



JANEL BRANDTJEN

STATE REPRESENTATIVE • 22ND ASSEMBLY DISTRICT

Testimony for Assembly Bill 638

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 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.

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 would be included in a typical diagnosis.

AB 638 would create an advisory council to 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, saving taxpayers and citizens the high costs of medical bills and unneeded stress. AB 638 would raise awareness and increase the possibility of early diagnosis, which is beneficial for the child, the family, and the community.

Thank you,



Representative Brandtjen

Alberta Darling
Wisconsin State Senator
Co-Chair, Joint Committee on Finance

TESTIMONY BEFORE THE ASSEMBLY COMMITTEE ON HEALTH
Assembly Bill 638
Wednesday, December 13, 2017

Thank you, Chairman Sanfelippo and committee members for holding a public hearing on Assembly Bill 638. The legislation before you today creates an advisory council within Department of Health Services to spread awareness of proper diagnosis and treatment for children with Pediatric Acute-Onset Neuropsychiatric Syndrome (PANS) and Pediatric Autoimmune Neuropsychiatric Disorders Associated with Streptococcal (PANDAS).

PANS and PANDAS are clinical diagnoses given to children who have a dramatic, sometimes overnight onset of neuropsychiatric symptoms. These disorders seize children's sensory and motor functions. They inflict tics, depression, aggression, insomnia, irritability, anxiety, and obsessive-compulsive symptoms. Like PANS, children with PANDAS exhibit similar symptoms, but patients test positive for a recent streptococcal infection.

The National Institute of Mental Health estimates that up to 30 percent of children currently being treated for mental health disorders could be restored to health by proper diagnosis and treatment of PANS or PANDAS. Most children with PANS or PANDAS in Wisconsin are not receiving proper medical care because their condition remains undiagnosed due to a lack of awareness and education of these disorders. This is causing families to travel out of state for treatment. Not only does this affect children, but it puts financial, mental, and emotional stress on entire families.

AB 638 will bring Wisconsin in line with 28 other states that have already recognized the severity of these diagnoses by creating similar councils. By promoting awareness, we can help children get proper medical treatment, which in many cases requires no more than a course of super-antibiotics.

I'd like to thank the many families who reached out to make us more aware of the situation. I would also like to thank Representative Brandtjen for her leadership on this issue. Thank you committee members for holding a hearing on AB 638 and I hope I can count on your support.

PANS and PANDAS

Pediatric Acute-Onset Neuropsychiatric Syndrome (PANS) is a clinically defined disorder characterized by the sudden onset of obsessive-compulsive symptoms (OCD) or eating restrictions, plus any two of the following:

- Anxiety
- Emotional Lability and/or Depression
- Irritability, Aggression, or Oppositional Behaviors
- Behavioral (Developmental) Regression
- Sudden Deterioration in School Performance
- Motor or Sensory Abnormalities
- Sleep Disturbances, Enuresis, or Urinary Frequency

Pediatric Autoimmune Neuropsychiatric Disorders Associated with Strep (PANDAS) is a *subset* of PANS. Unlike PANS, in which the trigger is not defined, diagnosis of PANDAS requires association with strep.

What is the impact on Wisconsin children?

Using NIMH data, there are an estimated 7000 children in WI with PANS.

Children with PANS/PANDAS frequently receive diagnoses of Tourette's, OCD, generalized anxiety disorder, depression, bipolar, oppositional defiant disorder, mood disorder, conduct disorder, anorexia, autism, and even childhood schizophrenia.

Most children with PANS in Wisconsin are not receiving proper medical care because their condition remains undiagnosed due to lack of awareness and education in Wisconsin. Nationwide, 33% of children see more than five doctors before being correctly diagnosed.

Wisconsin families who have a suspicion their child has PANS and have the financial means are traveling to Illinois to seek medical treatment. Consumer dollars are leaving Wisconsin as parents seek care in other states. Illinois has passed legislation creating an advisory council on PANS/PANDAS to educate medical providers, schools, therapists, etc.

What is the cost to taxpayers in Wisconsin?

Astronomical amounts of money are spent on in-patient psychiatric care, residential treatment, and psychiatric and anti-psychotic medications for children with undiagnosed PANS funded by Medicaid. The costs associated with one night in an in-patient psychiatric unit could adequately cover medical treatment for the majority of children with PANS. In many cases, prompt treatment of PANS requires no more than a course of antibiotics and NSAIDS similar to what would be used to treat strep throat or a respiratory infection. The mental health, motor skills, and cognitive functioning of many children with PANS is promptly restored with simple, safe, cost effective medical treatment. PANS can generally be diagnosed clinically based on symptoms.

Children with PANS often have significant regressions involving handwriting, fine motor, and math skills requiring special education services and IEPs in the school system. When PANS is not diagnosed and treated, children can require special education and occupational therapy services throughout their time in school.

The NIMH estimates up to 30% of children being treated for mental health disorders could be restored to health by proper diagnosis and treatment of PANS.

Generally, the longer a child remains undiagnosed and untreated, the greater the costs to treat PANS.

Where does Wisconsin stand compared to other states in addressing PANS?

28 states are working on or have passed legislation related to PANS. Other states have developed advisory councils that raise awareness and make recommendations for doctors, therapists, and schools related to promoting access to care and treatment.

Illinois PANS/PANDAS bill: <http://www.ilga.gov/legislation/publicacts/99/099-0320.htm>

Virginia PANS/PANDAS bill: <https://lis.virginia.gov/cgi-bin/legp604.exe?171+ful+HB2404>

Resources for Medical Providers

The PANDAS Physician Network (*Advised by physicians from Harvard, Yale, Georgetown, Columbia, Stanford, and the NIMH*)
www.pandasppn.org

Stanford PANS Clinic Academic Site
<http://med.stanford.edu/pans.html>

The Journal of Child and Adolescent Psychopharmacology
February 2015 Edition (available in entirety www.moleculeralabs.com)

The National Institute of Mental Health
<https://www.nimh.nih.gov/health/publications/pandas/index.shtml>

Many doctors are unaware of the significant body of research that has been completed in the past decade and still believe the myth that PANS is “controversial” because they’re not apprised of the latest research. Most are unaware, for instance, that Stanford has been running a successful PANS clinic for five years. The PANDAS Physician Network remains underutilized by Wisconsin providers as most are unaware of its existence.

The PANDAS Physician Network provides guidelines for diagnosis and treatment of PANS. Membership is open to Physicians, Nurse Practitioners, Registered Nurses, Physician Assistants, Psychologists, Social Workers, and Therapists.

