TESTIMONY HB 488 CHASE HOLTYN

Chairman Lipps, Ranking Member Boyd, and distinguished members of the House Health Committee,

Thank you for the opportunity to share our story and related information in support of House Bill 488 to require that health plan issuers cover treatments and services related to PANDAS.

My son, Chase Holtyn, was a healthy, happy child until about the age of two. He was bright, energetic, would play ball, ate a variety of foods, made good eye contact, and he wanted to be with other people.

Shortly after his second birthday, all that changed. Chase came down with a high fever and we just figured this was his first bad "bug". It resulted in an ear infection and a hoarse voice that lasted for months. His doctor said that ear tubes were going to be the solution, so we agreed to have this common surgery performed on him. However, we didn't realize there would be three surgeries, before the age of five. During this time, we noticed he was still struggling to hear, his speech was difficult to understand, he was always tired, he was isolating himself, he had no desire to read books or be read to, no desire to draw, color, or write. He couldn't and wouldn't hold a pencil or crayon properly and his food choices became very limited.

At two-and-a-half years old, we had him tested through the local school district for speech therapy. He quickly was enrolled into a parent-child play group to prepare him for attending the Early Childhood Special Education program. And so, after his third birthday, we put him on a school bus five days a week and sent him off to battle his demons alone.

Our family moved out of the school district, but the I.E.P. he obtained would follow him to his next school. At the exit interview, his special education teacher recommended we start to look for Autism schools. Autism was never brought up by any of his pediatricians or ear specialists before. We were stunned to hear this.

At age 4, our family moved to Ohio and Chase was attending a "typical" preschool to see how he would do prior to enrolling him in kindergarten. He was also receiving speech therapy and occupational therapy through our health care provider. He wasn't doing very well. He was still isolating himself, playing alone, away from the other children, and not doing the art projects or coloring activities without a lot of help. He looked and felt miserable. You could see it.

At age five, we enrolled him in kindergarten at a Montessori-style private school. We loved the atmosphere and mission of the school, that each individual child is a gift and has an opportunity to do their personal best. Chase was very knowledgeable, could read, and do math facts, but writing and being a full participant in class were not his strengths. So, the teachers quickly recommended an educational evaluation be done by the local school district, and soon a new I.E.P. was written up for him.

We also took Chase to an Autism specialist that diagnosed him Autism, and with that our world turned upside down. Especially since a year and a half, prior, he was tested for Autism by another group of doctors and it was decided that he was NOT Autistic, but rather delayed due to his hearing and speech difficulties. They said his behavior was associated with all those issues happening at a critical time in his language development.

In contrast, his new Autism doctor thought that with encouraged engagements and activities, Chase could improve to a high-functioning level of Autism. (This was encouraging to me.)

My wife took the lead and enrolled Chase in Karate, piano lessons, Cub Scouts, and Swim Team. She still logs the miles, every day, keeping this active pace. It was difficult to watch our son be the odd kid at these activities. We knew that he was struggling to keep up with his peers and we just hoped that he would slowly get better. Overtime, we did see improvement. For example, in his first month of Karate, he had to take private lessons in the office, away from the other kids, because he was so unfocused. He was finally able to join a Saturday group lesson and within a couple months, he earned his first belt. (we were overwhelmed with joy!)

The piano lessons were really helping his brain make connections with eye-tracking, coordination, and dexterity and we noticed improvements in his handwriting, coloring, and schoolwork.

The Cub Scouts were helping him to socialize better. However, while all this was encouraging, Chase was still struggling. He still would isolate himself. It just seemed that his life was going to be much harder than everyone else's.

At age six, Chase began First Grade and was assigned an aide through his I.E.P. to help him get through the day and keep up with his assignments. The Ohio Autism Scholarship awarded him $27,000 to cover the cost, and we re-apply every year to have it renewed. This will be his third year with his aide, and she is awesome!

The ear infections would reoccur from time-to-time and his speech therapist and my wife were starting to note a pattern of increased stuttering, defiant behavior, and complaining of tiredness right at the onset of getting sick. Antibiotics were prescribed and things improved a bit.

And this is where things, really, start to change…my wife was standing in our kitchen one evening and noticed how large Chase's pupils were. She compared them to everyone else's in the same light and quickly looked up "enlarged pupils, stuttering, and Autism" on the internet. The acronym PANDAS (Pediatric Autoimmune Neuropsychiatric Disorders Associated with Streptococcal Infections) popped up. The symptoms listed stunned us because they were very similar to Chase's issues.

A visit to our pediatrician, for yet another ear infection, produced a discussion about the possibility of PANDAS. Though doubtful, a recommendation was given to us. Within a couple of weeks, we met with another doctor to see if there was any merit to the PANDAS idea or were, we just off on another tangent. After evaluating Chase, the doctor thought the PANDAS syndrome was a distinct possibility. During that visit, he took some blood, prescribed antibiotics, and said," keep notes of any improvements". After a month we started to notice improvements.

We stayed the course with the medication and returned a couple months later with the hopes of more improvements. And there were more. Chase was a little more social, his writing and coloring were significantly improved, but he was still not where we wanted him to be.

In the spring of 2020, at age eight, Chase was off his medication and was having some regression. It was suggested to have an immunoglobulin transfusion performed. It was a two-day procedure and expensive ($10,000 range). After reading some medical papers and some long talks, we scraped up the money and took a leap of faith, with the hope that we could see real and lasting improvements. To come up with the money, we decided that I could drive my old truck another year. Maybe I'll get to 400,000 miles on it.

After the procedure, the changes were immediate and profound. I had not seen my son so happy since he was two! That first night home, his smile was different. It was genuine and his eyes were bright again, like a fog was lifted. And we played. I was chasing him around the house, and we had an indoor snowball fight. (It was great!) It was like a switch had been flipped and Chase was back. Another incredible, but frustrating moment happened two days later when I asked Chase how he was feeling at breakfast. He said, "Better. My brain is clean and bright!" I was very surprised and happy by his odd choice of words, but it was clear that he was feeling better. I was also very frustrated because it had taken us so long to help him. He must have been living his life in a distracted fog, battling his demons, with no clear way out. He had been living with pain and feeling sick for so long, not knowing it was abnormal to feel like that. It kills me inside knowing that we failed him for so long.

Since the spring of 2020, Chase continues to improve. He still has some behaviors that he needs to unlearn, but overall, he has better focus, better writing, better listening, better eye contact. He is playing with his classmates on the playground. He is trying new foods and joining us for dinner. He is showing affection towards pets and real emotions, like tears of sadness for the first time, not just tears of frustration. He is doing very well academically and his dependency, on his aide, is becoming less and less.

I believe the IVIG (Immunoglobulin transfusion) rebooted Chase and is giving him a chance at a normal life. While this procedure is not cheap, I think it is worth every penny. What we don't know is if this procedure will have to be repeated. If so, my wife and I will have to find a way to help him…maybe 500,000 miles on the truck!

With this procedure, we have an opportunity to save children's lives. We can prevent them from being labeled the bad kid, or the weird kid, or the jerk.

While my son was fortunate that his parents were able to scrape together the funds for the IVIG procedure, most children are not. We need this procedure and others to be covered by insurance so more children can be saved from a lifetime of unnecessary struggles and challenges. With a simple Immunoglobulin reboot covered by insurance, the lives of many children will be saved.

Thank you for letting me share our story and please pass HB 488.