



HOUSE OF REPRESENTATIVES
REPRESENTATIVE BOB YOUNG
HOUSE DISTRICT 36

Chairman Lipps, Vice Chair Holmes, Ranking Member Russo, and members of the House Health Committee:

First, let me say thank you for the opportunity to speak on behalf of HB 189, the Ohio PANDAS Act. Put simply, we are coming before you today to try and get 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.

PANDAS and PANS onset typically begins between the ages of 3-12, often beginning with a strep infection followed by an acute onset of neuropsychiatric disorders. Simply, the original strep infection trigger's the person's antibodies to not only attack the strep infection but certain parts of the brain and doing so causing inflammation in a still developing child's brain.

The symptoms of inflammations in the brain are quite dire at times. Symptoms may include, but are not limited to: motor tics, obsessive compulsive disorder, severe anxiety, depression (often with suicidal ideation), rages, inability to concentrate, emotional breakdowns, and much more. Often the scariest part of this is the acute onset. In some cases, the onset is within 24 hours. You will have a typical, normal, healthy child suddenly become physically and emotionally unable to function at home or school.

There are multiple treatments currently available ranging from a simple round of antibiotic/ibuprofen medications all the way to intravenous immunoglobulin therapy (IVIG) and/or Plasma Apheresis. If detected and treated early enough, these children can go onto a full recovery and lead a very productive life.

However, as many of the parents you will hear from can attest, getting to the right diagnosis can take years. Thus, families are stuck going down end roads, trying medications and therapies for the symptoms of PANDAS only to have the side effects of those create worse havoc on their bodies and minds. And all the while, the root of the problem is simply growing worse. My belief is the long-term cost is much greater to insurance companies and society having these children go untreated.

Then, once a family can find a doctor knowledgeable in this field, they are then stuck with the next hurdle--cost. Most likely, at this point the disease has most likely has progressed, thus the child is most likely past the point of a simple round of medications. They may have to undergo the IVIG mentioned

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earlier, which now takes multiple costly treatments. I have heard from some fortunate families who have the means to take out mortgages, use up inheritances, use savings, or use their child's college fund on treatments. And some families, they simply do not have those options and they suffer.

While more concrete data needs to be collected, there are estimates there are approximately 1-200 children between the ages of 3-12 can be affected by this disorder. Forty-four states in this country including Ohio have passed awareness resolutions and or filed a request for insurance coverage. Eight states have already passed insurance coverage bills. As legislators, we need to keep Ohio moving forward. Now the current version of the ICD-10 (international classification of diseases) does not recognize pandas, but the new version ICD-11 scheduled to come out in January 2022, in only 8 months does recognized PANDAS. This is huge first step concerning a medical code for insurance billing purposes.

As legislators we are all here to serve and do good work. This is an opportunity to help Ohio children and families. Please do not let Ohio fall behind other states concerning insurance coverage for PANDAS. Also, passing HB 189 will designate Oct. 9th as "PANDAS and PANS Awareness Day" in Ohio to hopefully shed light on this syndrome.

Thank you again for hearing this bill today, and now I'd be willing to answer any questions the committee may have.

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