Clinical Research Consortium

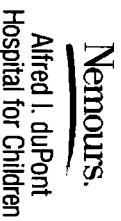
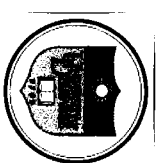
University of Arizona is one of the Founding Members of the National University Consortium on Pediatric Autoimmune Neurological Disorders



Yale University
School of Medicine



Seattle Children's
HOSPITAL · RESEARCH · FOUNDATION



PANS/PANDAS Clinical Research Consortium

National Standard Endorsement

The Consortium currently represents 25 different academic institutions from across the US, Canada and Australia, and includes not only clinicians with expertise in the diagnosis and treatment of PANS/PANDAS, but also experts in the fields of child psychiatry, pediatrics, infectious diseases, microbiology, neurology, neuroimmunology, immunology and rheumatology. **The contributing authors and all members of the PANS/PANDAS Clinical Research Consortium unanimously approved the final sets of guidelines. Thus, the guidelines truly represent a national standard of care, and the use of IVIG for moderate-severe PANS/PANDAS has been endorsed as a "best practice" by clinicians from all across the US and beyond.**

Pierre Kory, MD, MPA
6006 N. Highlands Ave
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212-518-1420
pkory@wisc.edu

December 11, 2017

Dear State Assembly Member,

I am writing today in support of Assembly Bill 638, a bill that has been created to ensure medical attention for children who fall ill with Pediatric Auto-Immune Neuropsychiatric Disorders.

Briefly, the reasons for my support are multiple:

- 1) My daughter, Ella Kory, aged 12, fell ill with a severe case of PANDAS a little over a year ago and subsequently suffered through evaluations by no less than 25 different physicians and specialists over 6 separate medical and psychiatric hospitalizations before an accurate diagnosis was made and effective therapy was initiated.
 - a. The prolonged and intractable suffering experienced by my daughter due to her uncontrollable and distressing verbal and motor tics and anxieties led me to unfortunately fall ill with PTSD, something I could never have imagined would befall me – ever.
 - b. The pervasive and systematic ignorance displayed by clinicians from multiple specialties within so many healthcare facilities has not been solved, despite the creation of a popular documentary which details the widespread failure of medical professionals in many regions of the United States to accurately diagnose and treat this disease (see trailer for documentary at www.mykidisnotcrazy.com).
- 2) The delay was inexcusable and insufferable. As an accomplished physician (I am currently the Medical Director of the main ICU at the University of Wisconsin, called the Trauma and Life Support Center. I have taught medicine for almost two decades and have a special focus on the methods and art of medical diagnosis. This horrific situation **MUST** be corrected in order to prevent more children from being unnecessarily hurt the way my daughter (and our whole family) was. I hope this bill will in some significant way begin the process of doing that – raising awareness and ensuring treatment for this terrible disease.
- 3) Please note that after the horrific delay in diagnosis and treatment, my daughter was eventually accurately diagnosed and effectively treated – however, it required a desperate visit to a specialist in Illinois for this to happen. Despite this, please note that the therapies used were **ALL** nearly immediately impactful and, without overstatement, saved all of our lives. Those therapies included plasmapheresis, IVIG, tonsillectomy/adenoidectomy, and chronic antibiotics. My daughter is now completely back to normal and has returned to

school after missing 7 months – thus, these treatments must be available and covered to avoid further cases of extreme harm similar to what befell my beautiful family.

Sincerely,

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

** Please note that this was a personal appeal letter and thus was not written on behalf of, or with the knowledge of, the University of Wisconsin.

Amy N. Malik, MD



6006 N. Highlands Ave
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amalik7@wisc.edu

December 5, 2017

Dear Representative,

My previously healthy 12-year-old daughter developed sudden onset of extreme emotional lability, bizarre behavior and neurologic tics not long after she was treated for pneumonia. She received several different psychiatric diagnoses from several different physicians. She was treated with high doses of psychiatric medications, not one of which offered relief of her symptoms or suffering. I asked all of her treating doctors if this was PANS/PANDAS and was told definitely that she did not have PANS/PANDAS.

As a physician and as a mother, I knew that she did not have “anxiety” or “panic disorder” (as she was being incorrectly labeled). Eventually, she became symptomatic 24 hours/day with severe uncontrollable movements (tics), loud outbursts of screaming and frequent episodes of catatonia. Her little sisters were scared to be around her. She eventually stopped eating and required an emergency department visit in light of dehydration with a subsequent admission to the ICU for sedative infusions to control her symptoms. Prior to the ICU admission, she had been hospitalized no less than 5 times in both medical and psychiatric facilities. Not one doctor could effectively diagnose what was wrong with her nor find any medication that relieved her symptoms.



I had to leave Wisconsin in order to find a physician who could provide a rational, expert diagnosis with an effective treatment plan – the diagnosis indeed turned out to be severe PANDAS. This pediatrician in Illinois (Dr. Miroslav Kovacevic) saved the life of both my daughter (and myself) by finally providing an answer and an escape route out of all the suffering over a period of 4 months. Fortunately, after antibiotics, several immunomodulatory therapies (including plasmapheresis, IVIG, rituximab) and a tonsillectomy, I am relieved to report that my daughter is 100% back to normal health. Please note that her response to these therapies was profound, rapid, and sustained.

Therefore, as a mother and a physician, I am in strong support of Assembly Bill 638 so all children with this devastating disorder can be properly diagnosed and treated within a timely fashion.

Sincerely,

Amy Malik MD
6006 N Highlands Avenue
Madison, WI 53705
Cell 917-605-4492



My son has been struggling with aggression, obsessive thoughts, tics, anxiety, school work including math and handwriting, and general socialization since he was 3 years old. We've seen behaviorists, occupational therapists, several psychologists, counselors, neurologists, and most recently an immunologist. He has been on every type of psychotropic drug imaginable without any improvement. We had a blood test in November of 2013 that showed high levels of strep (940, normal range 0-240) in Sawyer's system. We were told this may be PANDAS and started researching treatment options. Sawyer had his tonsils and adenoids out in January of 2014.

My son saw pediatric neurologist Dr. Ikonomodou in Spring 2014. She did all of the common neurology testing and then diagnosed my son with PANDAS. She ordered an IVIG treatment for him in June 2014 (which required a stay at AFCH). My son experience two solid years of improvement and even "graduated" from his IEP at school. In Fall 2016, symptoms such as tics, anger outbursts, trouble with math, poor handwriting, and obsessive thoughts came back. We contacted Dr. Ikonomodou in January 2017 to see if we can be treated further, and she responded and said our son no longer had PANDAS. I asked what our options were to seek further treatment and the scheduling person at neurology said we could see another neurologist. I reluctantly scheduled an appointment with Meredith Schultz and saw her on March 1, 2017. At the appointment, the first thing Dr. Schultz said when she entered the room to meet us is that she does not order IVIG for PANDAS patients. She then went on to explain that the success we saw from the IVIG the first time around was likely a placebo effect.

