

Dear Ohio Representatives,

I ask that you pass Ohio HB 189 in support of the children who suffer from PANS / PANDAS, including our son.

Our son is a mature, witty, and adventurous 11-year-old who loves rappelling, cliff jumping, roller coasters, Nerf battles, reading, history, and animals. He's a smart guy who understands intelligent theories but struggles with multiplication tables, constructing a paragraph, and even writing his name legibly. He struggled since preschool with sensory issues, which became behavioral issues, then severe anxiety and depression. The psychiatric community diagnosed him with a mood disorder but struggled to find any medicines that allowed him to function on a day-to-day basis. We discovered several years ago that antibiotics actually improved his ability to function, and soon understood that his behavioral issues have a medical origin of inflammation in his brain due to ongoing infections. Despite improvements at times, each illness he catches can send him right back into crisis mode.

We have been working with doctors for years now to improve my son's quality of life. There are not a lot of doctors with the experience to diagnose and treat PANS and PANDAS. Therefore, many families must seek out specialists who have that expertise, but these specialists are also more expensive. Because there are a lot of infections that can trigger this illness and a lot of systems in the body that are affected, there are often a high number of tests that are ordered, several of which are only done at one lab across the US, which also adds to the costs. Finally, treatment itself can be very expensive and is often not covered by even top-notch private plans. Families who are just trying to support their children's ability to go to school and function in everyday life end up spending more than they have to do so. Even with our insurance coverage, my family has spent well over \$15,000 a year to support my son's health.

While this illness is physically hard on the kids who have it, it is just as damaging that the adults (parents, doctors, teachers) who care for them don't better understand how deeply it affects them. This is not a rare illness as the scientists estimate that as many as 1 in 200 kids may be affected by PANS. But despite the prevalence of this illness, many doctors do not recognize the effects it can have on children's mental and behavioral health, and therefore many children are not diagnosed and treated as quickly as they could be. Our son's PANS diagnosis came 5 years after he first showed symptoms that something was wrong. By passing Ohio HB 189, you not only hold insurance accountable for covering treatment, you also raise the medical community's awareness of the illness so that children receive treatment sooner.

Please vote yes on Ohio HB 189 and help kids get the treatments they need!

Regards,

Jonna and Rob Cartwright