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Dear Senators of the Healthcare Committee,

I am writing to share our family's personal experience with PANS and to implore you to support SB 628. My son, Drew had his first onset of PANS symptoms at age 4.5. My son was a daredevil, outgoing and fearless before PANS. At first we noticed he had an increased sensitivity to smells, that he was struggling to use silverware and legos, and was not responding to basic directions. He developed anxiety, to the point he would vomit when separated from me. Then one morning he woke up with every OCD symptom imaginable, lining up objects, washing his hands repeatedly, fear of touching textures, and a fear of food and getting fat. He refused to eat, losing 7 lbs that week, then became afraid of drinking water. He would go into rages over the smallest things, escalating to two suicide attempts. On the first attempt he tried to slice his stomach with a knife, and the second incident he ran into traffic while screaming 'I want to die.'

Imagine for just one moment, if it were your little 4 year old child, who so lost control of their ability to regulate their feelings that they actually tried to kill themselves. Now imagine that this child did not get better. Imagine a child who remains in the throes of those feelings and symptoms, and the challenges that child's caregivers face. This is the reality of some of our families who are awaiting treatment.

We were lucky. My son's condition was identified early – not by medical personnel, but by a school psychologist. The doctors thought he had a brain tumor and subjected him to a spinal tap, MRI and a whole battery of tests, and found nothing. Fortunately, the third hospital was willing to treat his symptoms as PANS, and prescribed the antibiotics he desperately needed. Two days later, he was back. Not fully, he may never be the same, but the healing had begun. Since then he has had flares and setbacks, and we have so far continued to be lucky that less invasive treatments are effective. However, we live in constant fear that someday he will not come back, and nothing but expensive treatments will help him. I am a Special education teacher and my husband is a janitor, who had to retire early to care for our son through long illnesses and to keep him isolated when needed. We are a hard-working family who cannot afford high end treatments should they become necessary. I also wonder if he would have healed more thoroughly if we had been able to access IVIG early during that first flare.

As a special educator, I see the costs of the extra supports required by our most needy students. As per the Oregon Legislature: Pre-K -12 Special Education [Report] Nov. 3 2022; "Since eligible students with special needs are guaranteed specialized instruction, the State School Fund (SSF) formula provides **a double weight for these students.**" Cost per student is difficult to estimate, since each student is individual and services are tailored to their specific needs. Though my son is doing well overall and in a regular classroom most of the day, he is on an IEP for Communication and for Writing. Just one IEP meeting for him with 5 educators costs \$250 or more, and these meetings take place annually if not

more often. I know of several students with PANS who require intensive supports for behavior and academic needs. Tax payers are footing the cost of this disease being untreated, whether it be through the costs of special education, mental health resources, or loss of productivity....but our kids are paying the real price. It is nonsensical from both a financial and a humanitarian perspective to leave our kids without access to treatment.

Lastly, it has been frustrating the past three years to see news reports and read articles of IVIG being an accepted treatment for physical and psychological effects due to Covid. If symptoms are due to an infection that is anything besides Covid, somehow IVIG is experimental and mysterious. If anything good can come out of the experience of the pandemic, my hope is that the lessons learned from Covid can be applied to our children who are vulnerable to other illnesses as well.

Please make the moral, ethical and financially responsible decision to support SB 628. Thank you for your consideration.

Warm regards,
Jennifer Rowan