

February 17, 2021

Dear members of the Healthcare Committee,

First of all we want to acknowledge your dedication and service to the community.

We are writing to ask you to support HB 2390. I, Nathalie Paravicini, am a Dr. who treats cases of neuropsychiatric disturbances related to chronic infections. I want to share the case of one of my recent patients, to illustrate why it is unacceptable to have treatment denied purely for profit motives.

A.V. presented to the clinic with behavioral disturbances so severe, that at 9 years old he was recommended to be institutionalized – yes, separated from his family and placed in an institution for severe psychiatric disorders. His symptoms began soon after traumatic and poorly managed dental procedures. He developed extreme OCD, with severe meltdowns, combative behavior and sensory disturbances.

Mom refused; she looked for alternatives and was referred through a parent's group. Within 2 months of treatment to address the neuroinflammatory process, his OCD behavior decreased from taking 80% to 30% of his daily routines. It took another 20 months of treatment for him to have a "normal" life. While he sometimes still has difficult days with flares of OCD; A.V. was recently able to go to do a lab draw and even go to the dentist for two consecutive appointments.

I am presenting the case for several reasons:

1. The field of behavioral health is still very new and evolving. We are just starting to understand how physical factors contribute to behavior disturbances.

Although PANDAS/PANS has now been clearly demonstrated by research showing the presence of autoimmune receptors in the brainstem¹, that knowledge has not yet permeated through the medical sector: witness the recent AAP recommendations which are out of step with research.

¹ Jian Xu, Ph.D., Rong-Jian Liu, Ph.D., Shaylyn Fahey, B.S., Luciana Frick, Ph.D., James Leckman, M.D., Ph.D., Flora Vaccarino, M.D., Ronald S. Duman, Ph.D., Kyle Williams, M.D., Ph.D., Susan Swedo, M.D., Christopher Pittenger, M.D., Ph.D. (2020). Antibodies From Children With PANDAS Bind Specifically to Striatal Cholinergic Interneurons and Alter Their Activity. *American Journal of Psychiatry*. Published Online:16 Jun 2020
<https://doi.org/10.1176/appi.ajp.2020.19070698>

This is how a 9-year-old kid would have been sent to a psych ward, for what was actually an infectious/inflammatory process.

2. Behavioral health still receives inadequate attention and funding. Patients are given psych meds and/or dismissed as being the problem, like A.V. Even though there are clear high-level consensus papers as to diagnosis and treatment² coverage is still being denied.

The issues of inadequate coverage for neuropsychiatric conditions is particularly relevant because of the number of houseless/incarcerated people who suffer from psychiatric problems. *That is absolutely unacceptable. Would you allow insurance companies to deny recommended treatment for cancer or for multiple sclerosis?*

3. The costs to society are staggering, beyond what effective treatment would cost. We have to include the loss of income and loss of savings from parents, cost overruns in behavioral health care services (in addition to the unnecessary increased burden on that sector), loss of function and productivity of those affected, disability if left untreated - in addition to the personal tragedy of the affected families. *This becomes an economic and ethical imperative.*

4. This condition affects children more than adults – kids do not have the understanding or political standing to advocate for themselves. Even when parents try to advocate for their children, they are dismissed; *the problem is attributed to the family environment or uncooperative child, just as in the case of A.V.*

5. It is time we put Doctors in charge of healthcare in America; not insurance companies with a vested interest in increasing profits (ie increasing disease).

The US has the highest administrative costs of any industrialized nation (about 34% of total health care expenditures in the US)³. While overall healthcare costs continue to increase, life expectancy in the US started declining since 2014!!⁴

Furthermore, I do not know of a single doctor who is not frustrated EVERY SINGLE DAY by the burden of administrative hoops to get payment for services and needed medications paid for. Doctors are overseen by boards, complete CE every year and pay for malpractice insurance: we are surely able to decide on the best course of action for patients!

² Jennifer Frankovich, Susan Swedo, Tanya Murphy, Russell C. Dale, Dritan Agalliu, Kyle Williams, Michael Daines, Mady Hornig, Harry Chugani, Terence Sanger, Eyal Muscal, Mark Pasternack, Michael Cooperstock, Hayley Gans, Yujuan Zhang, Madeleine Cunningham, Gail Bernstein, Reuven Bromberg, Theresa Willett, Kayla Brown, Bahare Farhadian, Kiki Chang, Daniel Geller, Joseph Hernandez, Janell Sherr, Richard Shaw, Elizabeth Latimer, James Leckman, Margo Thienemann, and PANS/PANDAS Consortium.

Clinical Management of Pediatric Acute-Onset Neuropsychiatric Syndrome: Part II—Use of Immunomodulatory Therapies. *Journal of Child and Adolescent Psychopharmacology* Vol. 27, No. 7 Guidelines

Published Online: 1 Sep 2017 <https://doi.org/10.1089/cap.2016.0148>

³ Health Care Spending in the United States and Other High-Income Countries, Irene Papanicolas, PhD; Liana R. Woskie; Ashish K. Jha, MD, MPH. *JAMA*. 2018;319(10):1024-1039. doi:10.1001/jama.2018.1150

⁴ <https://www.aafp.org/news/health-of-the-public/20181210lifeexpectdrop.html>, accessed Feb 12, 2021

We personally find it absolutely unacceptable that we have to spend personal time to press for legislation, so that insurance companies be required to pay for recognized and recommended consensus treatment, for an established documented condition – because it affects behavioral health and primarily children.

Insurance companies were established for exactly that purpose: to spread the costs of large medical expenditures and facilitate preventative care. It is inadmissible that insurance companies are denying to fulfill their stated mission – in the process worsening outcomes and increasing costs for society.

This issue will not go away because we are seeing an increasing number of patients with this condition.

On behalf of our colleagues -both medical and behavioral health practitioners- my patients and their families, we urge to sponsor and support HB 2390.

Please feel free to contact me should you have any questions.

Thank you for your service to the community,

Greetings

A handwritten signature in blue ink, appearing to read 'Nathalie Paravicini'.

Nathalie Paravicini, ND
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