

Submitter: Wendy Nawara  
On Behalf Of: Northwest PANS PANDAS Network  
Committee: Senate Committee On Health Care  
Measure: SB628

Dear Members of the Senate Committee On Health Care,

My name is Wendy Nawara, and I am a Board Certified Patient Advocate currently functioning as a national advocate and consultant for families and children with Pediatric Autoimmune Neuropsychiatric Disorders. I have long been dedicated to improving the health of all children with PANDAS/PANS and continue to work directly on the legislation that requires insurance coverage for PANDAS/PANDAS treatments in the State of Illinois. We were the first state to mandate insurance coverage for children with PANDAS/PANS, and now also include Delaware, Arkansas, Indiana, Maryland, Massachusetts, Minnesota, New Hampshire, Rhode Island and Kansas to have followed. Those successes have more recently influenced grassroots efforts in many other states to take up the charge to act legislatively on behalf of the health of our children. This includes the State of Oregon! The recent work of the Health Evidence Review Committee is a beautiful example of the power of advocacy, as well as a clear demonstration that Oregon values the health of its children. I am hopeful that the State will expand on that through the passage of SB628.

Research out of Columbia University is showing that PANDAS/PANS is a type of autoimmune basal ganglia encephalitis, which is a swelling of the brain. This swelling impacts specific functions of the body and can reduce and regress a child to completely non functional in a matter of days or weeks. It is very serious and can be life threatening. Physicians who care for these children are prescribing treatments for PANDAS/PANS that were developed, peer-reviewed and published in 2017 by a consortium of experts who research and treat PANS/PANDAS patients every day. The full array of treatments are determined by the severity of the case and are medically necessary and proven effective. These include antibiotics, steroids, the heavily regulated and FDA approved use of of IntraVenous ImmunoGlobulin, and in the most severe cases, plasmapheresis, monoclonal antibody treatments that are very much like chemotherapy. Ideally, the earlier this condition is identified and treated, the more likely a child will recover with the least invasive treatment. Many patients will never need the more expensive and invasive treatments.

It is understandable that there are insurer concerns about the high cost of the effective treatments. But, not providing treatment to children due to costs does not erase the problem. It creates new problems and shifts the cost burden to the State and the school system. It is much more costly to continue on like we have been than it is to treat the illness correctly in the first place.

Denying medical care because it is expensive is unconscionable. We do not deny medications like Lipitor for high cholesterol or Humira for rheumatoid arthritis. These are expensive and potentially lifesaving medications. IVIG is a blood product that is also expensive, but using it properly has reduced the mortality of pediatric rheumatological and neuroimmunological diseases dramatically. PANDAS/PANS is a medical condition with a distinct pathology that can be treated. And very simply, children in the US should NOT go without medical treatment.

The time to act is now. Please join AR, DE, IL, IN, MA, MD, MN, NH, RI, and KA by requiring insurance coverage for PANS PANDAS that aligns with the recent OR Medicaid Health Evidence Review Committee recommendations by fully supporting SB628. It will make life much better for the estimated 1 in 200 children and patients struggling with PANDAS/PANS.

Wishing you the best in all your endeavors,

Wendy C. Nawara, MSW, BCPA  
PANS/PANDAS Advocate and Consultant  
630.479.7143 | [wendy@wendynawara.com](mailto:wendy@wendynawara.com)