We have been on a rollercoaster for most of Sawyer's childhood years. We found drastic improvements after the IVIG treatment in June 2014 and are seeking continued treatment. We have established care with Dr. Don Bukstein, an immunologist who has recommended another round of IVIG treatments. Dr. Ikonomodou finally ordered another IVIG infusion at the end of September 2017.

I'm in favor of Bill 638 so we can continue to learn about PANDAS/PANS and how we can treat our kids so they can be successful in all areas of their lives.

Thank you,
Tonya Schmidt

Dear Members of the Health Committee:

I am writing to obtain your support for Assembly Bill 638: An act relating to the creation of an advisory council for PANDAS/PANS. This bill provides support for families struggling with Pediatric Autoimmune Neuropsychiatric Disorder Associated with Streptococcus (PANDAS) and Pediatric Acute-Onset Neuropsychiatric Syndrome (PANS). Research is showing that PANDAS/PANS is a type of autoimmune encephalopathy (inflammation and swelling of the brain) usually brought about by a strep infection. It is very serious and can be life threatening.

Misdiagnosis of this disorder is very common. Often these children are labeled mentally ill with bi-polar disorder, obsessive compulsive disorder, Tourettes Syndrome, Attention Deficit Disorder, and are sometimes even misplaced on the Autism Spectrum. But what you must understand is that those labels only speak to the symptoms of the true underlying physiological medical condition. In children with PANDAS or PANS, the antibodies created in response to an infection mistakenly attack the brain and cause brain swelling and inflammation, an encephalopathy. If caught early, a simple long course of antibiotics can significantly improve the symptoms and abate the disorder. If the disorder has been missed or is more severe, immunomodulatory treatment such as IVIG (Intravenous ImmunoGlobulin) or Plasma Exchange is needed. But sadly, this is not what is happening for most of our families. This is because our frontline doctors, mental health providers, and school personnel do not know what they are seeing when they are seeing it.

But our families, on the other hand, certainly do know that something is wrong. They can tell you the day and sometimes even the hour that they witnessed the change in their children. Sometimes they report that the child they put to bed is not the same child who woke up the next morning. This abrupt change led them to seeking help in their schools, from counselors and therapists, from their doctors, as well as numerous other medical specialists. The symptoms that are displayed lead families to pediatrics, infectious disease, immunology, rheumatology, otolaryngology, neurology, psychiatry, and psychology. And most of these doctors just shrug their shoulders, and in the worst cases, give up entirely. Because they just don't know enough to help our families.

There is presently a tidal wave of medical change happening in all areas of neuroimmune illness. In the last few months the Journal of Child and Adolescent Psychopharmacology devoted an entire issue to the PANDAS/PANS phenomena, detailing a very clear standard of care. Top medical institutions like Stanford, Harvard, Yale, Duke and the National Institutes of Health and Mental Health are working tirelessly to both study and treat children with this complicated condition. There are 32 states currently engaged in legislative action; IL most recently passing PA 100-0024, Charlie's Law, to ensure insurance covered care and leading to the change of insurance policies across the country. But still our doctors, our therapists, our schools too often do not know how to help us.

The creation of this Advisory Council is the first step in getting PANDAS/PANS families the help they need. I sincerely hope that you will be part of this positive transformation by supporting Assembly Bill 638. Your favorable vote will allow for these brave children to be diagnosed quickly and treated appropriately.

Best regards,

Wendy C Nawara, MSW
PANDAS/PANS Advocacy and Support

Written Testimony Pertaining to Assembly Bill 638

December 10, 2017

On the first day of kindergarten, our youngest daughter happily hopped on the bus and waved goodbye. She was creative, academically advanced and incredibly social, making friends easily. In February, she got strep throat, a common bacterial infection in young children. After two days on antibiotics, her throat felt much better. Shortly after the antibiotics were finished, however, she began to experience symptoms very new to her: Anxiety, frequent urination, OCD and hallucinations. Gradually these symptoms increased and she also developed vocal tics, sensory processing disturbances and academic regression.

Frantically, we visited our primary care provider who quickly referred us to a psychologist. Still, we were shocked and confused about how quickly our once normal-functioning daughter had disappeared: Seemingly overnight. We dove into books about childhood OCD to educate ourselves on how to help her. One of the first chapters in one of the books was about PANDAS, describing how neuropsychiatric symptoms can be caused by streptococcal infections. We knew immediately that this was what our daughter was experiencing. We called our primary care provider back and requested referral to a specialist at UW to evaluate for PANDAS. Three referrals were placed, and three responses were received, all identical: "We don't treat PANDAS". At a loss, our primary care provider put a message out to all the pediatric providers in the clinic system, asking about PANDAS. All the responses were the same: "We don't know about PANDAS".

By this time, it was May. Our daughter's symptoms were worsening and our desperation was palpable. We drove our daughter to Illinois and paid out-of-pocket to see a specialist, who was able to diagnose her and provide a treatment plan. Armed with the confidence that our parental instincts had been correct all along, we went back to UW and fought for help. Our daughter had a tonsillectomy and adenoidectomy as well as an infusion of medicine to reset her immune system. These therapies resulted in a 100% return to her baseline with zero PANDAS symptoms.

These interventions may not have been necessary if she had received timely diagnosis and treatment. More importantly, early diagnosis and intervention would have lessened incredible trauma our family experienced in this situation. It disturbs us to know there are other families suffering from PANS who may lack the awareness and resources to get appropriate help. They are relying on their medical providers for answers and treatment. Unfortunately, the treatments many of these children are currently receiving are ineffective, expensive and sometimes traumatic. An advisory council on PANS and PANDAs would serve as a step forward, a step closer to providing efficient and effective care for Wisconsin children with this condition.

Scott and Erica Guetzlaff

Oregon, WI

December 10, 2017

RE: 2017 Assembly Bill 638

To Whom It May Concern:

I am writing in support of Assembly Bill 638 as a licensed medical provider in the State of Wisconsin and as a parent of a child with PANDAS. As a Physician Assistant with over 17 years of experience, I can attest to the need to educate medical professionals on diagnosis, promote awareness, and increase access to treatment for children with PANDAS/PANS. Along with my colleagues, I fully support this public health initiative to create an advisory council as outlined in the proposed legislation.

