



JANEL BRANDTJEN

STATE REPRESENTATIVE • 22ND ASSEMBLY DISTRICT

Testimony for Assembly Bill 722

Thank you Chairman Sanfelippo and the Assembly Committee on Health for holding this hearing today.

Twenty five years ago, researchers at the National Institute of Mental Health started noticing two distressing trends in a number of young children aged 3 to 12. Pediatric Acute-Onset Neuropsychiatric Disorder (PANS) is a condition caused when an infectious trigger creates a misdirected immune response and results in the inflammation of a child's brain. In turn, the child exhibits abrupt overnight symptoms including tics, irritability, depression, anxiety, sensory abnormalities, sleep disturbances, behavioral regression and more.

Similarly, Pediatric Acute-Onset Neuropsychiatric Disorder Associated Streptococcal (PANDAS) is a condition specifically caused when a strep infection is connected to the sudden onset of obsessive compulsive disorder (OCD) along with other listed clinical symptoms. PANS can be triggered by any infectious agent, while PANDAS is strictly triggered by strep. PANS and PANDAS also have different diagnosing criteria.

The fast change in children's behaviors can leave parents bewildered and searching for a diagnosis while handling the stress of treating the symptoms. Children are unable to attend daycare, parents have to take days off work, and medical bills pile up. These costs include visits to speech pathologists, physical therapists, psychiatrists, tutors, and other services that would be included in a typical diagnosis.

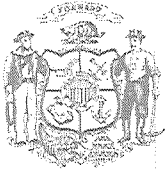
The testimony you will hear today describes the horrors of the disease, the atrocious impact on families, and the financial costs associated with the disease when it goes untreated. However, the most important takeaway today is that all the suffering, hardships and despair can be easily avoided with the right diagnosis. Unfortunately, for many diseases there is no solution and there is little the legislature can do. That is not the case here. We can act now to prevent families from future suffering due to misdiagnosis.

AB 722 would improve the awareness, education and help for the possible 7,000 children living with undiagnosed PANS/PANDAS in Wisconsin. This legislation is aiming to drastically reduce the number of undiagnosed children, and therefore, saving taxpayers and citizens the high costs of medical bills and unneeded stress. AB 722 would raise awareness and increase the possibility of early diagnosis, which is beneficial for the child, the family, and the community. The bill requires that practicing pediatricians view two hours of online instructional material, to be included in the 30 hours of continuing education that is already required. The educational material is now available and would be provided at no cost, for minimal financial impact on Wisconsin. The bill would sunset in two years for minimal footprint on the continuing education program for doctors.

Thank you,

A handwritten signature in black ink that reads "Janel Brandtjen". The signature is fluid and cursive, with the first name "Janel" being more prominent.

Representative Brandtjen



ANDRÉ JACQUE

STATE SENATOR • 1ST SENATE DISTRICT

Phone: (608) 266-3512

Fax: (608) 282-3541

Sen.Jacque@legis.wi.gov

State Capitol • P.O. Box 7882

Madison, WI 53707-7882

*Testimony before the Assembly Committee on Health
State Senator André Jacque
January 29, 2020*

Chairman Sanfelippo and Committee Members,

Thank you for holding this hearing on Assembly Bill 722, relating to requiring pediatricians and pediatric specialists to complete continuing medical education specific to neuroimmune disorders in children.

PANS (Pediatric Acute-Onset Neuropsychiatric Syndrome) is a treatable neurological disorder associated with the inflammation of the brain, that features seizures, OCD, tics, anxiety, motor and sensory impairments, restricted eating, and loss of motor and cognitive abilities in some cases.

PANS can become a life threatening condition, with some children taking their own lives, jumping out of moving vehicles, and otherwise exhibiting erratic and unpredictable behavior. Research from Stanford shows that families of children with PANS experience levels of caregiver burden so substantial that they are compared to diseases considered debilitating.

Taxpayer dollars are spent on school services, inpatient psychiatric care, residential treatment, and medication for children that go without proper diagnoses. In many cases, prompt treatment requires no more than a course of antibiotics.

The National Institute of Mental Health (NIMH) estimates that up to 30 percent of children being treated for mental health disorders could be restored to health by proper diagnosis and treatment of PANS. By NIMH estimates, 7,000 to 28,000 children in Wisconsin are suffering from PANS and have not received a proper diagnosis due to lack of awareness and education. Currently, less than 1% of Wisconsin children with PANS are treated within the state so most families must travel out of the state to seek treatment.

