

I am a mother of three girls. I am also a certified registered nurse anesthetist. My daughter Aurora was a normal healthy happy child until following a severe respiratory infection in February 2020. At that time she was so sick she ate no solid food for 8 days and missed 10 days of school. Several times my husband and I worried that Aurora would need to be hospitalized. However, with time she did recover. Shortly following her recovery we were all presented with a terrible new challenge-Covid-19. It started with a lot of hand washing. Which we initially did not think too much of since everyone was scared of this new virus that we didn't know much about. It quickly became obvious that something else was very wrong. Aurora would walk through our hallway and tap the door frame three times as she would walk by. It was a harmless thing so when we first noticed it we didn't say anything about it. But with in a few weeks the harmless taping progressed to walking all the way around the island 3 times in the kitchen before she would enter the next room, turning the light switch on and then off again if I switched it off as she was following me out of a room, and periods of uncontrolled emotions. Aurora began to have terrible night terrors

, and she would have so much fear about going to sleep which had never been a problem that it would take hours to get her to go to sleep. She would sleep next to me and have to hold my hand in order to fall sleep. As we began doing school work remotely we notice Aurora would put down and pick up a pencil seven times before she would begin to write. You can imagine how disruptive this was, especially as she was taking timed math fact tests. Aurora also suffered food restriction which means 80 % of what was on her plate at the start of a meal ended up on the floor. One day I specifically asked her why she was tapping the door frame when she walked by. Aurora told me that her brain was telling her that if she didn't do it she would be cursed. At that Confession I was freaked out. So I

took to the internet and became more educated about OCD. Eventually my reading and research lead me to a pandas/pans website. I thought oh my gosh. I think this is it. We are very lucky that a pediatrician knowledgeable about PANDAS was close in nearby Beachwood. He is the only one of five doctors on the pandas network website in Ohio who takes insurance. Aurora was subsequently diagnosed by Dr. Jan Kriwinsky as having PANS. He started Aurora on an antibiotic and over several months she improved. Her OCD symptoms, the tapping and repetitive picking up and putting down of the pencil were the first to go. After several months her food restriction improved. Aurora continued to have anxiety that caused difficulty concentrating. But we were happy for the improvement. However within a few months Aurora developed a small infection at her earring site (please remember she was taking an antibiotic two times a day at that time.). Almost over night She deteriorated, and the progress that had taken months to gain was gone! The OCD was back along with her rages. We called Dr. Kriwinsky and it took 2 full weeks for her to recover from this flare as he said. At her next visit with Doctor Kriwinsky he explained that Aurora having an infection while on antibiotics that cause such a severe flare told him that she was dependent on the antibiotic and would need to have IVIG. That day we began the process for approval of IVIG. In August 2021 Aurora underwent the two day treatment. This requires placement of an IV catheter two days in a row followed by four hours for the immunoglobulin to infuse. It was very difficult on her and our family. I was so worried that Aurora would be the child to have a severe complication like anaphylaxis. Aside from that imagine trying to explain this and doing all this with a child suffering with severe anxiety issues. The stress of it for her was terrible. The evening of her first treatment Aurora developed a very severe headache and vomiting. I remember how ill she was and looking into my husband's eyes and saying oh my god what

have we done to our child. Fortunately after several phone calls with doctor kriwinsky we gave her some anti nausea medication and an extra dose of steroid and she got better. After about the first week we again saw improvement. Unfortunately it only lasted about three weeks. Then her symptoms began to return. Not as severe and she was still on daily antibiotics. We eventually tried ibuprofen three times a day and then switched antibiotics. Aurora eventually underwent two more IVIG treatments back to back 4 weeks apart December 2021 and Jan 2022. Following her two IVIG treatments Aurora was 90% back to baseline. We were thrilled. She was able to go to school and function normally. Currently Aurora is about 60% back to baseline. Unfortunately April 1 2022 medical mutual made Dr Kriwinsky Aurora's doctor out of network. In January of this year since we had not paid any of our deductible the full amount of her treatment. Our plan is that after the \$6,000 deductible and then 90 percent was covered and we had to pay the other 10%. I am a healthcare worker, and my daughter's previously cover and approved medical treatment is no longer covered. If Aurora had diabetes or cancer her care would be covered. IVIG is a treatment that is used for other medical conditions such as myasthenia gravis. Aurora's PANS is a prior medical condition under the same insurance company and is now no longer covered! This is an atrocity! I do not know what to tell my daughter who cries because she is afraid she will never get better. This is not okay. We need to stop allowing insurance companies to dictate medical care. We need to be a voice for children like Aurora who are suffering. Please support HB 189 for the children in Ohio. Aurora is only one of many children who are suffering.