

My daughter, Leah, who is now 17, was diagnosed with PANDAS in December 2020. This was after a journey of many months of counseling for her with no progress in overcoming her symptoms and the symptoms only becoming progressively worse. Her symptoms started around January of 2020. She started with extreme anger, anxiety, and some OCD symptoms. She started to become concerned with being clean and things becoming contaminated. She was also always checking to make sure doors were locked. Her hands started becoming chapped from the amount of time she spent washing them. In summer of 2020 she also added a new symptom of urinary frequency and urgency. She started seeing a new counselor in September 2020 as we thought perhaps another counselor might be better at helping with her symptoms. After a couple months with nothing improving and her episodes of rage, anxiety, and OCD becoming worse, the counselor suggested it could possibly be related to PANDAS. After seeing Leah's PCP, she referred us to a rheumatologist. The rheumatologist ran several tests, and did not find anything definitive. I found a PANDAS specific doctor, Dr. Kriwinsky, to get his opinion. He immediately diagnosed PANDAS and started her on antibiotics. Some of her symptoms slightly decreased, but not much. In April of 2021, her OCD symptoms exploded and left her debilitated. Her contamination OCD became so bad that she could not leave our home, only go in 2 rooms of our house, eat packaged food, and take showers that were 2-3 hours long. She missed out on many family events, including her sister's high school graduation. Starting an antidepressant helped some, but not much. She was unable to finish the last couple weeks of school, but thankfully had done well enough throughout the year that her teachers allowed her to still pass her classes and complete her grade.

In the beginning of July 2021, Leah was approved for one IVIG treatment only after Dr. Kriwinsky did a peer to peer review with our insurance company. She received the IVIG infusion over 2 days. Ten days after her IVIG treatment, she began to get real food for herself and eat at the dinner table with us, something that she had been unable to do for months. She also picked up her clarinet and was able to attend band camp. She had left her clarinet untouched for months, due to her contamination OCD telling her that the clarinet was "dirty". This treatment was nothing short of a miracle for bringing our daughter from a debilitated teenager to a healthy, functioning one. It is my hope that insurance companies will make the process of paying for PANDAS treatment universally accepted, and get these kids the treatment they need.