

Chairman Lipps, Vice Chair Holmes, Ranking Member Boyd,

Thank you so much for allowing me, and later on these families, speak on behalf of House Bill 488, the Ohio PANDAS Act. Put simply, we are coming before you today to try to get legislation passed that would provide insurance coverage for a lesser-known childhood disorder most commonly known as PANDAS-Pediatric Autoimmune Neuropsychiatric Disorders Associated with Streptococcal Infections Or PANS-Pediatric Acute-onset Neuropsychiatric Syndrome. It is currently estimated approximately 13,000 children in Ohio may be affected by these disorders. This estimation is based off of national estimates as the National Institutes of Mental Health estimates that 1 out of every 200 children in America deal with some form of PANS or PANDAS.

PANDAS and PANS onset typically begins between the ages of 3-12, often beginning with a strep infection that triggers a person's antibodies to not only attack the infection, but to also attack the brain. The attack on the brain by these antibodies causes brain inflammation. The result of this is many symptoms including motor tics, obsessive compulsive disorder, severe anxiety, depression (often with suicidal ideation), rages, inability to concentrate, emotional lability, rages and more. Often, the scariest aspect is that the symptoms occur literally overnight to children with PANDAS and PANS. A typical, normal, healthy child will suddenly become physically and emotionally debilitated and unable to function at home and school. These illnesses are also characterized by flares, which are similar to remissions and exacerbations of the illness brought on by infectious triggers. Another autoimmune condition you may relate to is rheumatic fever and how it affects joints. PANDAS and PANS could be described as "rheumatic fever of the brain".

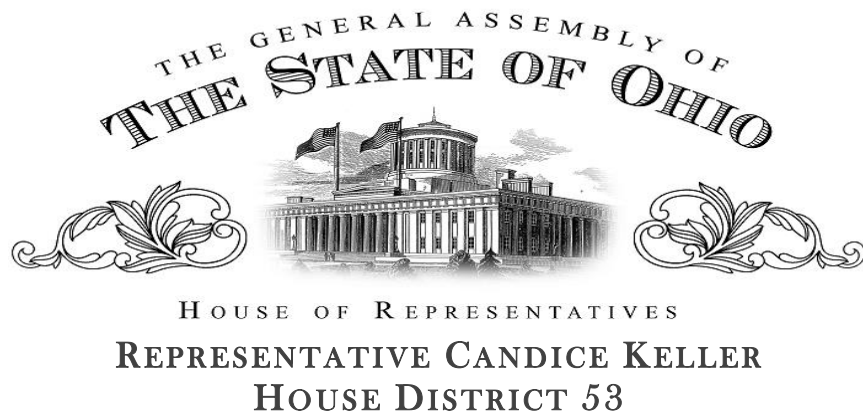
There are multiple medical treatments available for PANDAS and PANS such as antibiotic therapy, the use of ibuprofen, antiviral therapy, which are simple and often effective. However, one of the most effective treatments for PANDAS and PANS is intravenous immune globulin (IVIG). It is often a necessary treatment and recommended by the National Institute of Health for some of the most severe cases of PANDAS. IVIG is not covered by most health insurers for PANDAS and PANS in Ohio. In an NIH study in 2016, IVIG treatment resulted in a greater than 60% success rate and the closest treatment to a cure that is known at this time for PANDAS and PANS.

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PANDAS was first identified at the National Institutes of Mental Health through the work and research of Dr. Susan Swedo in 1998. Yale, Harvard, Stanford all have done multiple studies on PANDAS and PANS. The Journal of Pediatric and Adolescent Psychopharmacology has treatment guidelines for PANDAS and PANS. Just recently, PANDAS/PANS received a code in the latest ICD-10 billing codebook.

However, many families are struggling to get insurance coverage, leading to the second victims in this scenario—the families. Many, if not most times, the hardest struggle is the years and years of misdiagnoses from doctors who refuse to see the underlying cause of their mental health condition. These years of misdiagnoses include time and money spent needlessly as when caught early, PANDAS is a very treatable disease. However, due to this wasted time and money, the child condition's worsens and by the time they receive the correct diagnosis, the treatment needed is pretty intense and very costly. For example, IVIG was mentioned earlier. It has a greater than 60% success rate. However, one treatment can cost approximately \$18,000 and it takes multiple treatments. If it progresses further, the child may be a candidate for Plasma Apheresis—another treatment that you need multiple times which costs approximately \$50,000 each time.

Many of the parents here today will tell you the toll that this disease—this treatable disease—has caused on their families. It's not just about money. It's the time, the doctors who tell you you're "crazy", it's being viewed as a bad parent when your child has a fit in the store even though you nurture and discipline your child to the best of your ability, it's the emotional toll and the sleepless nights.

There are so many more things this syndrome can do to a child and to a family, but the good news is there is a solution. This is a treatable, curable disease especially when screened for and diagnosed early. And we here as the Ohio House have a hand to play in it. HB 488 is the first step by ensuring that insurance companies here in Ohio will cover the screening, diagnosis, and treatment of PANDAS. There are currently seven states that have already took this step to help its families, including our neighbor Indiana, and 15 that are currently in the legislative process.

Additionally, this bill designates Oct. 9th as "PANDAS and PANS Awareness Day" in Ohio, to shed light on this syndrome. As I mentioned earlier, it's estimated around 13,000 children may be suffering from it and not even know. Thank you again for hearing this bill today. I honestly believe this is the very least we owe our families here in Ohio, and I am willing to answer any questions you may have.

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