

Dear legislatures,

I would like to formally address Chair Representative Rachel Prusak, Co-Chairs Representative Andrea Salinas and Representative Cedric Hayden. I am writing in support of HB 2390. We want insurance companies to be required to cover the cost of treatment for Pediatric Autoimmune Neuropsychiatric Disorders Associated with Streptococcal (PANDAS) and Pediatric Acute-onset Neuropsychiatric Syndrome (PANS). These words may not mean much to you now, but please, allow me a few moments of your time and I can show you just how much damage this diagnosis can have on a family.

It's no secret that sickness is one of the worst things a family can go through. For years I watched my little sister suffer with this illness. It tormented us every single day. My sister was unrecognizable. Her childhood snatched away from her. OCD, verbal tics, depression, you name it. Every day life was living Hell for our family. Watching my sister lose a little bit more of herself every day broke my heart in two. The worst part was hearing her cry out that she didn't want to live anymore. I could hear her screaming through the wall between our bedrooms. I silently cried myself to sleep, not wanting to add a bigger burden on my parents. My parents struggled immensely. They weren't the same either. None of us were. I felt so alone. Nobody understood what we were going through. Hope seemed to be lost until we heard of treatment options. My sister's doctor recommended IVIG treatment.

The only catch was that the treatment would cost tens of thousands of dollars. My dad began going back and forth with our insurance company. He was constantly on the phone, trying to figure out how we were going to pay for this. I can remember my mom telling me to take my sister to her room and close the door. My dad had just got off the phone with our insurance company, and he was sobbing. Nobody would help his little girl. My sister would say things like "this is my fault" and "I'm sorry". She took responsibility for my parent's battle with our insurance company. Think about that for a minute. A little girl, very sick, taking on the blame. Taking on the stress we felt trying to find funds to treat her illness. The ONLY thing she should've been worried about is healing. We of course tried to explain to her that it was NOT her fault. But she knew the struggle was because she was sick. Our insurance company added a huge load of stress onto our family. After hearing of our battle with insurance, Friends and family began donating money towards my sister's treatment. Pretty soon, we had sufficient funds to move forward with treatment. Without these donations, my sister would still be very sick. There is no possible way we could have afforded to treat her illness. Insurance did nothing to help my family.

Unfortunately, there are thousands of children who aren't so lucky. Thousands of children go without proper care due to financial struggles. The unfortunate part is insurance companies CAN cover this treatment. It doesn't cost them much. So why aren't they covering it?

I can attest to the fact that this treatment works wonders. I have my little sister back. I remember the days after my sister returned from her second round of treatment. She was loud. Laughing, joking around, talking nonstop. We laughed, and agreed that she was definitely feeling better, because she was back to her loud bubbly self. That was one of the best days ever. She was back. The smiley girl I grew up with was back. My built in best friend was back. There's no better feeling. She still had some fighting left to do, but she was well on the right path to recovery.

I pray every child receives proper care, regardless of their family's financial situation. Please, think of the children. What if it was your child?

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