

House Bill 189 Proponent Statement
Ohio House Health Committee
May 10, 2022

Chairman Lipps, Vice Chair Holmes, Ranking Member Liston and Members of the Ohio House Health Committee,

My name is Erin Keil and I am from the Washington Township/Centerville area in Montgomery County, just south of Dayton. First, I want to say thank you to the Ohio House Health Committee for giving families like mine a chance to share our stories again in support of HB 189, the PANDAS bill.

This is now the third time that I have shared our story with this committee. I unfortunately have a previous commitment on the day of the hearing and I wish I was able to give this testimony in person. Below is a recap of my family's journey with PANDAS, a story that is still being written.

On April 2, 2019 the life of my family was forever changed. Our son, then 7.5 years old, went to school that day as a typical 1st grader and that same night became of shell of himself, suddenly crippled by severe anxiety and OCD. I had just started a job as a substitute teacher at my daughter's preschool and we had just returned from a spring break trip to Missouri to visit my grandmother. By April 3rd, Jack was refusing to go to school and had severe sensory meltdowns, anxiety attacks, constant OCD behavior, was attempting to escape our home and school, had headaches and severe separation anxiety. He was becoming a child we didn't even recognize. He could no longer cope with the real world, at home or at school. He made several attempts to escape the school playground during recess. One unfortunate day, the school came minutes from calling the Montgomery County Sherriff's office to look for him after they believed he was missing. 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. 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 2019 3rd quarter report card, could now no longer cope in a 1st grade classroom with his peers. We knew he couldn't stay safe in that current school environment. We rapidly moved to home instruction for him with the help of his teacher and school and I quit my job as a substitute teacher.

After dealing with his symptoms for a few weeks, 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. Jack was officially diagnosed in May 2019 with PANDAS. As we have worked to put the pieces together of the timeline of events for Jack, we have since found out that a very contagious and prevalent strain of strep was running rampant through Jack's class and surrounding classes as the students returned from spring break.

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 our insurance believed IVIG 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 some of 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 2019 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 most of his 2nd grade public school experience. He started the school year in a typical 2nd grade classroom with 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.

The exact day when the earlier version of this bill was first formally introduced back in January of 2020, 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 many months of fighting our insurance company and different levels of appeals, in April of 2020, 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 our son, 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 2020, 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. After this treatment he was able to complete most grade level school work via homeschooling and he was much happier in general. He was 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. Jack is working on wrapping up 4th grade via homeschooling. Without IVIG I do not believe he would have been able to successfully complete his schooling, completing work similar to his peers in public school. We hope that with continued healing from these IVIG treatments, he will be able to return to a classroom with his peers sometime in the near future.

Treatment for this horrific illness is not always a one (or two) and done approach. Jack has proven that he has more of a difficult case. Jack has so far needed a total of 5 IVIG treatments. Jack has grown over the years, and without insurance coverage we would have paid approximately \$45,000 to \$50,000 for

these 5 treatments. This is not something that our family could have been able to financially sustain. We are very grateful that Jack is now at a much more stable place and at this time does not seem to need additional treatments. He is back to participating in activities with his peers in our community. I do not even want to imagine what everyday life would be today without these treatments for our son.

Just in the time since our son's diagnosis, more and more research on PANDAS and other similar immune issues has been published. As even more research continues to come out in the coming months and years, more can hopefully be done to help kids around our great state and nation. Once they have access to proper treatments, kids will no longer need to suffer for years with debilitating symptoms. This bill will go a long way in providing more access to treatments for these kids in Ohio.

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 a 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.

I am asking that you to support the further advancement of this very vital bill. Ohio is truly a family friendly state, which is why our family has continued to live here. Ohio families deserve to have the correct and medically necessary health care options for their children. We were fortunate to win our insurance battle but every day 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