Last session the Assembly unanimously passed a similar bill that created a 15-member advisory council within DHS, made up of pediatricians, parents with affected children, medical researchers, physicians and others. Since then, an online training seminar featuring experts from Stanford University, University of California-San Francisco, Rutgers, and other top institutions that will assist medical doctors in diagnosing these debilitating diseases, has been developed and is funded by Foundation for Children with Neuroimmune Disorders, a 501c3 nonprofit organization. This new approach will be more effective and less expensive than an advisory council.

Assembly Bill 722 sunsets in two years, has no costs to physicians, and requires only two total hours of education, which can be completed at any point within the two-year period.

Thank you for your consideration of Assembly Bill 722.

Dr. Erica Guetzlaff

mom of 2 children with PANS/PANDAS

Three years ago, our happy, outgoing six-year old got sore throat. We went to urgent care, where the doctor followed a well-established protocol of a throat swab and antibiotics for strep throat. Shortly after finishing the course of antibiotics, everything changed. Our vibrant, carefree girl was gone—literally overnight. She developed severe OCD, washing her hands until they bled and having scary, violent intrusive thoughts. She sobbed as she confessed every tiny wrongdoing of her short life, another common OCD behavior. She had auditory (hearing), sensory (touch) and olfactory (smell) hallucinations. She had urinary frequency and became afraid to go anywhere far from a bathroom. She began having vocal tics, saying the phrase, “I might have just spit on that” hundreds of times a day. At the height of her illness, she said to me, “Mommy, I know this will make you sad, but I wish I could die so all of this would go away”. We thought surely our daughter had a brain tumor or something of the sort. In a panic, we went to the doctor again. The doctor said, “It’s going to be okay. We know just what to do”. We breathed a sigh of relief. The doctor continued, “We will get her referred to a great therapist”. We nearly fell off our chairs. A therapist? At a loss, we took the appointment and bought a book on parenting a child with OCD.

The second chapter of the parenting book was about PANS/PANDAS. It described our daughter’s illness exactly.

We called the doctor again and asked about PANDAS; she didn’t know about it but put in referrals to Immunology, Infectious Disease and Neurology. All three clinics denied the referrals, stating they don’t treat PANDAS. By now our family was in a complete state of crisis. We drove to Illinois to see a PANDAS specialist, who diagnosed our daughter and told us what to do to help our daughter. We returned to Wisconsin and begged for the care we knew she needed. We told the doctors what the specialist said, and printed articles from medical journals and information from the National Institutes of Health to support our requests. We kept telling our story until someone listened and helped us. The good news is that our daughter is doing amazing. She is again our happy, outgoing, vibrant girl with many friends and a budding gymnastics career. My husband and I, however, are still dealing with the trauma of those 4 months. The system we had placed our trust in to be

there for us when illness struck had failed us in every way. We watched our daughter suffer immensely and felt powerless. We paid thousands of dollars for doctor visits that weren't covered by insurance and traveled out of state to see them. This disease has the potential to destroy children and to tear families apart.

One of the providers at my daughter's clinic guiltily refers to himself as part of my daughter's "failed care team". This disease can be as easy to treat as the strep throat that started it all, but providers don't know and they're not learning it in medical school. Yes, my husband and I take every opportunity to educate a provider or nurse (or anyone, really!) about PANS/PANDAS, but we're two people. It devastates us to think about the children who are currently misdiagnosed and not getting any better despite therapy appointments, psychiatric medications or stays in a psychiatric hospital. Our society is paying the price for the misdiagnosis of PANS in many ways.

Our nation is in a mental health crisis, particularly of our youth, and I promise you misdiagnosed PANS is part of it. Let's let Wisconsin lead the way. Let's let other states wonder why, in 2 years, our ER visits are down for youth in mental health crisis or why we are seeing fewer behavioral issues in our schools. Let's empower our providers to know better and then do better.



University of Wisconsin
SCHOOL OF MEDICINE
AND PUBLIC HEALTH

Department of Medicine
Allergy, Pulmonary and Critical Care Medicine

Pierre Kory, MD, MPA
Medical Director, Trauma and Life Support Center
Chief, Critical Care Service
University of Wisconsin School of Medicine and Public Health

January 28, 2020 Re: AB 722

Dear Health Committee,

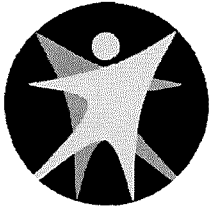
I am writing in support of AB 722 which would mandate participation of Wisconsin pediatricians in free CME on-line video webinars intended to increase their ability to both recognize and treat children with inflammatory brain disorders such as PANS (pediatric autoimmune neuropsychiatric disorders).

