



JENNIFER FRANKOVICH, M.D., M.S.
Assistant Professor of Pediatric Rheumatology
Co-Director, PANS Clinic

KIKI CHANG, M.D.
Professor of Psychiatry
Director, Pediatric Bipolar Disorders Program
Co-Director, PANS Clinic

February 24, 2014

To: Massachusetts Senate Joint Committee for Financial Services
Re: ***Massachusetts Bill H.984: An act relative to insurance coverage for PANDAS/PANS***

Dear Financial Services Committee,

We are writing to urge your senate to support for ***Massachusetts Bill H.984: An act relative to insurance coverage for PANDAS/PANS.***

PANS/PANDAS is currently recognized, by our center, to be caused by inflammation. Some cases are clearly triggered by an infection, while in other cases, the triggering agent is occult. Regardless, most cases respond to medical therapy (antibiotics and/or immunotherapy). Given the complexity and heterogeneity of host factors and different triggering agents, it has been difficult to design clinical trials. Additionally, there has been a paucity of research in this area. However, this is changing. We held the first PANS Consortium meeting at Stanford in May 2013 where we (researchers and physicians from 7 University Medical Centers) met to outline the diagnostic work up of PANS and formulate research agendas. The diagnostic guidelines should be published soon. The PANS consortium will meet again in May 2014 to create Consensus Treatment Guidelines for PANS/PANDAS and we will plan to have these published by May 2015. These guidelines will outline a number of therapy options, both antibiotics and immunotherapy will be included and will be 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 on the basis of 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 has 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 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.

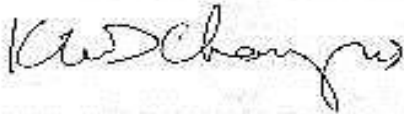
Long lasting and often permanent neuropsychiatric sequelae occur when PANS/PANDAs goes untreated. At Stanford, we have studied 60 patients with PANS and it is clear that in many cases, untreated flares result in a worsened baseline and many patients become disabled by permanent neuropsychiatric symptoms. Your state could 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 and please feel free to contact us with any questions.

Sincerely,



Jennifer Frankovich, M.D., M.S.
jfranko@stanford.edu
Assistant Professor of Pediatric Rheumatology
Co-Director, PANS Clinic
Stanford University School of Medicine



Kiki Chang, M.D.
kchang88@stanford.edu
Professor of Psychiatry and Behavioral Sciences
Director, Pediatric Bipolar Disorders Program
Co-Director, PANS Clinic
Stanford University School of Medicine