

Members of the House, thank you for allowing me to be present today and to testify before you about the importance of passing HB 2390. Thanks to our chief sponsor, Rep Rachel Prusak, Senators Gorsek and Lieber and all our co-sponsors for championing this critical bill on behalf of the sickest children with PANDAS/PANS in our state. I'd like to acknowledge all the Oregon children and families, which is estimated to be over 4,300 children, who are living with this disorder. I'd also like to recognize the handful of medical and behavioral health providers who are providing treatment for these children and whose practices are overwhelmed with the number of incoming referrals because there is an extreme shortage of knowledgeable providers. Lastly, I want to acknowledge with immense gratitude the endorsements of support we've received for this bill from the Oregon Association of Naturopathic Physicians, Oregon Nurses Association, National Pediatric Nurse Practitioners-Oregon Chapter, Oregon School Nurses Association, Oregon School Counselors Association, Oregon NAMI, Oregon Easterseals and the International OCD Foundation.

I am the co-founder and Executive Director of the Northwest PANDAS/PANS Network (NWPPN). I am also the parent of a 12-year-old daughter who was diagnosed with PANDAS at 8 years old. PANDAS devastated our family. It ripped the joy out of the eyes of my beautiful and carefree child and replaced it with debilitating anxiety and fear. She became a prisoner in her own body. Having your own child beg you to take away their pain is every parent's worst nightmare.

There are formalized national diagnostic and treatment that have been in place since 2017, as well as an expert medical body known as PANDAS Physician Network who recently updated these guidelines in December of 2020. The emerging evidence on PANDAS/PANS is that it is increasingly being classified as a form of Autoimmune Encephalitis. PANDAS and PANS are now considered a form of basal ganglia encephalitis demanding attention and urgent care, as argued in recent editorials by esteemed physicians in Immunology, Neurology & Psychiatry of PANDAS/PANS. The National Institute of Mental Health recognizes these treatments as a consideration for 'acutely and severely affected children with PANDAS' and further supports that these treatments 'can improve global functioning, depression, emotional ups and downs, and obsessive-compulsive symptoms'. Such efficacy has been further demonstrated in rigorous studies published since 2015. From a recent efficacy report compiled by NIMH Emerita Sue Swedo and Dr. Mark Pasternack of Harvard, "Recent evidence overwhelmingly supports inclusion of IVIG in the levels of treatment available for children with PANDAS and PANS. Based on extensive systematic reviews from several specialty areas, treatment studies, and the national consensus guidelines of the PANS Research Consortium and PANDAS Physician Network, IVIG is indicated for the treatment of a small but significant subset of children who meet the criteria".

We are here today because while Oregon acknowledged the need to raise awareness for these disorders in 2019 by signing into law a permanent awareness day, the sickest children in our state remain unable to access **medically necessary care** because most Oregon insurers deny coverage for these treatments. Their denials indicate that these treatments are 'investigational' or 'experimental' when they are indeed the gold standard for the most severely afflicted subset

of cases. However, some insurers in Oregon, and others across the United States, recognize the efficacy of IVIG treatment for PANDAS patients, and have repeatedly covered these treatments. These insurers provide coverage because they consider IVIG to be proven and effective. The precedent is established because some insurers have recognized the efficacy of IVIG and PE already by providing coverage for these treatments. All Oregon families deserve equal care, which is not currently available because of this disparity in coverage. HB 2390 makes no change to the rights or ability of insurers to challenge a prescribed course of care. As with any prescription or medical treatment, insurance providers are able to review, consult, deny, or process appeals for IVIG or Plasma Exchange treatments they might question. In addition, HB 2390 does not MANDATE treatment, it merely allows a medical provider to prescribe the appropriate treatment for their patient based on severity and presentation of case. Not all children require IVIG or Plasma Exchange but those that do, cannot access this treatment equitably because of certain Oregon insurers choosing to withhold this care.

We ask you to not delay care to these critically ill children in our state any longer. We ask that you recognize the health disparities inherent in our healthcare system and vote to change that by recognizing that all children with PANDAS/PANS deserve access to care, not just those that can afford it or are lucky enough to win over their insurance company.

These children and families don't have time to fight insurance companies. Living with PANDAS is a daily fight. It is a fight to secure a diagnosis, to find a treating provider-who many travel out of state for, a fight to get your child to comply with medication when they are not stable, a fight to keep them safe, to keep them in school or to make the decision to homeschool, a fight to keep their siblings safe, a fight to keep yourself safe. These families are already in the fight of their lives as they furiously work towards healing their child and regaining the child they have lost. They have no fight left in them. We are here representing these families.

Please cast a vote today that shows Oregon families living with PANDAS that they no longer have to fight insurance companies. Please cast a vote today that shows Oregon children living with PANDAS/PANS that they matter, and the state of Oregon will do everything it can to ensure they have a rich childhood with the access to care they deserve.

Thank you for your time.

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