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Chairman P. Scott Lipps  
House Health Committee  
77 S. High St., 13th Floor  
Columbus, Ohio 43215

Chairman Lipps, Ranking Member Boyd, and Distinguished  
Members of the House Health Committee:

Thank you for having us here today and for the opportunity to provide proponent testimony in support of House Bill 488, which would require health plan issuers to cover treatments and services related to Pediatric Autoimmune Neuropsychiatric Disorders Associated with Streptococcal Infections and Pediatric Acute-onset Neuropsychiatric Syndrome; this bill would also designate October 9<sup>th</sup> as PANDAS/PANS Awareness Day.

My name is Heather Groves. I am a nurse with almost a dozen years of experience, 9 of those years spent specializing in psychiatric and behavioral health nursing. Unfortunately, it is not that experience that brings me here to urge you to pass HB 488, but rather it is my experience as a mother of a child who suffers from this newly recognized but debilitating illness that has me standing before you today.

March 29<sup>th</sup>, 2019 was the day that changed our lives forever. All three of my children came down with strep throat two weeks prior, and as this isn't an unusual occurrence in a household with school aged children, we treated the strep with antibiotics and didn't think anymore about it. My then 12 year old daughter Nevaeh was a perfectly healthy and hilarious young lady who excelled on her school basketball team, was a member of student council and had been a straight A student her entire life. Nevaeh loved drama and

had aspirations to be a voice actress or comedian – she absolutely loved being the center of attention and was known at school for being friends with everyone – that girl didn't know a stranger and strived to make everyone feel included. I had no doubt that with her sense of humor and kind heart, she would excel at whatever she set her mind to. So when I sent her to school the morning of March 29<sup>th</sup>, I could have never imagined that that would be the last time I would embrace that version of my daughter.

Nevaeh came home from school with uncontrollable physical and verbal tics to the point that she couldn't hold a cup of water without spilling it everywhere. That night we went to 2 hospitals, where she was discharged as being "stressed." The following day we drove down to Cincinnati Children's Hospital, and again we were discharged home with the advice to see a counselor. Over the next two weeks Nevaeh's condition rapidly declined; she developed severe social anxiety, violent physical and verbal tics, emotional regression, hallucinations and chronic fatigue, headaches and episodes of syncope. As a nurse with a behavioral health background, I knew that these symptoms were not caused from "stress" or "attention seeking behaviors", as had been implied by the medical professionals that we had seen up to that point, and as someone who has Lupus, an autoimmune disease, I insisted that she be tested for neurological autoimmune illnesses. By the grace of God we were able to have her seen by a doctor in Ohio that is familiar with PANDAS, and within 3 weeks of onset Nevaeh was diagnosed with PANDAS based on positive autoimmune, inflammatory and neurological laboratory panels.

Nevaeh missed the next 5 months of school while we sought aggressive treatment for an illness that caused her own antibodies to attack the basal ganglia in her brain, causing

inflammation and possible long term damage if not treated quickly. Devastatingly, we quickly discovered that the most appropriate treatment options for her are not covered by the majority of health plans in the state of Ohio, leaving us to seek more affordable, but less effective and short term out of pocket treatment plans that quickly amounted to tens of thousands of dollars within the first year. In the fall of 2019 I refinanced my house to pay off \$15,000 in credit card debt that was directly related to the cost of Nevaeh's care.

It's been a year in a half since Nevaeh was diagnosed with PANDAS; when we were able to aggressively seek treatment, we saw positive results and a return to an almost normal life for her. Although she was still plagued by fatigue, periodic tics and other mild symptoms, her quality of life had improved substantially from the onset of this devastating disease. Unfortunately, as a single mother of 3 and with insurance not covering her treatments, when my life savings ran out, so did our treatment options. Nevaeh has since relapsed, and has regressed back into the dark shadow of the once vibrant and fun loving young lady that she used to be. Her social anxiety is so severe that we are unable to host birthday parties for her or her 8 and 9 year old brothers, or to celebrate family holidays or to go out to eat as a family. She has never been to one of her brothers' football games, which continues to break the heart of my middle son, who, as the starting quarterback, longs to impress his sister. My children grew up in church, and Nevaeh was a member of youth group her entire life; we have attempted church as a family twice since her diagnosis and had to leave both times because her tics caused her extreme embarrassment and anxiety. Last month we attempted to go on a "girls" date to get our nails done. Despite being so excited to go, within 5 minutes Nevaeh's tics and anxiety were so severe that she left the salon crying.

The once social butterfly has withdrawn back into her cocoon, losing friends and academic opportunities along the way. Concerts, plays, basketball, Student Council, National Honor Society, drama... all of these things that she once cherished and strived for now serve only as a reminder of what she has had to sacrifice to this tragic disease.

The pain that you experience when you have a chronically ill child is unfathomable, but the despair that feel when you watch your child suffer, knowing that there are safe and effective treatments that could literally save her life and permanently put her in remission, but that these treatments are being withheld from her because of bureaucratic red tape... this is a pain that I can not begin to describe and one that I hope and pray none of you ever have to experience. Anyone that knows us can tell you that Nevaeh was, and is, my best friend, my sidekick, my mini-me. And while I am so grateful that she is alive and I thank God every single day for His providence and protection over her, I can't put into words the guilt that I feel for mourning the loss of a child who is still with me. I mourn for what she has had to sacrifice, and for the pain that she feels daily, and for the future that she envisioned which was so very bright, and for the family memories that we have lost, and for her absolutely breathtaking smile that I never get to see anymore. I grieve daily. And there are thousands of families just like mine who endure this same trauma, witness this same suffering, and feel this deep sense of helplessness, but it doesn't have to be this way. And that is why I implore you, Members of the Health Committee, to compassionately advocate for and pass House Bill 488; by doing so you could save the lives of thousands of Ohio's children, while preserving the futures of their families.

Thank you from the bottom of my heart for giving me this opportunity to share my daughters story, and for considering the approval of HB488. I will now answer any questions that you may have.

Heather Groves