

House Bill 189 – Proponent Testimony
Ohio House Health Committee
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May 17, 2022

Chair Lipps, Vice Chair Holmes, Ranking Member Liston, and members of the Ohio House Health Committee, thank you for allowing me to provide proponent testimony for House Bill 189, which would require health plan issuers and the Medicaid program to cover treatments and services related to Pediatric Autoimmune Neuropsychiatric Disorders Associated with Streptococcal Infections (also known as PANDAS) and Pediatric Acute-onset Neuropsychiatric Syndrome (also known as PANS). My name is Jamie Escola, and I am a parent of a child diagnosed with PANS.

In 2016, my three-year-old daughter Kaiya suddenly began displaying alarming behaviors and symptoms. One day, she stopped feeding herself and showed no interest in playing. The next day, she had developed a violent tic, in which she would jerk her head, often hitting her jaw on her shoulder. My husband Erik and I had never seen these behaviors before and were scared and overwhelmed.

For two months, Kaiya was a completely different child, and because she could not yet speak, we had no idea what all she was going through. Incredibly, at the end of that time period, the tic disappeared, and Kaiya returned to her normal behavior over the course of a couple of weeks. It was like nothing had ever happened, and our sweet, affectionate, funny little girl was back.

Four months later, it happened again suddenly with a new tic but many of the same strange behaviors as the first time. We began seeking answers and met with numerous health care providers. In 2017, we eventually were able to land on a diagnosis: Kaiya was suffering from PANS. We had never heard of this condition prior to experiencing this with our own daughter. From the sudden onset of obsessive thoughts and behaviors to bedwetting, the inability to feed herself, tics, headaches, mood swings and developmental regression, we were dealing with an overwhelming number of symptoms all at once.

After connecting with other families and talking with doctors, we were desperate to try IVIG (intravenous immunoglobulin). We'd learned that this treatment could lessen symptoms, and for some children, it was able to reverse the disorder. But we soon discovered that it was not a treatment that was covered by our insurance and one that we wouldn't be able to afford ourselves.

Since then, we've tried countless therapies, and none of them have not been covered by our insurance. We started working online with a PANDAS/PANS specialist in Texas and pay for him and the supplements and tests he orders completely out of pocket. We paid \$6,000 for hyperbaric oxygen therapy and

have also tried acupuncture, behavioral therapy, and holistic medicine to ease Kaiya's symptoms. All of these things are completely paid for out of pocket. One of our go-to treatments has been ibuprofen to bring down the inflammation in her brain, but there's the constant worry of trading long-term issues from the ibuprofen for current relief and quality of life. It's a difficult decision we make daily for our now 8-year-old daughter.

Kaiya's wellbeing and happiness is worth every penny spent, every moment figuring out what to try next. No matter what, we would continue to pay for the non-traditional therapies, organic diet and numerous supplements to improve her quality of life. But these things only go so far. They have lessened the severity of her symptoms, but as I write this today, her body jerks with her most recent tic, and she's been obsessing about multiple things to the point of tears and tantrums. A treatment like IVIG could change her life, but it's out of reach for our family. Knowing what it could possibly do to change Kaiya's life troubles me every day.

The passage of House Bill 189 will provide immense help to Ohio families like ours who are affected by the conditions of PANDAS and PANS. I would like to thank the sponsor Representative Young for introducing this bill and working with interested parties along the way. Again, I support the passage of House Bill 189 and urge the committee to be supportive as well. Thank you for the opportunity to testify. I can be available to answer any questions you may have.