

April 12, 2022

Dear Representative Bob Young and Chairman Lipps,

My name is Jessica Call and I reside in Strongsville with my husband, Bill, and two boys, Luke, 8, and Nate, 6. Not only do I live in Strongsville, but I also work for Strongsville City Schools as an intervention specialist. I have my master's degree in special education with a focus on autism. Given my professional career, I have spent the last 13 years advocating for children. I will now do that for my son and all other children who have PANS/PANDAS.

As you could have guessed, I unfortunately have first-hand experience with PANDAS. My son, Luke, was diagnosed in 2019 just five days before his sixth birthday. It was a day I will never forget. Who was going to support him? What accommodations would he need for school? How were we going to afford treatment? Thankfully at least, unlike many other children, we did not have to spend months waiting for a diagnosis. We dealt with a sudden change in my son beginning in November and a month later he was diagnosed with PANDAS, thanks to Dr. Jan Kriwinsky.

Let me rewind to before his diagnosis. Like many other families, our general pediatrician tried to discourage me from seeing a PANDAS specialist. In my son's previous doctor's visit notes from 2019, he stated, *"we talked alot about his current symptoms and the lack of consistent scientific evidence for PANDAS and treatment. I advised that standard evaluation for these things would be more along the lines of developmental peds and psychology for counseling/coping/behavioral therapy and possibly even eventually medications if needed. Would advise against general PANDAS's only treatment especially if costly since not proven to work."* As not only an intervention specialist, but a mother with a child professionally diagnosed with PANDAS, you can imagine how disheartening that is to read. I mention this not to put down doctors, but to urge the need for awareness of PANDAS. Families and children are suffering. Children are being diagnosed and put on medications that are not helping them overcome this awful, overlooked disease.

Another difficulty that families are faced with is paying for endless appointments and treatments out-of-pocket. I, like many other parents, find it extremely heartbreaking that because my child does not have a common diagnosis, he is limited to resources, doctors and care. My son's first IVIG treatment was covered by insurance and we had to pay \$1,300 out of pocket. Now, since insurance is no longer covering my son, his next treatment will need to pay \$10,300 out of pocket. Given my expertise, in ten years, I firmly believe PANDAS will be no different than an autism diagnosis, especially because of COVID-19. Mental health in youth continues to decline. Maybe we need to discover the "why" and come to determine that illnesses can create tremendous deficits in mental health. Why make children, in 2022, suffer and decrease their opportunity for remission because of a lack of recognition in PANDAS?

My son has changed me – he has changed me for the better. I have learned patience. I have learned to not be judgemental. I have learned that there are good days and bad days. I have learned that my heroes are the parents that are investing their time and money into helping their children when no one else will help them.

We need you to help with this. We need doctors educated. We need families and support services to understand how detrimental this diagnosis is. HB 189 would designate October 9 as PANS/PANDAS awareness day. This would be life changing for many families –our voices would be heard.

I urge you to please look at our stories. Look at our children. Look into their eyes and see they are suffering. We need help. We need awareness. We need medical coverage. We need YOU to support us. Without your support, thousands more children will be swept under the rug and the mental health of youth will continue to decline. You can be the change. You can help support the mental health of not only the children who suffer from PANDAS but also their families. It takes a village and I hope that you will join our village and support our children. I encourage the committee members to support HB 189 and appreciate your consideration.

Be the change we need,

Jessica Call