In the fall of 2014, our then 5 ½ year old son changed overnight and developed tics, OCD, and rage attacks – among other symptoms. As parents, we were desperate to figure out what was going on and we went to 8 different top specialists at the University of Wisconsin American Family Children's Hospital and other related facilities over the next 18 months. We got no answers but did spend almost \$10,000 in out of pocket medical expenses in that timeframe. No one could tell us what was wrong and he continued to deteriorate.

Ultimately, our son was correctly diagnosed with PANDAS because of collaborative research between our school nurse and me. Once we started appropriate treatment, he started to improve within 3 days – this after 18 months of turmoil. We thought once we had a correct diagnosis we would find it easy to find a treating medical provider in WI, but we were wrong. The specialists at UW and Children's Hospital of Wisconsin refused to see my son in consultation once they heard "PANDAS." We were told this was not a legitimate diagnosis and that further testing or treatment was not necessary. We have been fortunate to receive excellent medical care but all out of state and at great expense.

I completely support Wisconsin education and attended Marquette University. I regularly precept PA and medical students from UW, Marquette, and the Medical College of Wisconsin. I will be the first to tell you there is no educational framework about PANDAS/PANS at these programs currently. Scores of medical providers are graduating and completing programs with no understanding of this disease. And when a patient presents to their office, like my son, the provider is not equipped to evaluate, diagnose, or treat the child's condition. These children are suffering significant neurological and psychological consequences, and many are being placed in mental hospitals – at great cost to the State. This disease is so easily managed if the diagnosis is made in a timely fashion and appropriate treatment initiated.

The public health impact and breadth of education possible with this bill would be enormous. Thank you for your consideration and work on behalf of the children of Wisconsin. Your support of this bill will have a truly positive impact on the health of many.

Sincerely,

Sarah J. Barnett, PA-C
Physician Assistant, Watertown Regional Medical Center
WI PANDAS Parent
119 Birch Rd.
Delafield, WI 53018
(262) 443-9520

December 11,2017

RE: 2017 Assembly Bill 638

To Whom It May Concern:

I am writing in support of Assembly Bill 638 as a licensed health care provider in the State of Wisconsin. As the Supervisor of District Nursing Services, Kettle moraine School District, I can attest to the need to help to educate medical professionals on diagnosis, and treatment and promote awareness, and increase access to treatment for children with PANDAS/PANS. Along with my colleagues, I fully support this public health initiative to create an advisory council as outlined in the proposed legislation.

During my 30 year tenure as a school nurse I have had at least a dozen students diagnosed with PANDAS/PANS and unfortunately have seen many of these students go undiagnosed for years and in the process be placed multiple psycho-tropic medications and require inpatient mental health treatment. Today I have at least 6 students diagnosed with a form of pediatric autoimmune neuropsychiatric disorder. The diagnostic process has been inconsistent and treatment is not standardized. For the past 3 years I have averaged over 400 medically confirmed cases of strep throat in my school district of just over 4000 students. I strongly support legislature that will promote education of the medical community that hopefully will help bring awareness to the school community and these children will receive the appropriate medical care and educational programming to become success learners.

Thank you for your consideration and work on behalf of the children of Wisconsin.

Sincerely,

Melinda Vose, RN BSN

Nursing Supervisor /Kettle Moraine School District /Wales, Wisconsin

12/5/17

RE: 2017 Assembly Bill 638

To Whom It May Concern:

I am writing in support of Assembly Bill 638 as a licensed medical provider in the State of Wisconsin. As a Physician Assistant, I can attest to the need to help to educate medical professionals on diagnosis, promote awareness, and increase access to treatment for children with PANDAS/PANS. Along with my colleagues, I fully support this public health initiative to create an advisory council as outlined in the proposed legislation.

Thank you for your consideration and work on behalf of the children of Wisconsin.

Sincerely,

Kate Blank, PA-C

Madison, WI 53716

Lisa Andreoni
290 Westfield Way
Pewaukee, WI 53072

December 13, 2017

RE: Support for State of Wisconsin 2017 Assembly Bill 638 - advisory council on PANDAS & PANS

Thank you for the opportunity to share why I whole-heartedly support Assembly Bill 638 to raise awareness and improve treatment of PANS and PANDAS in Wisconsin.

My name is Lisa Andreoni, and I am a resident of Pewaukee, Wisconsin.

I remember the day my outgoing, bright, confident 17-year old daughter suddenly changed into a different person. She had been sick, off and on, for 2 months. First a fever and cough, then mono, then pneumonia. She was still recovering from pneumonia, when, on February 1st, 2015 her mind started racing and it wouldn't stop - for hours. Her body randomly twitched and her leg wouldn't stop shaking. The next day, she went to school and she couldn't focus on the lessons. My straight A junior in high school couldn't write a paragraph that made sense. She was scared and said "Mom, I think I'm going crazy. Please take me to the doctor." Her pediatrician knew her recent medical history. The doctor listened to the new symptoms and referred us to a psychiatrist. The psychiatrist's diagnosis was OCD, ADHD and anxiety. "My daughter?", I thought. It didn't make sense.

In hindsight, if these two doctors had been aware of PANDAS and PANS, the recent illnesses combined with very sudden onset of OCD, ADHD and anxiety should have been a HUGE RED FLAG. She could have been treated from day one. Instead this was the beginning of a psychiatric nightmare that included high anxiety, mood changes, refusal to eat, psychosis, 2 heart-wrenching inpatient stays at Rogers hospital, more doctors and multiple psych meds. But she didn't get better. She was no longer the same girl.

It wasn't until a friend of a friend asked if we'd tested our daughter for Strep, that I first learned of PANDAS. I was skeptical. I had never heard of such a thing. Then another friend referred us to Dr. Hale-Richlen who happened to understand and treat PANDAS and PANS. The first strep test came back as "raging" positive despite no sore throat or fever. Her mycoplasma pneumoniae antibodies were high.

Six months after the initial onset, we were finally able to treat the root cause and slowly started getting our daughter back. She is now a sophomore in college and thriving. But we got lucky. I can't imagine what her life would be like right now if we had not found a doctor who knew how to diagnose and treat PANS and PANDAS.

This is why I ask you to please support this bill to help Wisconsin children and parents get the help they need. We desperately need to raise awareness and improve the diagnosis and treatment of PANS and PANDAS in our state.

RE: 2017 Assembly Bill 638

To Whom It May Concern:

I am writing in support of Assembly Bill 638 as a licensed medical provider in the State of Wisconsin. As a Nurse Practitioner for the past 20 years who teaches both medical and nurse practitioner students, education is lacking.

I can attest to the need to help to educate medical professionals on diagnosis, promote awareness, and increase access to treatment for children with PANDAS/PANS. Along with my colleagues, I fully support this public health initiative to create an advisory council as outlined in the proposed legislation.

