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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. I pleaded, and reminded her that getting 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, 50 minutes late. The first hour on I-71 N was quiet - Lily sat in the back seat and gave me a thumbs-up when I asked how she was.

But halfway to Columbus, things changed. Lily fought to control her anxiety, taking deep breaths with her eyes closed, clenching her fists, using all the tools she'd been taught. 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. Soon, Lily was trying to open her car door (I've learned to put the child locks on the doors and windows,) 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 Integrative Pediatrics, 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 called into the office and a staff member arrived to help. Suddenly, Lily sat up, climbed from the cargo hold of my SUV, and walked inside, still wearing her hooded owl pajamas. Fighting back tears, I asked if we could go straight to a room... By the time we left, 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 desire to participate in life. It tears their families apart, destroys parents' marriages and ruins careers. Our sweet Lily can no longer attend school with her peers, so I had no choice but to quit my job in order to stay home and care for her.

Yet, there is new hope for our family. Just this week, Lily finished her first round of IVIG, a treatment we believe will have a significant benefit to her health and well-being; it might even save her life. We are fortunate enough to carry good insurance that covered the bulk of her treatment costs. Many, many families are not so lucky.

The National Institute of Mental Health estimates that at least 350,000 children in the U.S. suffer from PANS/PANDAS; 1 in 200. These kids are falling through the cracks, abandoned to grow critically ill,

when prompt, proper treatment could rescue them from a lifetime of mental illness, medication, and possibly homelessness and/or 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; some have succeeded,) but the lives of their siblings and parents, as well. *We must mandate that insurance companies fund treatment of these very ill Ohioans.*

Having a child with PANS/PANDAS is like having your house on fire... everyone can see the flames, but they're all just standing around, watching it burn, and *no one is doing anything.*

Do something. Please. I implore you to pass House Bill 488.

Respectfully,
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Justice will not be served until those who are unaffected are as outraged as those who are. - Benjamin Franklin