November 2020

Dear Speaker of the House, House of Representatives, and Health Committee Representatives:

This is our PANS/PANDAS story. We live in Cedarville, Ohio. My 12 year old daughter Audrey's struggle with P/P is fairly recent within the past year. At Christmas time last year, we had a bout of flu that 3 of my 4 daughters went through. Each of them had Tamiflu. Everyone else recovered ok, but Audrey did not. She not only slept A LOT, like 20 hours a day for 5-7 days, but when she was awake, she was very despondent and her behavior was very defiant and mocking. She's always been a respectful, fun-loving, social child, so this was out of the ordinary for her. At first, we thought it was side effects from Tamiflu. But after Tamiflu and not fully recovered, she was seen by a family physician's assistant in NC while visiting family and she had a bronchitis-type infection. She was not positive for strep at this time, but was given azithromycin (Zpack) and she was more like herself after this now-identified FLARE of P/P symptoms.

She was fine until February, when she came home after school one day and shared how she was beginning to feel "strange" like she did at Christmas time when she had the flu. We immediately took her to our family practitioner locally and she tested positive for strep immediately. Our doctor here gave her an amoxicillin prescription. This episode FLARE was similar and different in the way it affected my daughter. She was not only despondent and withdrawn, but this time, experienced terrible separation anxiety (never leaving my side, and even following me to the bathroom). She also did not want to see or talk to friends or return to school. Audrey could only work on just a few assignments as it was very difficult for her to concentrate and focus while in a flare. Audrey normally slept soundly, but during this flare, she would wake up with terrifying nightmares and would call out for me.After 7 of 10 days on the amoxicillin she was prescribed for strep, her behavior slowly began to return to normal. By this point, my husband and I did more research and God connected us to other PANS/PANDAS parents/families. When we tried to see our family doctor about Audrey for follow up, she could only refer us to a psychologist because there was no medically recognized diagnostic code. And hearing from other families' experiences, we were encouraged to go straight to a specialist rather than go through a non-specialist psychologist. We were then directed to see a leading functional/integrative medicine practice in Columbus (Sancta Familia). They tested Audrey for very specific markers in her bloodwork and was formally diagnosed with PANS (which also includes PANDAS for Audrey). Because our specialist is out of network, we've had to pay several thousands of dollars out-of-pocket, self-pay (which includes doctor visits and supplements). Our insurance only covered some of the lab work and prescribed prophylactic antibiotics, but denied personally submitted claims for supplements which have been helping to keep my daughter in remission. I truly believe that Audrey has currently been in remission since her last flare in February because of early intervention. The out-of-pocket cost is a heavy burden, and would be a lot more if we didn't go directly to a P/P specialist and started Audrey on a good treatment regimen. Awareness and recognition by the medical community and access to proper medical care would be extremely helpful in easing the pain and suffering our PANS/PANDAS children and families go through in navigating this auto-immune illness.

Thank you to the Speaker of the House, House of Representatives and Health committee representatives for taking the time to listen/read our story. Passing HB#488 will make a tremendous impact on ours and thousands of families who struggle with PANS/PANDAS.

Sincerely,

Esther Shephard