Thank you for your consideration and work on behalf of the children of Wisconsin.

Sincerely,

Sharon A Krukowski APNP BC FNP

Milwaukee Wi 53217

December 6, 2017

RE: 2017 Assembly Bill 638

To Whom It May Concern:

I am writing in support of Assembly Bill 638 as a licensed medical provider in the State of Wisconsin. As a nurse practitioner, I can attest to the need to help to educate medical professionals on diagnosis, promote awareness, and increase access to treatment for children with PANDAS/PANS. Along with my colleagues, I fully support this public health initiative to create an advisory council as outlined in the proposed legislation.

This is a huge issue for many families. There is a dearth of information, even among providers regarding PANDAS/PANS. This can slow diagnosis and treatment, making it more difficult for our patients to have greater access to care and support .

Thank you for your consideration and work on behalf of the children of Wisconsin.

Sincerely,

Kristin M Schultz, B.A., M.A., R.N., M.S.N.

Nurse Practitioner, FortHealthcare Family Practice, Lake Mills

December 12, 2017

Representative Joe Sanfelippo
Wisconsin State Capitol
Room 306 North
PO Box 8953
Madison, WI 53708

Dear Representative Sanfelippo,

I am writing to you regarding Assembly bill 638 pertaining to an advisory council on pediatric autoimmune neuropsychiatric disorder associated with streptococcal infections and pediatric acute-onset neuropsychiatric syndrome.

The following individuals wished to share with you and the Committee on Health that they support this bill:

Nokomi Caves, Brookfield, WI
Lynda Mountford, Oregon, WI
Sheryl Guetzlaff, Sun Prairie, WI
Daniel Cobus, Waukesha, WI
Kelly Severson, Fitchburg, WI
Donna Twining, NP, Janesville, WI
Alicia Hynek, Cottage Grove, WI
Eve Manke, Oregon, WI
Ericka Zuehlke, Oregon, WI
Chad Cuellar, Brookfield, WI
Keith Thoms, Pewaukee, WI
Michelle Thoms, Pewaukee, WI
Gail Williams, Milwaukee, WI
Steven DuFresne, Hartland, WI
Bob Paquette, Boscobel, WI
Sue DuFresne, West Allis, WI
Craig Snyder, Hartland, WI
Jeffrey D. Loe, New Berlin, WI
Anthony Joseph Berg, New Berlin, WI
Travis Conkey, Colgate, WI
Marie Claire Berg, New Berlin, WI
Jena Berg, Milwaukee, WI
Catherine Olig, Menomonee Falls, WI
Anthony Minotte, New Berlin, WI
Michelle R. Jermier, Pewaukee, WI
Caitlin Strobel, Milwaukee, WI
Lydia Lambert, Milwaukee, WI
Catherine S. Engel, Wauwatosa, WI
Dianora Siragusa-Rivera, Caledonia, WI
Aneta Spadlo, Milwaukee, WI
Teresa Wargula, Brookfield, WI
Dawn Mueller, PA-C, Oregon, WI
Shana Schwarz, Oregon, WI

Michelle Minter, Oregon, WI
Abby Huckelberry, Verona, WI
Erica Burchette, Madison, WI
Jenny Wagner, Oregon, WI
MaryAnn Aylesworth, Verona, WI
Laura Aylesworth, Stoughton, WI
Gail Schroeter, Madison, WI
Genea Grossen, Oregon, WI
Ron Dworak, Appleton, WI
Katie Schafer, Oregon, WI
Craig Culver, Neosho WI
Crystal Zuniga, Oregon, WI
Melissa Melcher, Milwaukee, WI
Sara Aylesworth, Madison, WI
Laura Yell, Whitefish Bay, WI
Paul Aylesworth, Madison, WI

Jacki Bussian, PharmD, Oregon, WI
Julia Lederer, Oregon, WI
DeeAnn Polacek, Spencer, WI
Jill Adams, Oregon, WI
Rick Dworak, Appleton, WI
Emily Leggin, Oregon, WI
Katie Poole, Cottage Grove, WI
Heidi Beck, Oregon, WI
Katie Wallace, Verona, WI
Jennifer Ibrahim, Oregon, WI
Michelle Hegg, Oregon, WI
Cami Broe, Oregon, WI
Brandon Broe, Oregon, WI
Katie Kavanaugh, Oregon, WI
Brian Kavanaugh, Oregon, WI
Scott Reitmeier, Oregon, WI
Susan Reitmeier, Oregon, WI
Lisa Betow, Appleton, WI
Leia Esser, Madison, WI
Sarah Schmidt, Madison, WI
Shawnda VanDerel, Waukesha, WI
Melissa Hinderman, Oregon, WI
Lisa Eiche, Oregon, WI
Jennifer Wokasch, Oregon, WI
Ellen Kleinmaus, Waunakee, WI
Tina Jones, Oregon, WI
Stephanie Christensen, Verona, WI
Anna Relerford, Madison, WI
Susan Sippola, Fitchburg, WI
Carrie Janes, Oregon, WI
Jennifer Landas, Oregon, WI
Stacy Sergent, Oregon, WI
Dawn Goltz, Oregon, WI
John Goltz, Oregon, WI
Kathy Ruhde, Verona, WI
Andrea DeNure, Oregon, WI
Monica Mountford, Oregon, WI
Phil Mountford, Oregon, WI
Lisa Esser, Madison, WI
Dawn Clemment, Fitchburg, WI
Frank LaVora - Franklin, WI
Heidi Schuster - Franklin, WI
Steve Schuster - Greendale, WI
Lisa Jenewein - Kenosha, WI
Sydney LaVora - Franklin, WI
Sally Dollar - Greenfield, WI
Brian Dollar - Greenfield, WI
Mary Rinzel - Waterford, WI
John Rinzel - Waterford, WI
Maria Johnson - Franklin, WI

