

Hello,

I would like to support medical coverage for PANDAS in Ohio. My daughter Ava exhibited her first symptoms when she was 4 years old. The year of 2016. She woke up one day with extreme anxiety and OCD. She complained of her brain being hot and her body on fire. My daughter started rituals that were debilitating and consumed her. I searched the internet just researching what this could be. I ran across something called PANS which then led me to find PANDAS. I knew immediately that PANDAS was exactly what my daughter had. Her pediatrician had heard nothing about PANDAS but did offer antibiotics after a blood test showing strep in her bloodstream. It took 9 months to get her into Nationwide Children's Hospital in Columbus. I would call crying because my daughter was wiping her privates until she was bleeding. She had severe separation anxiety when I was work. The Dr at Nationwide had us see a neurologist to rule out anything in the brain. Neurologists apparently do not believe in PANDAS because they claim there is no scientific evidence. My daughter was put on Zoloft and sent home. The Zoloft did not do anything good for her and she was on it for 5 weeks. It made her anxiety worse and she couldn't sleep. She literally was crawling out of her skin and having panic attacks at the age of 4-5ish. We stopped the meds and stopped going to Nationwide after a few years because she was getting no help. Her pediatrician ended up putting her on Prozac which seemed to help a bit. I searched and searched for a new Dr educated on PANDAS. I took her to numerous psychiatrists but they offered little help. Everything I did for my daughter I researched and used trial and error just to get her to be able to function daily. About a year ago I found Dr. Kawinski in Beachwood Ohio. He put her on numerous rounds of antibiotics to see if they'd help. He finally suggested IVIG. I fought with my insurance for months to get it covered. I appealed the denials twice. Then one day I got a call saying they approved it. My daughter had the IVIG done in Oct 2021. I found out that month my insurance was dropping her Dr in April. She didn't even get the follow up covered and we now have to pay for visits out of pocket. The insurance company blamed the Dr. The Dr had a lawsuit with the insurance company (medical mutual) due to them refusing to cover treatment for kids with PANDAS. As of right now there are few Dr's in Ohio that are educated on PANDAS and the one I have will now cost me out of pocket. It is sickening how a child can be refused treatment due to insurance. These kids suffer. My daughter suffers. This is a summed up version of a painful 5 year journey. Thank you for advocating.

Sonya Larick