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On Behalf Of:
Committee: Senate Committee On Health Care
Measure: SB628

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A testimony in request for the passage of SB 628 Relating to health benefit plan and health care service contract coverage of pediatric autoimmune neuropsychiatric disorders associated with streptococcal infections (PANDAS) and pediatric acute-onset neuropsychiatric syndrome (PANS).

My daughter had just turned six years old, and we were excited to celebrate this milestone in February 2016. The winter had brought many illnesses to my children, and they had had strep, Influenza A, and Coxsackie virus. Two weeks after my daughter's birthday, and overnight, she had OCD, tics, anxiety, food issues and night terrors.

We visited other doctors and did not have any answers. My wife 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, my wife presented her findings to our child's 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. The doctor 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 dropped by 75%.

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?

For six years, we suffered alone in our home as my daughter's rage, terror, and worry dominated our lives. Her PANDAS specialist placed her under a medical regimen that helped her maintain a behavioral level that was less difficult, but the extreme behavior was always near because of illnesses passes around at school. We were

never able to truly regulate her flare-ups with just her prescription medication.

For six years, my daughter would start regular school, and then within months, we would pull her out of school and struggle through home school for the rest of the year. The last school she had to leave was a top rated charter school that would be very difficult to return to.

Last year, OHP was approved to cover IVIG treatment for PANDAS children with extreme cases. Our specialist determined that our daughter was a great candidate for this treatment, and after 6 months of treatments, my daughter has blossomed and excelled. She is on the honor roll, and has received other certificates recognizing her work. We have a completely different child.

I want other families affected by PANDAS/PANS in Oregon, who are not covered by OHP, to have the option of treating their child with IVIG, if their specialist believes him or her to be a great candidate.

Thank you in advance for recognizing the need to have insurance parity with OHP for desperate parents with PANDAS/PANS children in need by passing SB 628.