



Oregon Council of
Child & Adolescent
Psychiatry



OREGON PSYCHIATRIC
PHYSICIANS ASSOCIATION

Date: January 30, 2019

To: The Honorable Mitch Greenlick, Chair
Members of the House Health Care Committee

From: Craigan Usher, MD, President
Ajit Jetmalani, MD, Council member
Oregon Council on Child and Adolescent Psychiatry

Craig Zarling, MD, Co-Chair, Legislative Committee
Maya Lopez, MD, Co-Chair, Legislative Committee
Oregon Psychiatric Physicians Association

RE: Position statement on HB HB 2511

The Oregon Council of Child & Adolescent Psychiatry is an organization for medical doctors trained to diagnose and treat mental disorders in children, adolescents, and adults using biological, psychological, and social approaches. OCCAP is a regional organization of the American Academy of Child & Adolescent Psychiatry. The Oregon Psychiatric Physicians Association (OPPA), a district branch of the American Psychiatric Association, was established in 1966. OPPA serves as the organization for medical doctors (psychiatrists) in Oregon working together to ensure humane care and effective treatment for persons with mental illness, including substance use disorders, and compassion for their families.

Senate Bill 2511 seeks to increase awareness and support the identification and treatment of children who may be suffering from a profoundly disabling neuropsychiatric syndrome. We wanted to provide informational testimony for your consideration.

The 2015 PANS evaluation guideline (Chang et al) and 2017 treatment guidelines (Swedo et al) reflect practice based guidelines developed by a multidisciplinary group of clinical experts and researchers. As Dr. Swedo states, these clinical guidelines are based on evolving science and do not reflect an evidence base that is fully supported by randomized controlled studies. Many institutions, researchers and advocates are seeking better scientific clarity to diagnose, stratify and treat children who present with concentric circles of acuity, severity and symptom specificity. If this bill passed, legislation mandating dissemination of information about pediatric acute-onset neuropsychiatric syndrome (PANS) and pediatric autoimmune neuropsychiatric disorder associated with streptococcal infections (PANDAS) would occur before the scientific and clinical community has fully embraced well-established diagnostic findings and randomized controlled trials that demonstrate benefit to the population we are hoping to reach.

While newly described health conditions undergo rigorous study, the suffering of individuals who have the core or related findings, now, drive empiric treatments as a response to suffering; sometimes this creates untoward risk and adverse outcomes. In addition, people with some of the findings but not all, may seek treatments that developing guidelines caution should only apply to a narrow subset of individuals described. As such, people may feel that their insurance providers or medical providers are withholding vital treatment in situations where caution—about risks and benefits—may be prudent.

An information campaign at this stage of knowledge may increase confusion for families and care givers alike, raising the risk of decreasing access to effective care.

We acknowledge that children and families facing these profound developmental disruptions deserve care that is safe and effective. We want to advocate for them. We certainly have worked with many families and young people who clearly demonstrate the kinds of symptoms outlined in the PANS/PANDAS literature whom we desperately wish to help. Again, we want to find solutions for them that are safe.

Our concern with this legislation as written is two-fold. One, if we offer education about an *emerging* set of diagnostic criteria and nascent treatment guidelines that have not been thoroughly vetted and do so in a

manner that suggests conclusive evidence for diagnosis and safe, effective treatment has been reached, we risk providing false hope for families and alienating practitioners. We have seen this in our collaboration with colleagues who refuse to work with children with PANS/PANDAS spectrum illness—feeling that too many families come into clinic with expectations based on Facebook group discussion or other anecdotal evidence that they simply cannot meet. We hence want to make sure the state and treatment community take a pragmatic opposed to didactic approach to building awareness.

Our second concern with this legislation is that it may lead to misdiagnosis and improper and wide spread utilization of treatments that have significant risk, including IVIG, plasmapheresis and chronic broad-spectrum antibiotic administration—with accompanied risk of antibiotic resistant organisms to the general population.

Again, we emphasize that there is sufficient evidence to suggest PANS/PANDAS phenomena are real and potentially treatable. We would recommend formation of a multi-disciplinary panel of independent experts working with HERC to regularly review the evolving literature in preparation for periodically updated bulletins regarding PANS and PANDAS to Oregon Providers and families. Perhaps this panel could in turn determine scientific readiness for a more robust information campaign.

Thank you for the opportunity to provide information and to be a resource for the committee.

Chang K, Frankovich J, Cooperstock M, et al. Clinical evaluation of youth with pediatric acute-onset neuropsychiatric syndrome (PANS): recommendations from the 2013 PANS Consensus Conference. *J Child Adolesc Psychopharmacol*. 2015;25(1):3-13.

Swedo SE, Frankovich J, Murphy TK. Overview of Treatment of Pediatric Acute-Onset Neuropsychiatric Syndrome. *J Child Adolesc Psychopharmacol*. 2017;27(7):562-565.