Our child was diagnosed with PANDAS/PANS at age 6 by her pediatrician, after my presentation and education regarding my daughter's symptoms. From December 2015 to the end of January 2016, she had contracted Strep, the Coxsackie virus, and Influenza A from students in her kindergarten class. By February, she was unable to leave the house, had urinary urgency, refused to eat, had night terrors, extreme anxiety, a bent neck tic, and could not attend school.

Upon administration of the Augmentin antibiotic, her symptoms were 75% reduced within 48 hours. Over the last 6 years, we had tried every treatment available to us: antibiotics and ibuprofen, a cupboard full of supplements, CBT and therapeutic counseling, even a tonsillectomy in late winter 2021, which revealed hidden staph bacteria, yet nothing returned our child to her fully healthy self. Something as benign as a loose tooth can trigger an over-active autoimmune response in our child, and we will soon begin to see her refuse food, have increased anxiety and repetitive thoughts, become over-sensitized to her environment, and be unable to perform activities of daily living, including being unable to perform her school tasks successfully, even though she is in the Talented and Gifted program.

Due to being a single-income family, raising two neurodivergent children and needing to be available to provide seasons of homeschooling (even before COVID), occupational and psychological therapy for both our children, specialized tutoring, and also spending hours every week researching service providers, calling insurance companies about coverage, making calls and getting put on wait-lists that last months or even years, to help my child in her ongoing health crisis, we had not considered IVIG before this, as we knew we simply could not afford it. After months of testimony to the Health Exchange Review Committee over the last year, we were pleased to discover that Medicaid, and our coverage through Pacific-Source Community Solutions (OHP) WOULD cover IVIG for our child. After 6 months of intravenous immunoglobulin treatments (IVIG), she is thriving, succeeding in school, and learning new skills. Our child has joined a youth-led film production crew. She is an Honor Roll student for the first time, and she is making new friends and starting to find joy in her life. None of this would have been possible without IVIG treatments.

There is nothing worse than knowing there is an effective treatment available and recommended by a medical provider, yet being unable to access it for a sick and suffering child. We hope that the evidence reviewed, the advocacy and treatment guidelines provided by so many PANDAS/PANS subject experts, and the testimonies given by families detailing the obstacles in access to diagnosis and treatment of PANDAS/PANS would move this committee to pass SB-628 forward to ensure insurance coverage of all tiers of treatment recommendations for PANDAS/PANS, including IVIG to be made available to all who need it, no matter their insurance carrier, in parity with the Oregon Medicaid program. Your income bracket and your insurance provider should not prevent your ability to help your child to live without this devastating illness, when access to a cure is available.

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