

Hello. My name is Rich Wright. I live in Negley, Ohio, which is located in Columbiana County. I want to thank the health committee and Chairman Lipps for giving me a chance to share my family's journey with PANDAS. Also, thank you to Speaker Cupp for this opportunity.

I have been in education for 32 years, as a teacher and a football/wrestling coach. I coached football and wrestling for Beaver Local Schools for 24 years. I spent a few years at Wellsville as football coach and for the last five years I have been a principal and football coach at Southern Local in Salineville. So not only am I a dad, but I have the responsibility of a lot of kids from preschool all the way up through high school.

I am in a unique situation because I have 2 daughters, both of which have been diagnosed with PANDAS. My youngest daughter Jordyn is 14. She has had this illness for 4 years. At age 10 Jordyn was healthy, happy and active in competitive cheer, theater and an honor roll student. 3 weeks after having an occurrence of strep throat we were at a Christmas Banquet. Jordyn was happy. She was helping someone pull tickets for baskets. She was enjoying herself. Without warning she stood up and said she was scared. She had to get home and that we needed to leave. Jordyn became very sick and lost a tremendous amount of weight. She refused to eat. She refused to leave the house. We had to pull her from school. It took 10 months and 4 different hospitals to finally get her diagnosed with PANDAS. Jordyn was lucky. After a month of being on antibiotics she recovered. 4 years later she still takes antibiotics and supplements, and she is doing great.

The story of my oldest daughter Lexi is quite different. 2 years ago Lexi was 14 at the time and was diagnosed with strep throat 2 times within 6 months. She too had been a very active kid. She loves volleyball, theater and was an honor roll student.

Not long after her second occurrence with strep throat, her personality changed just as quickly as my other daughter Jordyn's had changed. With Lexi however our worlds were about to be flipped upside down. The change was not only abrupt but frightening. She was scared all the time and refused to go to school. She wouldn't leave the house. She would hide under blankets or in closets. She had rages and turned our home into a war zone. She broke pictures and would hit and scream. It was literally as if someone stole my child overnight. She became immature, couldn't write or do school work. She had OCD so badly it controlled everyone's lives. I honestly thought she developed some form of mental illness.

My wife and my youngest daughter Jordyn were terrified to be home alone with Lexi. My wife would call me in tears begging me to get home as soon as I could, because Lexi was raging. She would scream for hours on end. She would curl up in a ball and beg us to help her. She told us her head felt like it was going to explode and she wanted to die.

We took her to the same doctor that Jordyn goes to for PANDAS. Jordyn's symptoms were different from Lexi's, so I was unsure if he could help. After months of antibiotics and with only slight improvement her doctor said she needed to have a treatment called IVIG. This procedure has had great success in helping kids with PANDAS recover. We were desperate and willing to do whatever it took to get her well. Unfortunately, the insurance company denied her treatment. We couldn't understand how there is a treatment that has been proven to help these kids but insurance can deny it. It took months and months of fighting with our insurance company to finally get it approved. Months of living with symptoms that could have been alleviated with IVIG. Honestly, had we not caught a HIPPA violation on their end, we would still have been fighting.

Lexi has now had two IVIG treatments. The improvements she made were remarkable. She lettered in volleyball as a freshman and is back on the honor roll. It is amazing to me how this treatment turned our lives around. If you would have told me 2 years ago, a time when Lexi screamed in pain, begged for help, had rages and many other symptoms, that she would be back in school and letter in volleyball I wouldn't have believed it. IVIG has improved her life tremendously and it is a tragedy that it is withheld from so many children because insurance companies find ways to deny treatment.

Unfortunately, Lexi has had a set-back and her symptoms have crept back in. She was due to have a 3rd IVIG in April but the insurance has denied her treatment, even though we proved that it helped her and renewed her health and she returned to school and all other activities. Because of this denial that we have been fighting for months, Lexi is now 1 year past her last IVIG and she is continuing to decline. She cries because she knows it is getting worse and she is scared. She says that doesn't want to live like this. I worry about suicide because the fear these kids live with and the inflammation it causes in their brain causes so many terrible symptoms, but our family simply does not have the money to pay out of pocket for these treatments.

As a dad it is my job to protect my children and help to keep them safe. I did all of the right things to prepare for this role in life. I went to college and became a teacher, a coach and now an administrator in an elementary school. However, none of that can fix my child. IVIG can fix her but my insurance won't pay for it even with our communication and appeals. I don't understand how I can make the right choices and yet my daughter is being pushed aside. My fear is that the longer she goes without the appropriate treatment, the more damage that is being done to her brain...damage that may become permanent and lead to mental illness, and difficulty with short-term memory. She was a healthy child and PANDAS changed that. IVIG brought her to baseline, but now she is basically being told that she can no longer have that normalcy of life.

As a principal this also concerns me. I fear that PANDAS and PANS are creating mental illnesses in our children. Left untreated, these children will become mentally ill adults. The burden on our state and society will become problematic because of the unpredictable nature of mental illness. I can tell you from experience, had my daughter gone untreated, the only thing left in her future was to be hospitalized. The cost of a lengthy hospital stay and long term care would have been extremely higher than the cost of IVIG treatments.

My family is losing hope. I don't know how much longer Lexi's brain can endure the inflammation that PANDAS creates. It certainly makes me wonder how many adults have been diagnosed with a mental illness, when in reality their brain is under attack just like my daughter's. How many could be helped if they had the proper medical treatment? This illness is NOT going away. In fact, since my daughter was diagnosed I know of 6 more children in my county that now have this illness. 2 of which are in my school where I work.

If PANDAS and PANS are not treated properly, they will continue to cause a growing financial, educational, socioemotional, and societal burden as these children grow up to become adults. We have to do something NOW to ensure these kids get the help that they need. I am concerned as a dad and as an education administrator what our future will look like if swift intervention is not put into place.

I want you to stop and think about your children...or maybe you have grandchildren. I have no doubt that at some time in your life, you will either know someone that has a child with PANDAS or PANS, or you may be touched by this illness in a personal way. It might be your child or grandchild. It might be a friend's child or grandchild, but somewhere down the line you are going to come across a family that suffers just like my family does.

I want to thank you for your time and for listening to the personal stories you have heard today. It is my hope that you vote in favor of house bill 488 to ensure that the children of the state of Ohio are cared for and receive the medical treatment needed to become contributing citizens to our state and not a burden to society.

Thank you, I will now accept any questions that you may have.