

Chair and Members of the committee. Good afternoon and thank you for the opportunity to testify. I'm here in support of house bill 2390.

My name is Jennifer Matson. I have a 13-year-old son with PANDAS.

My son was diagnosed with PANDAS just after his 12th birthday. After dental work and a simultaneous strep infection in his younger brother, he became acutely obsessive, anxious and depressed. He restricted his eating to what he perceived as "healthy" foods and started exercising compulsively. He refused to look at computer/phone/television screens, because screens were deemed unhealthy. His hands shook. He got out of bed repeatedly to urinate. He only slept 4-5 hours a night. His weight dropped precipitously. He started saying he wanted to die and that our family would be so much happier if we didn't have to deal with him. Eventually he was hospitalized for anorexia nervosa. His heart rate dropped into the 30s at night. While I was acutely concerned about his mental health, I was completely unaware of the dire state of his physical health. It is important to note that prior to this, he did not have a history of any serious mental health issues.

The last night at home before he was hospitalized, he screamed "I want to die" repeatedly. I took my younger son outside for a walk down the street. We could hear him shouting four houses away. I don't know how my family made it through that night. The pain and fear I saw in his eyes haunts me to this day. I begged for him to hold on, promising that I'd figure out what was wrong with him. That it wasn't his fault. PANDAS is debilitating and devastating to families.

After a week in the hospital he spent another eight weeks in a partial hospitalization program. During this time he was unable to attend school.

While he was hospitalized, I gathered as much info as I could about PANDAS. According to some experts, the presence of anorexia is cause to consider more aggressive treatment including IVIG or plasmapheresis. Physicians in the hospital would not consider a PANDAS diagnosis, and could barely tolerate discussing the possibility with me. He didn't have an active infection. Reluctantly he was started on antibiotics and ibuprofen. As soon as he was out of the hospital, his ND started a steroid burst. I sought the counsel of Dr. Kovacovic, a pediatrician in Chicago who treats many children with PANDAS. He recommended a tonsillectomy and potentially a round of IVIG. He plainly explained that classic presentations of PANDAS like tics are annoying, but anorexia can kill you.

After my son regained enough weight to be medically stable, he had his tonsils and adenoid removed. He received IVIG in Chicago approximately three months after his surgery. IVIG treatment was originally denied by my insurance company, despite a letter of medical necessity. However, based on the knowledge that IVIG is a mandated covered treatment in multiple of states my self-insured employer wrote a waiver for coverage at my request. That was almost 1 year ago. It pains me to think about the other children with moderate/severe PANDAS who do not had access to this medication.

Today I have a happy, healthy 13 year old boy with no residual symptoms of PANDAS.

I have a Bachelor of Science in Biomedical Engineering from Boston University and a Master of Public Health from Johns Hopkins University, where I studied epidemiology and health policy. I have worked in clinical trials for 15 of my 20-year professional career. I understand that randomized controlled clinical trials are the gold standard of evidence in the medical community. However, how many more studies are needed before more treatment options can be offered to the most ill children?

My insurance company paid \$34,000 to acutely treat my son in a hospital. They paid \$12,000 for IVIG treatment. In the year since, his total medical care has cost \$1200. I don't understand why any insurance company would risk paying for more hospitalizations to treat symptoms, when there may be a medication to treat the underlying cause of disease.

While I wouldn't wish this experience on anyone, I'm hopeful that through the process of caring for my son, the local medical community has learned from his clinical course, and that the committee will pass this bill. Not every child who has PANDAS needs IVIG or plasmapheresis, but access to those medications/treatments could save their life. This bill will remove the roadblock of insurance denials for the sickest children with PANDAS and empower physicians to make medical decisions based on what is best for their patient.

Background:

Insurance paid the following (contracted rates):

- Hospitalization (1 week): \$12,920
- Partial hospitalization program (8 weeks): \$21,204
- IVIG (drug, MD/surgical center): \$6690, \$2384/\$3453: \$12,527 total

Total medical care since IVIG treatment: \$1250