The current understanding and comfort level with these disorders among the pediatric health care community is leading to widespread, incalculable harm given how common they are: by NIMH estimates, there are between 7,000 and 28,000 children in Wisconsin with a neuroimmune disorder like PANS or PANDAS, most of whom are not having their medical needs met in state.

The lack of recognition and treatment is leading to burdensome and ineffective psychiatric referrals with many instances of inappropriate psychiatric hospitalizations - please note the recent and multiple reports of suicides by kids devastated by their poorly controlled symptoms. This is truly a major health issue in the community, and although, yes, there are many deserving health care topics clinicians should be educated about, I would maintain that none encounter the poverty of insight and understanding by clinicians that PANS has - it, without a doubt, has the worst mismatch between general knowledge and frequency of disease in Pediatrics- i.e "the most common disease that no-one knows about". Please help correct this travesty and prevent more children and families from the devastation wrought by the ineffective care widespread throughout our system.

Kindest Regards,

Pierre Kory, MD, MPA, Medical Director, Trauma and Life Support Center
Chief, Critical Care Service, Associate Professor of Medicine
Division of Allergy, Pulmonary, and Critical Care, University of Wisconsin Hospital and Clinics
University of Wisconsin School of Medicine and Public Health



State of Wisconsin
Department of Health Services

Tony Evers, Governor
Andrea Palm, Secretary

TO: Members of the Assembly Committee on Health

FROM: Lisa Olson, Legislative Director

DATE: January 29, 2020

RE: AB 722, relating to: requiring pediatricians and pediatric specialists to view presentations about neuroimmune disorders in children

Thank you for the opportunity to submit written testimony for information only on Assembly Bill (AB) 722. AB 722 requires each physician who specializes in general pediatrics or a pediatric specialty to view at least 2 hours of live presentations or webinars about neuroimmune disorders in children, including pediatric acute-onset neuropsychiatric syndrome (PANS) and autoimmune encephalitis. The webinars or live presentations would have to be designated by the Department of Health Services (DHS) and approved as a continuing education program or course of study by the Medical Examining Board (MEB). DHS would also be required to select several dates during both 2020 and 2021 for the live presentations or webinars and make that information available on its web site.

While the Department works closely with hospitals, local and tribal public health departments, and individual providers on a number of public health programs and services, DHS does not believe this is an appropriate topic for which it should designate training materials for physicians.

Given the uncertainty related to the population-level health impact of this syndrome and the absence of scientific consensus surrounding best clinical practices, the Department does not believe it is appropriate for us to designate required training materials for physicians. Further, the Wisconsin medical community as a whole remains undecided about PANS/PANDAS diagnosis and treatment. The etiology of these syndromes has yet to be determined, and there is a lack of consensus among physicians about their existence as distinct clinical entities. For these reasons, the Department is supportive of the MEB maintaining an oversight role on continuing education decisions for their members.

If members of the committee have questions surrounding the Department's testimony on this bill, please do not hesitate to contact me at 608-266-3262 or lisa.olson@dhs.wisconsin.gov.



Wisconsin Medical Society

TO: Assembly Committee on Health
FROM: HJ Waukau; Director, Policy
DATE: January 29, 2020
RE: Opposition to Assembly Bill 722 – requiring physicians and pediatric specialists to view neuroimmune disorders in children

The Wisconsin Medical Society (Society) is the largest association of physicians in Wisconsin, and it is our mission to improve the health of the people of Wisconsin by supporting and strengthening physicians' ability to practice high-quality patient care in a changing environment. The Society appreciates the efforts of the authors to try and improve care for the patients of Wisconsin. However, we think that AB 722 creates unnecessary government interventions into healthcare and imposes improper mandates on the education and training of physicians. For these reasons we **oppose AB 722**.

Physicians are the best judges of what education they need to serve their patients. The continuing medical education (CME) requirement created by AB 722 assumes that physicians do not already devote significant time and resources towards learning about new and emerging health care issues, preventions, and treatments. Keeping up to date on the newest treatments and diagnoses is a core part of the physician profession and responsibility. Mandating training through legislation disrupts that process and creates a slippery slope for future government interventions. In addition, government-mandated CME could take certain education opportunities away from physicians as they are only offered at certain times and locations throughout the year.

Physicians are already required under state law to complete 30 hours of CME per two-year cycle on top the requirements placed on them for their board certifications. Additional government mandates for education will only create more administrative burden for physicians. For example, the recent opioid CME requirement that applied to most physicians was successfully created through the action of the Medical Examining Board, not through legislation.

We appreciate the concerns of the bill authors to try and address a situation they believe merits consideration. But it is the Society's position that the CME requirement created by AB 722, while well-intentioned, is another example of government interference and regulation in medicine.