Grant Johnson - Franklin, WI
Jeff Voyer Jr. - Grafton, WI
Shelly Voyer - Grafton, WI
Linda Francaviglia - Waukesha, WI
Steve Francaviglia - Waukesha, WI
Anne Warchol - Brookfield, WI
Laura Martine - Franklin, WI
Jay Jacomet - Franklin, WI
Suellen Dworak-Appleton, WI
Jodie Jacomet - Franklin, WI
John Leszczynski - Muskego, WI
Cathy Leszczyski - Muskego, WI
Asa Schommer - Franklin, WI
Cindy Thota - Muskego, WI
Venkata Thota - Muskego, WI
Liz Marcott - Franklin, WI
Mike Marcott - Franklin, WI
Jeff Warchol - Brookfield, WI
Mike Coello - New Berlin, WI
Rebecca Coello - New Berlin, WI
Judy Caruso - Franklin, WI
Phil Caruso - Franklin, WI
Val Thomson - Pewaukee, WI
Mark Thomson - Pewaukee, WI
Karin Wasiullah - Milwaukee, WI
Masood Wasiullah - Milwaukee, WI
Linda Voyer - Milwaukee, WI
Jeff Voyer Sr. - Milwaukee, WI
Bernadette Gard - Greendale, WI
Paula Heimerman - Neenah, WI
Ted Heimerman - Neenah, WI
Mary Zuel Schuster - Cudahy, WI
Joe Schuster - Cudahy, WI
Dorothy DeGrace - Neenah, WI
Bob DeGrace - Neenah, WI
Kerri Pearson - Franklin, WI
Paul Pearson - Franklin, WI
Julie Gard - St. Francis, WI
Dave Gard - St. Francis, WI
Darlene LaVora - Milwaukee, WI
Pam Mateo - Milwaukee, WI
Raul Mateo - Milwaukee, WI
Josh Haase - Franklin, WI
Lisa Haase - Franklin, WI
Julia Westphal - Pewaukee, WI
Ben Westphal - Pewaukee, WI
Angelia Vogt - Pewaukee, WI
Chris Vogt - Pewaukee, WI
Deb Braun - Oconomowoc, WI
Brice Brown - Oconomowoc, WI

Michael Boye - Milwaukee, WI
Marilyn Boye - Milwaukee, WI
Rick Briscki - Germantown, WI
Lynn Briscki - Germantown, WI
Tricia Unger - New Berlin, WI
Ryan Unger - New Berlin, WI
Larry Bower - Milwaukee, WI
Jan Bower - Milwaukee, WI
Mary Jordan- Village of Pewaukee, WI
Todd Jordan - Village of Pewaukee, WI
Todd Goodman - Whitefish Bay, WI
Elizabeth Goodman Whitefish Bay, WI
Mary Beth Pelletier - Franklin, WI
James Pelletier - Franklin, WI
Michael Bersch, Milwaukee, WI
Robert Bersch, Shorewood, WI
James Bersch, Brown Deer, WI
Jill Bersch, Brown Deer, WI
Rebekah Arthurs - Milwaukee, WI
Joni Arthurs - Milwaukee, WI
Steven Arthurs - Milwaukee, WI
James Stanislawski - Greenfield, WI
Lucille Stanislawski - Greenfield, WI
Mary Klinger - Wauwatosa, WI
Dean Klinger - Wauwatosa, WI
Janet Rakowski - New Berlin, WI
Mark Rakowski - New Berlin, WI
Cyndi Gasvoda - New Berlin, WI
Alan Gasvoda - New Berlin, WI
Christina Preuss - Waukesha, WI
Ben Preuss - Waukesha, WI
Tim Fischer - Hales Corners, WI
Larry Gard - Milwaukee, WI
Jessica Brost - Milwaukee, WI
Therese Hanneman - Franklin, WI
Michael Hanneman - Franklin, WI
Robert Kroeninger - Franklin, WI
Ed Dee - Franklin, WI
Anne Bonneau - East Troy, WI
Barry Bonneau - East Troy, WI
Doug Arnold - Franklin, WI
Chris Arnold - Franklin, WI
Kathy Missurelli - Franklin, WI
Mark Missurelli - Franklin, WI
Nancy Winston, Milwaukee, WI
Joel Winston, Milwaukee, WI
Nicole Winston, Milwaukee, WI
Andrew Winston, Milwaukee, WI
Tonya Schmidt, Waunakee, WI
Kay Ehlers, Whitefish Bay, WI

Dave Ehlers, Whitefish Bay, WI
Lisa Sayre, Cambridge, WI
Shari Hanneman, Franklin WI
Joy Braund, Lake Mills, WI
Tim Braund, Lake Mills, WI
Jennie Shea, Appleton, WI
Justin Shea, Appleton, WI
Robert Nelson Mequon, WI
Laura Nelson, Mequon, WI
Jennifer Szyszkiewicz Vernon, WI
Brett Szyszkiewicz, Vernon, WI
Bill Hartenberger, Neshkoro, WI Caroline Hartenberger, Neshkoro, WI
Bernard Sayre- Cambridge, WI
Kathleen Sayre- Cambridge, WI
Erica Guetzlaff, Oregon, WI
Scott Guetzlaff-Oregon, WI
Rachel Zarling, Waukesha, WI
Jake Zarling, Waukesha, WI
Casey Auer, Neenah, WI
Paul Auer, Neenah, WI
Julie Cuellar, Milwaukee, WI
Joe Cuellar, Milwaukee, WI
Maja Cuellar - Brookfield, WI
Nicole Scieszinski Franksville, WI
Annette LaVia, Westfield, WI
Beth Braun, Madison, WI
Sylvia Porubsky New Berlin, WI
Frank LaVora, Franklin, WI
Heidi Schuster Franklin WI
Anne Mulhollon, Waukesha, WI
Valerie Judkins, West Allis, WI
Charles Judkins West Allis, WI
Brooke Dykema, Mequon, WI
Hans Dykema Mequon, WI
Jenni Cialdini, Hales Corners, WI
David Cialdini, Hales Corners WI
Janice Greening, New Berlin, WI
Robin Schnitzler, Madison, WI
Brenton Barnett, Delafied, WI
Sarah Barnett, Delafield, WI
Gary Vose Delafield, WI
Melinda Vose - Delafield, WI
Micah Vose Milwaukee, WI
Ryan Mercier, Delafield, WI
Susan Mercier, Delafield, WI
Laura Skrypczak, Appleton, WI
Valerie George, Green Bay, WI
Matt George Green Bay WI
Cassie Wolfgram, Madison, WI
Matt Wolfgram , Madison, WI

