

**Chairman Lipps, Vice Chair Holmes, Ranking Member Liston and members of the Ohio House Health Care committee:**

My name is Mary Beth Lewis. My son Tommy is 14 years old, and has chronic severe PANS.

At age three Tommy quit eating and drinking entirely for 82 days, and became an entirely different child. He nearly died from Sepsis and Anorexia that year, eventually inserting a tube for feeding. At age three we paid for IVIG treatments out of pocket, two of them, to help him get closer to baseline.

Tom has suffered with this disorder for over 11 years. In this time he has had Hallucinations, suicidal thoughts, raging, severe OCD, intrusive thoughts, oppositional defiance, school refusal, severe separation anxiety, tics, hoarding, anorexia and is most often home bound. Sent away from school in 4th grade we were told he should be admitted to psychiatric hospital.

We have travelled for care to pediatric neurologists, infectious disease doctors, psychologists, psychiatrists, naturopaths, integrative medicine doctors, allergists, homeopaths, chiropractors, Lyme disease specialists, a rheumatologist, an acupuncturist, numerous PANDAS specialists and we were admitted to Mayo Clinic. As you can imagine much of this was not covered by insurance due to the diagnosis. I was forced to give up my career to take care of my son, and we have lived on one income instead of two with a huge burden of medical bills ever since.

Four years ago Tom was so sick he was living in my car (the only safe place) naked under a blanket, using a bucket as a bathroom, hoarding all the wrappers from the fast food he ate because everything in my house was contaminated including me. He had not showered in nearly a year and a half, his hair matted to his head and he refused meds. I dragged him naked and screaming into Dr Kriwinsky's office begging for help. It took us an appeal, a peer to peer conversation and endless phone calls/threats to get IVIG treatment approved through our insurance company who is required by law to pay for treatment.

Tom got his second IVIG treatment in 2018 and has gotten them periodically since, when we can get insurance to cover the cost. Always having to repeat the process of hours of phone calls, and endless denials.

I am happy to report because of these treatments, Tom now lives in my house, showers regularly, eats normally, has minimal rages and can function as a normal teenager.

We are formerly from Chicago and I helped to get the first law of this kind passed in Illinois. I have also resorted to paying a consultant and attorney in Illinois to force my Insurance company to follow the law. BCBS of Illinois has tried instituting policies and finding every loophole in order to not cover treatment. Apparently they prefer to pay for the much more expensive hospital stays.

Unfortunately on January 1 of this year Tommy suffered a stroke in his spine. He's paralyzed from just under his shoulders down. We will never know the exact cause of the clots as all tests were negative (he has a clot in his lung as well,) but the doctors suspect inflammation from PANS. We spent months in the hospital and were forcefully released early from rehab because Tom's PANS issues were keeping him from fulfilling all the requirements. So home now, a mound of new bills and a son that needs even more care, I just found out our insurance is going to change. I am terrified I won't be able to get treatments that keep Tom mentally stable so he has a chance at recovery from his stroke.

My son has lost his entire childhood to this disorder. He has never had a friend. I have given up everything for this loving, sweet, intelligent boy who has done nothing to deserve all that is thrown at him. This legislation doesn't even apply to us as my husband's company is international and the likelihood of insurance being based in Ohio is slim. But if each state were to pass a bill such as this one, our kids (and their parents/siblings) have a chance at living better lives. Thank you for your consideration.

Mary Beth Lewis  
426 N Hambden  
Chardon, Ohio 44024  
216-408-5903