



February 11, 2021

REGARDING HOUSE BILL 2390 INSURANCE COVERAGE FOR PANDAS/PANS CHILDREN

Dear Chair Representative Rachel Prusak and Healthcare Committee Members,

I sincerely ask for the approval of **HB 2390** that requests a mandate of Insurance Coverage for PANDAS and PANS children in the State of Oregon. Thank you for your consideration.

I urge you to be a leader on behalf of our children and the EIGHT state to cover medical treatment for our children (current coverage is allowable under law in Illinois, Maryland, Massachusetts, Minnesota, New Hampshire, Delaware and Arkansas). PLEASE pave the way for others and recognize important new, cutting edge research led by research and treatment clinics at Columbia, Yale, Stanford, Harvard, and Arizona Universities!

I have been the Executive Director of PANDAS Network since 2013, a national 501c3 organization recognized as an NIMH (National Institute of Mental Health) Outreach Partner. We represent 30,000+ children and families in the U.S. and worldwide. These children have been hurt by this pediatric autoimmune disease that damages the blood brain barrier and injures the brain. Early diagnosis and treatment prevents permanent lifelong injury.

As you read through this letter you may have many questions. I ask you to consider having a PANDAS-PANS expert researcher testify in Oregon. We are happy to help with this professional testimony if you will allow it. A consortium of experts from multidisciplinary backgrounds are investigating the most efficacious treatment of PANDAS-PANS. They have recently published guidelines for the Diagnosis and Treatment of PANDAS-PANS in the Journal of Child & Adolescent Psychopharmacology (2017). New 2020 research by Stanford, Yale and Columbia Universities prove that brain inflammation is occurring with strep and other infections in a discreet subset of children. We also believe there is a genetic component making these children more susceptible; but, they are not incurable! They can heal with treatments that are available but costly without insurance coverage.

Insurance coverage is critical because the expense of treatment together with debilitating, daily symptoms make lack of coverage inhumane and devastating financially. Early recognition of illness onset of PANDAS-PANS has the best chance of assuring children a rapid and substantial recovery. The average age of onset is between ages 4-10. **Untreated the child will often struggle with lifelong neurological and psychological problems.** Families and social services will incur financial costs potentially well into the hundreds of thousands of dollars and affect the social, medical, educational systems of Oregon.



Treatment guidelines have been written by experts and the prognosis for healing is excellent if these guidelines are followed. Treatment for this illness involves the use of anti-inflammatory treatments and medications which include: antibiotics/antivirals, steroids, or immune modulating treatments like IVIG or plasmapheresis. These are not exotic treatments and routinely used in other illnesses. Our children deserve coverage as well and we would be grateful to share this hopeful information with legislators.

On a personal note, both my daughter and son developed PANDAS in 2007 at the age of 7 and the other in 2016 at age 12. My very healthy boy and girl changed overnight after a strep infection. They each had intense debilitating fears, tourette-like movements, obsessions, fatigue, confusion, and more. With the use of IVIG and anti-inflammatory medication both children (now ages 16 and 20 years) have had full and, thus far, lasting remissions. Like many other families our family needed to fly out of state for costly, uninsured medical treatment.

Finally, please consider, that in our lives as adults we are presented with so many recalcitrant *illnesses and issues* but **HB 2390** can *reverse tragic illness and potentially STOP social and economic problems* the Oregon community as a whole will certainly face without this bill's passage.

Sincerely,

Diana Pohlman, Executive Director
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