Sarah Sobecke, Milwaukee WI
Jess Arrigo, Sturgeon Bay, WI
Zachary Hassilev, Sturgeon bay, WI
Andrea Mandel, River Hills, WI
Robert Mandel, River Hills, WI
Tim Vander Grinten, Fond du lac, WI
Katie Vander Grinten, Fond du lac, WI
Sarah Kirschling, Waukesha, WI
Angela Howard, Franklin, WI
Alison Campbell, Madison WI
Judy Mackay, Franklin, WI
Loni Kopp, Lake Mills, WI
Donald Braund, Cottage Grove, WI
Sandy Braund, Cottage Grove, WI
Jenny Lindmeier, Cambridge, WI
Jenny Ranguette, Fort Atkinson, WI
Kelly Mitchell, Lake Mills, WI
Laura Beckett, Lake Mills, WI
Rob Zilliox, Lake Mills, WI
Angi Zilliox, Lake Mills, WI
D'Laney Thelke, Lake Mills WI
Bonnie Roberts, Stoughton, WI
Sue Huss, Madison, WI
Matthew Braund, Stoughton, WI
Laura Braund, Stoughton, WI
Kari Buchholtz, Lake Mills, WI
Carol Grunewald, Watertown, WI
Nicole Bastin, Helenville, WI
Rebecca Crenshaw, Lake Mills, WI
Jeni Breaker, Waterloo, WI
Jon Doty, Sun Prairie, WI
Nick Burling, Lake Mills, WI
Craig Quest, Lake Mills, WI
Misty Quest, Lake Mills, WI
Ian Lawrence, Lake Mills, WI
Jen Lawrence, Lake Mills, WI
Jacob Caster, Jefferson, WI
Mari Caster, Jefferson, WI
Melissa Walker, Lake Mills, WI
Shannon Bridger, Lake Mills, WI
Tami Hajcak, Lake Mills, WI
Shelley Navis, Fort Atkinson, WI
Briann Susdorf, Madison, WI
Cindy Kramp, Walworth, WI
Mark Ward, Lake Mills, WI
Gayle Maerz, Sun Prairie, WI
Lisa Sayre, Cambridge, WI
Melissa Felio, Deerfield, WI
Taunya Hammonds, Jefferson, WI
Russell Thomas, Lake Mills, WI

Dale Braund, Rio, WI
Rebecca Gonzalez, Cambridge, WI
Dan Christensen, Madison, WI
Karla Christensen, Madison, WI
Debbie Kulow, Lake Mills, WI
Judy Furseth-Sherven, Stoughton, WI
Brenda Welhoefer, Stoughton, WI
Rick Christensen, Madison, WI
Jean Hagerstrom, Cottage Grove, WI
Karla Redepenning, Wisconsin Rapids
Michele Zitlow, Madison, WI
Brianna Zitlow, Madison, WI
Lori Shaw, Stoughton, WI
Sandy McNamee, McFarland, WI
Amy Krause, Whitewater, WI
Bernard Sayre, Cambridge, WI
Kathleen Sayre, Cambridge, WI
Kim Church, West Allis, WI
Geraldyn Schultz, City of Brookfield, WI
Marie Grandelis, City of Brookfield, WI
Jon Grandelis, City of Brookfield, WI
Christine Hemmer Sheboygan, WI
Paul Hemmer, Sheboygan, WI
Suzanne Kallinger, Brookfield, WI
Charles Kallinger, Brookfield, WI
Monica Fleming, Town of Brookfield, WI
Pamela Purcell, Village of Pewaukee, WI
Margaret Flynn, Milwaukee, WI
Sandra Rose, Muskego
Molly Jordan, Village of Pewaukee, WI
Pamela J. Weisel, Brookfield, WI
Kris Williams, Sheboygan, WI
Dave Williams, Sheboygan, WI
Nancy Kroll, Sheboygan, WI
Meghan Abraham, Fond du lac, WI
Kevin Abraham, Fond du lac, WI
Robert Klinker, Winneconne, WI
Katie Klinker, Winneconne, WI
Mary Ellen Fiel, Winneconne, WI
Rachel Nagode, Sheboygan, WI
Justin Nagode, Sheboygan, WI
Jean Anhalt, Fort Atkinson, WI
Karen Howard, Oconomowoc, WI
Cynthia Martin, Green Bay, WI
Shannon Bridger, Lake Mills, WI
Suzie Reichert, Johnson Creek, WI
Diane Kiefer, Oconomowoc, WI
Lisa Riggs, Watertown, WI
Haley Nemitz, Watertown, WI
Laurie Kuntz, Juneau, WI

Heather Burnham, Horicon, WI
Alicia Larson, Beaver Dam, WI
Kristin Schultz, Johnson Creek, WI
Katrina Holcolm, Watertown, WI
Hilary Rein, Watertown, WI
Rhonda Reith, Watertown, WI
Amy Bunch, Oconomowoc, WI
Jennifer Daley, Waukesha, WI
Kate Blank, Monona, WI
Rachel Leonard New Berlin, WI
Katie Aronin, Delafield, WI
Megan Hackel, Waukesha, WI
Emily Siedschlag, Watertown, WI
Amy Malik, Madison, WI
June Suwanabol, Waukesha, WI
Casey Brown, Dousman, WI
Nina Pitcl, Watertown, WI
Susan Mertins, Waterloo, WI
Roy Marsden, Cambridge, WI
Theresa McNutt, Watertown, WI
Ed Krukowski, Sheboygan, WI
Angela Crandall, Watertown, WI
Sheila Timm, Watertown, WI
Elizabeth Shimon, Fitchburg, WI
Emily Copps, Cedarburg, WI
Anne Seraphine, Oconomowoc, WI
Marjorie Barnett, Pewaukee, WI
Stephan Korb, Waukesha, WI
Patty Treiber, Nashotah, WI
Amy Morgan, Wauwatosa, WI
John Treiber, Nashotah, WI
Emily Tietz, Horicon, WI
Caitlin Gunderson, Cottage Grove, WI
Leah Teske, Dousman, WI
Jenny Martin, Waukesha, WI
Scott Carlson, Madison, WI
Aine McMenamin, Whitefish Bay, WI
Ed Weisse, City of Brookfield, WI
Stephanie Weisse, City of Brookfield, WI
Sharon Krukowski, Whitefish Bay, WI
Joanne Wirtjes, Sheboygan, WI
Lisa Andreoni, Pewaukee, WI
Michael O'Brien, Pewaukee, WI
Kelsey O'Brien, Pewaukee, WI
Linda Rohde, Pewaukee, WI
Jennifer Keller, Jackson, WI
Jordyn Rolli, New Berlin, WI
Karl Barthel, Greenfield, WI
Cynde Dornuf, Franklin, WI
Nerida Youngwith, Wauwatosa, WI

Ralph Jay Olson, Menomonee Falls, WI
Mary Jo Maslowski, Menomonee Falls, WI
Jim Maslowski, Menomonee Falls
Michelle Minessale, Brookfield, WI
Mark Minessale, Brookfield, WI
Mary Monday, Pewaukee, WI
Tim Monday, Pewaukee, WI
Stacy Pink, Brookfield, WI
Joe Pink, Brookfield, WI
Maria Cartier, Brookfield, WI
Quentin Cartier, Brookfield, WI
Debe Storts, Brookfield, WI
Mike Storts, Brookfield, WI
John Burke, New Berlin, WI
Mary Burke, New Berlin, WI
Maureen Burke, New Berlin, WI
Bonnie Caye, Brookfield, WI
Tim Caye, Brookfield, WI
Kim Rymer, New Berlin, WI
Tim Rymer, New Berlin, WI
Morgan Rymer, New Berlin, WI
Kayla Rymer, New Berlin, WI
Jonathon Rymer, New Berlin, WI
Maribeth Delforge, Pewaukee, WI
Dean Delforge, Pewaukee, WI
Bob Rohde, Pewaukee, WI
Becky Rolli, New Berlin, WI
Al Rolli, New Berlin, WI

