing.

But about halfway to Columbus, things changed.

Lily was fighting to control her anxiety, taking deep breaths with her eyes closed, clenching and unclenching her fists, using all the tools she'd been taught in years of therapy. It was clearly a losing battle, however, and it wasn't long before she'd unbuckled her seat belt and tried to climb between the front seats, begging me to turn the car around and take her home NOW. Thankfully, I'd learned to put the child locks on the doors and windows, because soon Lily was trying to open her car door, grabbing the steering wheel, screaming at me, hitting me, desperate. I began to cry and scream myself, and hoped my anguish would somehow reach that place deep in her core where my beloved child still resided... By the time we pulled into the parking lot of the doctor's office, Lily had shrieked that she wanted to *DIE*, that I did not love her, and that she was going to "punch me to death" when we got home. I was shaking when I called into the office and a staff member quickly arrived to assist me. Suddenly, Lily sat up, climbed from the cargo hold of my SUV, and walked inside, still wearing her hooded owl pajamas. I fought back tears and asked if we could go straight to a room rather than sit in the waiting area... By the time we left there an hour later, Lily had been diagnosed with **PANDAS**; *Pediatric Autoimmune Neuropsychiatric Disorders Associated with Streptococcus*.

This insidious illness destroys everything in its path. It robs children of their childhoods, isolates them from their schools, activities, and friends. It steals their intellect, their education, their independence and their very desire to participate in their own lives. It tears their families apart, it destroys parents' marriages and it ruins careers. Since the age of seven, our smart, spunky, independent Lily had been through hell, her brain and body growing sicker with every infection, every virus, with nothing offered to help her but a useless SSRI and therapy that was quickly voided by the monster that is PANDAS. She suffered from crippling separation anxiety and OCD, verbal and motor tics, blackouts, ADHD, sensory overwhelm, age regression, short-

term memory issues, seizure-like events, horrific intrusive thoughts, hallucinations, impulsivity, irritability, the loss of math and reading skills, and much, much more... After a bout with strep throat had decimated her final month of elementary school, Lily looked forward to beginning fifth grade, and enjoyed a whopping week and a half of attendance with her classmates. Then she developed a 5-day fever, followed closely by walking pneumonia, the straw that broke the camel's back, and the rages and school refusal took over our lives. We made the difficult decision to pull her out, and I quit my job to take care of her.

Lily missed FOUR YEARS of school.

FOUR YEARS of living her young life.

FOUR YEARS of her childhood that she can never get back.

Yet, for our family, after much horror, there is hope. In November of 2020, Lily received her first round of IVIG, a treatment that offered significant benefit to her health and well-being. It may've even saved her life. Since a second round of IVIG last July, Lily has returned to school. She attended football games and the Homecoming Dance. She joined the Improv team. She played her guitar and sang a song that she wrote herself in the Variety Show. She auditioned for and performed in the school musical with her beloved older brother. And best of all, she made new friends, and rejoined the old ones. She is weeks away from completing her freshman year. None of this would have been possible without IVIG... Our family was fortunate enough to carry good health insurance that covered the bulk of Lily's treatment costs, which have now amounted to around \$60,000; more than we paid for our first house.

Many, many families are not so lucky.

The National Institute of Mental Health conservatively estimates that at least **350,00 children in the U.S. alone** suffer from PANS/PANDAS; **1 in 200, or in other words, about 8 students at my son and daughter's school alone**. Most are being misdiagnosed and mistreated; being thrown to the wolves of psychotropic drugs and terrifying psychiatric hospitalization. These kids are falling through the cracks; ignored, abandoned and left to grow critically ill, when prompt, PROPER treatment could rescue them from a lifetime of mental illness and medication, possibly even homelessness and state-dependent care. Ohio bears a responsibility to not only save the lives of children afflicted with this devastating illness (yes, many of them attempt to end their own lives, and heartbreakingly, some have succeeded,) but to salvage the lives of their siblings and parents, as well. *We must mandate that insurance companies fund treatment of these critically ill Ohioans.*

I've often said that having a child with PANS/PANDAS is a lot like having your house on fire... the fire department has arrived, the neighbors have all come running... and everyone can see the flames. But they're all just standing around, watching, as **your life** burns to the ground, and *no one is doing anything.*

Do something. Please.

I implore you to pass House Bill 189.

Thank you for your time,
Jennifer Hurrell