

February 5, 2021

To: Oregon House Health Care Committee

Re: **Oregon's House Bill 2390**; Requires health benefit plan and health care service contract coverage of pediatric autoimmune neuropsychiatric disorders associated with streptococcal infections and pediatric acute-onset neuropsychiatric syndrome.

To Whom It May Concern:

We are writing to urge your legislators to support **Oregon's House Bill 2390**; advocating for health benefit and service contract coverage of pediatric autoimmune neuropsychiatric disorders associated with streptococcal infections (PANDAS) and pediatric acute-onset neuropsychiatric syndrome (PANS).

PANS/PANDAS is an abrupt-onset psychiatric disorder currently recognized, by our center and at least 15 other academic pediatric centers affiliated with Universities. Based on 3 imaging studies and at least 20 basic science publications, it has been concluded that inflammation is playing a role in the onset of symptoms of this debilitating psychiatric illness. Some cases are clearly triggered by an infection, while in other cases, the triggering agent is occult. Regardless, most cases respond robustly to medical therapy (antibiotics and/or immunotherapy) which can be curative as opposed to palliative.

Given the complexity and heterogeneity of host factors and different triggering agents, research and clinical trials are scarce; however, there is a phase 3 IVIG clinic trial that shows promise, and several additional planned trials on the horizon. Despite these efforts, the illness remains largely foreign to the medical and lay communities.

The first PANS Consortium meeting was held at Stanford in May 2013 where we (researchers and physicians from 7 University Medical Centers) met to outline the diagnostic workup of PANS and formulate research agendas. Since this meeting, we have published diagnostic and expert opinion recommendations that outline several therapy options, both antibiotics and immunotherapy, based on the host factors including documented triggers, unknown triggers, host factors, and severity of illness.

In the field of pediatric rheumatology, we treat a large number of autoimmune and autoinflammatory illnesses based on having only indirect evidence of immunological causes. Most of these diseases are managed with immunomodulation despite the absence of successful trials—and as a result, the morbidity and mortality of pediatric rheumatologic diseases have dramatically improved over the decades despite the lack of trials. Like PANS/PANDAS, rheumatologic diseases are difficult to study in trials due to insufficient numbers, high cost of trials, and vast heterogeneity of disease. Pediatric rheumatologic diseases are now being

treated according to Consensus Guidelines, and the different protocols are subsequently compared. In this model, the burden of cost goes to the insurer.

Despite the abundance of compelling basic science evidence, including both human and animal models, uninformed physicians and insurers are still turning away patients with treatable PANS/PANDAS. It is our opinion that the diagnosis and treatment of PANS/PANDAS is no longer “controversial” and now it is just a matter of refining the treatment and finding optimal regimens for the different subsets of PANS diseases.

Permanent debilitating neuropsychiatric sequelae occur when PANS/PANDAs go untreated. At Stanford, we have studied 300 patients with PANS, and it is clear that in many cases, untreated flares result in a worsened baseline and many patients become disabled by permanent neuropsychiatric symptoms. The state of Oregon could significantly reduce the burden of these psychiatric sequelae by increasing coverage for both medical and psychiatric therapies including but not limited to IVIG, steroids, and Plasmapheresis.

Thank you for your consideration of this request, your decision on this piece of legislation could make a substantial impact on the lives of these patients and their families. Kindly reach out with any questions or for additional resources evidence you may need to best inform your decision.

Sincerely,



Jennifer Frankovich, MD, MS

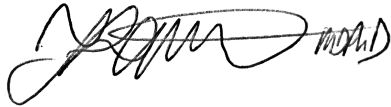
Clinical Professor | Pediatrics – Allergy, Immunology, Rheumatology
Co-Director, Stanford Children's Immune Behavioral Health Clinic
Director, Stanford Immune Behavioral Health Research Program
Stanford University School of Medicine
700 Welch Rd, Suite 301, MC: 5896 | Palo Alto, CA 94304



Margo Thienemann, MD

Clinical Professor of Psychiatry
Stanford University School of Medicine
Director of Psychiatry Services, Stanford Children's Immune Behavioral Health Clinic
Clinic Phone: 650-497-9063 or 650-736-4364 Clinic Fax: 650-736-4344

PANSclinic@Stanfordchildrens.org

**Theresa Willett, MD, PhD**

Clinical Assistant Professor | Pediatrics - Allergy, Immunology, Rheumatology

Co-Director, SCH Immune Behavioral Health Clinic

Stanford University School of Medicine

700 Welch Rd, Suite 301, MC: 5896 | Palo Alto, CA 94304

Ph: 650-497-9063 | FAX: 650-736-1525 | Mobile: 617-645-0938

twillett@stanford.edu