Letter in support of Assembly Bill 638

December 8, 2017

Wisconsin Legislatures

Madison, Wisconsin

Dear Legislature,

I am writing to you to consider passing the Assembly Bill 638. I am a mother of a 9-year-old son who suffers from PANS. It was nearly 5 years ago when our nightmare began. For nearly 5 years we've seen too many specialists in Wisconsin who were unable to correctly diagnose my son. At the age of 4, teachers were suggesting to me that he has ADHD. When he turned 6 he officially got the ADHD diagnosis (by a psychologist), but that didn't end there. A year later he was diagnosed with Tourette's syndrome (when he developed tics). He continued to get ODD (Oppositional Defiance Disorder) diagnosis (by a psychiatrist). The daily calls from the school principle, that my son is aggressive and is threatening to kill his friends (in SECOND GRADE!); that he's running away, not listening to anyone and no one has control over him; To getting expelled from the YMCA summer program because he wanted to drown another child in a pool – are just few of the examples of the nightmare that we lived through.

In November of 2016, his psychiatrist wanted start treating him with anti-psychotic meds, my motherly instincts kicked in when I didn't agree with the treatment. I started my own research to figure out what is wrong with my child. It was because of a post on a private forum that parent after parent continued to tell me to look into PANDAS/PANS. The second I read the symptoms, I knew exactly that my son had either PANDAS/PANS. Just like any other parent of a child who appears to be sick, I scheduled an appointment with the pediatrician and tell him that I suspect that my son has PANDAS/PANS. I had to bag the pediatrician to test my son for strep as he didn't show any signs of it. The next day I got a call from the doctor himself to let me know that my son had strep. He got a 10-day course of antibiotics and by day 3 his teachers were asking me who is this child, because they couldn't recognize him. His behavior changed, and his tics went down by 60%. At that point I had my answer – my son has PANDAS/PANS. I knew that I wasn't going to get any support from the pediatrician as he seemed unfamiliar with the illness. I started to look on websites (from Children's hospital, to private practice) to see if I could find a specialist for my son in Wisconsin. I was unable to find one, so just like any other parent who would do anything for their child, I found the best doctor who has seen over 3000 kids with PANDAS and PANS. Unfortunately, he wasn't anywhere near Wisconsin – he's in New Jersey. In April of this year, we packed our entire family into our car and drove 14 hours to see the best doctor who helped my child. It is because of that doctor I have my son back! The sweet, loving, affectionate child that I remembered before the age of 4 – he was back!

Letter in support of Assembly Bill 638

My son started 3rd grade this year. The entire school, including the nurses, school psychologist, his support team (special education teacher, occupational therapist, language pathologist) can't even believe the progress that my son has made. He no longer runs away from teachers; he knows how to interact with his friends (and is actually very liked by others). He is helpful and knows when to apologize when he does something wrong. There are no more tantrums, uncontrollable yelling, hitting and hurting others – IT'S ALL GONE!

You ask what the solution was – antibiotics! My son didn't require psych meds (or as I like to call them Skittles that many doctors like to prescribe).

I have been a big advocate to educate anyone around me about this horrible disorder that has a very simple fix to it and when caught early on the child has a high chance of recovering faster and be back to normal. After speaking with the district nurse at my son's school, she mentioned to me that she has seen PANDAS in some kids and even suggested to the parents of those children to consider PANDAS/PANS. The problem is, that the parents go to see the pediatrician and since they're not educated about this disorder, the cycle closes there.

As a parent of a child who was able to recover from PANS I plead you consider passing this bill. This bill will save so many, not only children but families.

I would like to thank you in advance for your consideration and for reading my letter.

Sincerely

Maja Cuellar

14180 Ranch Rd.

Brookfield, WI 53005

Testimony of having a child with PANDAS.

My son was in 4K when we began to notice an increase in hyper activity and sensory issues, over the summer into 5k things got worse we sought out advise from our primary doctor, that lead to a neuropsychology exam and integrative medicine specialist. We had great results in treating with diet change, vitamin deficiencies, etc. It also lead to and IEP in school which did help also gave us a way of tracking things. One tool we used a communication notebook and one thing we notice was there was a direct correlation between when there was a spike in "behaviors" at school he was shorty after be treated for an end illness with antibiotics and issues at school got better. Was not until the end of first grade when we thought something was taking over our child then we found PANDAS. It was by talking with parents that followed the dietary program we also followed that told us to look into PANDAS. We promptly took him to the doctor to be tested for strep. He had ZERO "typical" signs of strep throat. His symptoms consisted of emotional liability, tics, OCD, night terrors, increased urinary frequency, sensory issues, aggressive behaviors, talk of wanting to "just die". This was in a matter of a weeks time. We were lucky the integrative medicine specialist had heard of PANDAS and also did some blood work. She did diagnosis him which was great, as for proper treatment protocols she was not well versed and after a few months she recommended seeing a doctor out of state. Our primary care physician said he did not know about PANDAS therefore could not help us. It was the help of other parents with children who have this diagnosis that lead us to an ENT that has read good research on PANDAS and did what they could to help us. Then with a lot of advocating on our son's behalf he was seen by a neurology. The neurologist agreed with the diagnosis after several tests. We were able to get IVIG treatment covered by insurance for our son. Even after that we have sought out treatment from the one specialist in the state that treats this diagnosis. We know that we have a long road to recover our son's immune system.

I am a social worker by profession, although I work with adults with variety of disabilities. I have learned a lot about this diagnosis over the last year and a half, particularly that if untreated a diagnosis of PANS or PANDAS can lead to any number of neurological and psychological issues that will require long term care services. This is also a financial issue for our state. I can say from experience that the average cost of residential placement is anywhere from \$2800.00-\$6000.00 a month. As shown in the documentary "My Kid Is Not Crazy" the need for residential placement is a real possibility. There is also the cost of psychiatric care both in patient and out patient. If adequate treatment was available these costs could be avoided or minimized. We have a financial responsibility to address this diagnosis and pursue education, awareness, and proper treatment availability in our state.

12/13/2017

Joy Braund