

Nichole Florkowski
191 Audas Street
North Lewisburg, Ohio 43060
October 12, 2020

Representative Scott Lipps
Health Committee Chair
77 S. High St.
13th Floor
Columbus, Ohio 43215

Dear Representative Scott Lipps:

I am writing you today to urge you to consider passing HB 488, which recognizes October 9th as PANDAS/PANS Awareness Day and requires health plan issuers to cover treatments and services related to Pediatric Autoimmune Neuropsychiatric Disorders Associated with Streptococcal Infections and Pediatric Acute-onset Neuropsychiatric Syndrome.

I'm not just writing for the general population, but for a mother and her daughter who are very dear to my heart. My dear friend Heather and her daughter have been dealing with Pandas for several years. I have witnessed Neveah go from a free spirited, thriving pre-teen to a girl who ticks uncontrollably and wants to hide from the world. She is so anxious at most times that she doesn't even participate in her own family functions. We went to get our nails done about a week ago and she was so excited to go. We were all seated and she started ticking and left the salon extremely embarrassed. She couldn't get her nails done and neither did her mom as she wanted to be sure her daughter was ok. Neveah's mother, Heather has spent thousands of dollars, often maxing out credit cards to provide alternative treatments for her daughter. The passing of HB 488 would allow this family to have access to the proper treatment. This would be lifechanging for this family.

When a child is stricken with PANDAS/PANS, a simple strep infection, influenza, or other typical childhood illness can strike a child with debilitating tics, OCD, anxiety, psychosis, or a myriad of other neuropsychiatric symptoms overnight!

Recently, 8 states across the country have passed legislation requiring insurance coverage of PANDAS/PANS, a newly recognized autoimmune illness that afflicts more than 162,000 in the U.S. alone. Our goal is to heighten public awareness of this potentially devastating pediatric illness, average age of onset being 4-12 years of age, and to ensure that these children are given the opportunity to receive the lifesaving treatments that they so desperately need.

Early treatment within the first year of onset remits the majority of children. Untreated, the child will often struggle with lifelong neurological and psychological problems. Untreated, families will incur financial costs potentially well into the hundreds of thousands - affecting social, medical, educational, family systems, which is why it is so important to require health plan issuers to cover treatments and services for this devastating disease.

We urge you to move HB 488 forward, to require insurance companies to recognize this treatable and curable condition, and so children and families all over Ohio can be set free from this debilitating disease.

Thank you in advance for your consideration.

Sincerely,

Nichole Florkowski

Nichole Florkowski