

April 15, 2019

A Testimony in request for the passage of HB2510 : Relating to PANDAS/PANS Awareness Day; declaring an emergency.

For the record, my name is Christina Cronin-Vejar, and I am a resident of Salem. Chair Monnes Anderson, and Members of the Senate Health 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 2510 can be a positive step forward for children all across Oregon.

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, 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. We paid more than \$1300 for her in 2018, for medical treatments and labs for her and this was a third of what we have paid in the years previous. It has only been since January of this year that we have seen gains for her and she has had a great period of health in the last few months, although we wait on pins-and-needles. What if someone in her class gets strep, or what if she picks up some kind of illness and it decimates her immune system all over again?

We want other families affected by PANDAS/PANS in Oregon to know that they are not alone. It took years for me to find other families like ours here in Oregon who know and understand what this illness is and what it does to our children and families. An awareness day has and will continue to help families in Oregon. When I share about PANDAS/PANS with people now, 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. It is not rare, it is not controversial. States such as Connecticut, Massachusetts, New Hampshire, and Maryland are all currently working on legislation for recognition, diagnosis, treatment and insurance coverage, and states such as Illinois and New York already have PANDAS/PANS legislation approved. 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 a permanent PANDAS/PANS awareness day by your approval and passage of HB2510.