

November 6, 2020

My name is Erin Keil and I am from Washington Township in Montgomery County, just south of Dayton. First, I want to say thank you to the Ohio House of Representatives Health Committee for giving families like mine a chance to share their story.

Our now 9 year old son was officially diagnosed in May 2019 with PANDAS. In April of 2019, our son Jack, became of shell of himself and was suddenly crippled by severe anxiety and OCD. He literally went to school one morning as a typical 1st grader and by that night he was a child we didn't even recognize. Jack had severe sensory meltdowns, anxiety attacks, constant OCD behavior, headaches and severe separation anxiety. He could no longer cope with the real world, at home or at school. His extremely sweet teacher tried her best to help him, but we quickly realized that he could no longer handle a typical public school classroom. He made several attempts to escape the school playground and we knew he couldn't stay safe there. We were terrified! Our child who had scored in the 98th and 99th percentile in reading and math in the fall of 2018 and who had just come home with an almost perfect 3rd quarter report card, could now no longer cope in a 1st grade classroom with his peers. We rapidly moved to home instruction for him with the help of his teacher and school. After dealing with his symptoms for several days, we thankfully got a pending diagnosis of PANDAS from his pediatrician through blood testing. We then quickly sought out the treatment from a PANDAS specialist.

The doctor who officially diagnosed him, put him on long term antibiotics, but after trying for several months, realized that we needed a more involved treatment plan for him. Some of his most severe symptoms seemed to improve over the summer of 2019 but he was not back to where he had been before April. His doctor prescribed IVIG at the end of July 2019. The doctor immediately submitted a preauthorization into the insurance we have through my husband's employer. The insurance company took until mid-September to officially send their denial for preapproval for IVIG. We quickly appealed their decision. We were denied an expedited review so we were forced to wait the typical 90 day period. The day after Christmas, we received a packet of information stating that our appeal had been denied and that it was not medically necessary for our child. Later that same week, we had a follow up appointment with our son's doctor. At this point, my husband and I agreed that we would use our savings and pay the over \$6,800 bill for IVIG out of pocket, in hopes of getting our son closer to his pre April condition. We couldn't continue to watch him decline while we waited for the results of the next level of appeal with our insurance.

In the midst of the appeal with our insurance company, Jack lost out on his 2nd grade school experience. He started the school year in a typical 2nd grade classroom on a 504 plan but about two weeks into the school year, he got sick with a normal respiratory virus. Because of this virus and other factors, many of the symptoms that had been resolved over the summer returned. We yet again made the decision that the public school setting was not what he needed at that time. We are still currently home schooling because his immune system, brain and mental health cannot handle public school at this time.

The exact day when this bill was formally introduced back in January, we were sitting in Cleveland with our son, who was attached to an IV machine receiving IVIG. With his extreme anxiety we were not sure

if we could even get the IVIG accomplished. Thankfully, he successfully finished this IVIG treatment on January 30th.

After months of fighting our insurance company, in April of this year, we received word that our final appeal with our insurance company was successful. The physician who reviewed our outside appeal agreed that IVIG treatment was medically necessary for him, based on the successful results of his first treatment. We not only received a pre authorization for future treatments but we got a back payment for the treatment that we had paid out of pocket for in January.

This news came at just the right time because Jack's health was starting to get worse again. He had made some major gains with his first treatment but we had also been informed by his doctor from the beginning that he could need more than one treatment for lasting healing. At the beginning of July of this year, Jack had another treatment in Cleveland with his specialist. That treatment brought Jack back to a place of health that we had not seen since the onset of his illness in April 2019. He is now able to complete most grade level school work via homeschooling and he is much happier in general. He is back to doing more of the things he loves, like studying history, geography and politics! We know without a doubt that these IV treatments are truly helping heal our child. As we approach the 5 months mark since his last treatment, we are fully aware that he could need another treatment in the near future. Without insurance coverage we would not be able to continue to afford these treatments for him. We had the funds saved to pay for one treatment out of pocket but now knowing that he will need additional treatments for true healing, paying out of pocket would no longer be an option.

When you have a child with a severe medical problem, the last thing you want to deal with is worrying about how you will pay for the treatment your child so desperately needs. We spent countless hours, which could have been spent caring for our children, contacting our insurance company and preparing information for our appeal.

Before Jack's onset of PANDAS, I was volunteering in my community, spending time helping at my childrens' schools, substitute teaching, and hoping to return to work at least part time. All of that has been put on hold while we focus on healing our child. Our 6 year old daughter has missed out on so much because we are often confined to our home due to her brother's health.

I am asking that you to support this bill. Ohio is truly a family friendly state, which is why our family has continued to live here. Ohio families deserve to have the right health care options for their children. We were fortunate to win our insurance battle but so many others in Ohio are not as fortunate. I truly believe that Ohio can do better for our children. Treatment for this terrible disease should not come down to whether or not a family has the money to pay out of pocket for treatments or the time and the ability to fight insurance companies for months on end. Our story, just like so many of the other stories you will continue to hear, is still being written. You have the chance to change the lives of the children and families of our great state who are facing this devastating illness.

Thank you so much for taking the time to read my story,

Erin Keil