

A Testimony in request for the passage of HB2390 : Relating to PANDAS/PANS Requires health benefit plan and health care service contract coverage of pediatric autoimmune neuropsychiatric disorders associated with streptococcal infections and pediatric acute-onset neuropsychiatric syndrome.

For the record, my name is Christina Cronin-Vejar, and I am a resident of Salem. Chair Rachel Prusak, and Members of the House Healthcare Committee, I want to thank you for hearing this bill, and for giving me an opportunity to tell you a little bit about what our family has been going through, and how HB 2390 is so critical for children in Oregon afflicted with this terrible illness.

We were so excited to celebrate our daughter's 6th birthday in February 2016. It had been a long, hard winter, when she and her twin brother had Strep, Influenza A, and the Coxsackie virus through most of December and January. Two weeks after our daughter turned 6, she became a different person. The doctors didn't have answers and so I spent days and nights researching her symptoms and trying to figure out why she seemed to be in an extreme mental health crisis at such a young age. Within weeks, I was able to present my findings to her pediatrician, who had only heard of PANDAS/PANS at the time and is one of very few pediatricians in Oregon who even recognizes this disorder, and she was prescribed Augmentin, a very strong antibiotic. Within 48 hours, her symptoms of night terrors, rage, food restrictions and weight loss, complaining of upset stomach, anxiety about school, and fear of throwing up were reduced 85-90%.

We had to stop antibiotic treatment for our daughter in 2016, due to an illness related to antibiotic treatment called CDiff, and it has taken years of trying to find knowledgeable doctors to provide alternate treatment options, performing labs that cost thousands of dollars out-of-pocket, buying medications and supplements of all kinds not covered by our insurance, and trying to find a way to bring her back to baseline. For instance, we paid more than \$1300 for her in 2018, for medical treatments and labs for her and this was just a third of what we had paid in the years previous. Her illness has waxed and waned depending on exposure and autoimmune response. COVID has reduced the severity of her illness in the last year, but even something as benign as tooth loss, and new eruption of teeth, has caused a recent flare of symptoms for the last three months. We have paid for all of her testing, treatment and diagnosis out-of-pocket. To consider whether we could afford IVIG (immunoglobulin treatment) if her condition were to spiral out-of-control would decimate our already precarious financial situation, especially due to employment changes related to COVID. We are a one-income family, due to my child's condition, as she has never been able to complete a full year of public school due to flares brought on by overactive autoimmune response.

When I share about PANDAS/PANS with people, frequently someone will tell me that their friend's daughter or the son of a co-worker has been diagnosed with PANDAS. A conservative estimate is that 1 in 200 children are diagnosed with this disorder. This illness has both an extreme emotional and financial impact on a family. Treatments like IVIG are a last-stop, not a first approach and insurance companies, who treat other pediatric disorders with IVIG, must take the same care and consideration of the children and families, to provide the treatments

needed to heal from this terrible disease. No insurance company would prevent a child with cancer from their needed chemotherapy treatments, and no insurance company should withhold IVIG from a child with PANDAS/PANS, when their autoimmune illness has been mis-diagnosed, or under-treated, and with this treatment approach, can literally save a child's life.

Eight states have already passed insurance coverage legislation for PANDAS/PANS. We want Oregon children and their families to know that they are being heard, affirmed and supported by our legislators and so we thank you in advance for recognizing the need to send HB2390 to the House and Senate for a vote to affirm this legislation.

Thank you.

Christina Cronin-Vejar