

The Schmitt family of Chester County, PA; Buck and Dawn and their daughter Kiley have used their struggles with an autoimmune syndrome known as PANS to spread awareness. The medical community has a difficult time acknowledging PANS due to its complexity in nature. Every child experience is different and it presents as a psychological disorder when it is actually neurological.

Answered prayers came on February 6, 2019; the winter of her 6th grade year, Kiley was diagnosed with PANS. PANS is the acronym for Pediatric Acute-onset Neuropsychiatric Syndrome. According to the Stanford PANS Program, "the cause of PANS is unknown in most cases but is thought to be triggered by infections, metabolic disturbances, and other inflammatory reactions."

PANDAS, short for Pediatric Autoimmune Neuropsychiatric Disorders Associated with Streptococcal Infections, is a subgroup of PANS, and is believed to occur when strep triggers a misdirected immune response attacking the child's brain.

Children, like Kiley, can experience a range of mental health symptoms including, anxiety, intrusive thoughts, rage, Sensory Processing Disorder, Obsessive-Compulsive Disorder symptoms and more.

Healthcare institutions like Al Dupont, Stanford and Mass General have doctors who research and treat PANS/PANDAS, but they are not universally accepted diagnoses and often not covered by insurance.

Although it was scary getting a diagnosis of something so controversial, it was a relief to know there were answers and we could help her. In February Kiley's new doctor prescribed her 5 days on a high dose of an anti-inflammatory drug along with an antibiotic, and Kiley quickly felt the difference.

Today, January 2020, Kiley is about 85-90% recovered. Our family, along with another local family struggling with PANS, launched a social media challenge #pieforPANS. October 9th was PANS Awareness Day and our families felt we needed to do something to spread awareness and raise money for research.

Kiley said, "I wanted to do this so other kids don't have to suffer like I did. So it doesn't take so long for doctors to believe this is real so kids can get help."

The 'Pie for Pans' challenge raised \$50K in one month for the PANDAS Network. They are dedicated to improving the diagnosis and treatment of children with PANDAS and PANS. Although the challenge didn't catch the attention of Ellen DeGeneres as the kids hoped, it did catch the attention of local media ABC news, and our families were

featured in a segment in November! The funds raised will go to Georgetown to research for tonsil adenoid immune marker analysis. They believe sometimes the tonsil tissues is driving some of the inflammation to the brain. Knowing this will help get surgery more available and or create more targeted antibiotics or immune therapy.

Kiley has great improved academically and medically this year. She no longer needs the classroom support as she did in the past, her SPD has dramatically improved, and most of her watching her shine her light and smile and just be a kid again is the biggest answered prayer.