

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

TESTIMONY BEFORE THE SENATE COMMITTEE ON GOVERNMENT  
OPERATIONS, TECHNOLOGY, AND CONSUMER PROTECTION  
Senate Bill 535 and its companion Assembly Bill 638  
Wednesday, January 24, 2018

Thank you, Chairman Stroebel and committee members for holding a public hearing on Senate Bill 535. 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.

SB 535 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 SB 535 and I hope I can count on your support.



# JANEL BRANDTJEN

STATE REPRESENTATIVE • 22<sup>ND</sup> ASSEMBLY DISTRICT

## Testimony for Senate Bill 535

Thank you Chairman Stroebel and the Senate Committee on Government Operations, Technology and Consumer Protection 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.

SB 535 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. SB 535 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

## **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](http://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](http://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

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## PANS/PANDAS Clinical Research Consortium National Standard Endorsement

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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.**



## Written Testimony Pertaining to Assembly Bill 638/Senate Bill 535

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 11,2017

RE: 2018 Assembly Bill 638/Senate Bill 535

To Whom It May Concern:

I am writing in support of Assembly Bill 638/Senate Bill 535 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

December 10, 2017

RE: 2018 Assembly Bill 638/Senate Bill 535

To Whom It May Concern:

I am writing in support of Assembly Bill 638/Senate Bill 535 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

119 Birch Rd.

Delafield, WI 53018

(262) 443-9520



12/5/17

RE: 2018 Assembly Bill 638/Senate Bill 535

To Whom It May Concern:

I am writing in support of Assembly Bill 638/Senate Bill 535 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

December 6, 2017

RE: 2018 Assembly Bill 638/Senate Bill 535

To Whom It May Concern:

I am writing in support of Assembly Bill 638/Senate Bill 535 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

RE: 2018 Assembly Bill 638/Senate Bill 535

To Whom It May Concern:

I am writing in support of Assembly Bill 638/Senate Bill 535 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

My name is Dr. Barbara Hale-Richlen. I am a board-certified child, adolescent and adult psychiatrist. I have a private practice in Brookfield, Wisconsin where I have been inundated with patients and families seeking evaluation and treatment for PANDAS/PANS. Many of my patients drive long distances and have already been seen by multiple doctors in many specialties including; psychiatry, pediatrics, family practice, neurology and immunology. I see their frustration and desperation as they try to find help for their child who came down with a seemingly harmless common childhood infection and then developed debilitating neuropsychiatric symptoms that rapidly escalated and incapacitated their child in spite of traditional psychiatric medications, therapy, intensive psychiatric treatment and hospitalization.

Many primary care providers are eager to learn more about the diagnosis and treatment of PANDAS and PANS, but they find it hard to keep up with the rapid pace of research, publications and treatment advancements on top of seeing patients in their already busy practices. As such, education is crucial. Bringing together different medical specialists to form an advisory council on PANDAS/PANS will result in more direct and effective communication amongst doctors from varied medical specialties statewide. In addition, sponsorship of national speakers like Dr. Sue Swedo from the NIH will greatly add to the medical knowledge at our largest institutions. She has accepted an invitation to give Grand Rounds Presentations in March at MCW Dept. of Psychiatry, at Aurora Hospital in Milwaukee and at the American Family Children's Hospital in Madison.

What is more disheartening is when the barrier to care is resistance in the medical community to accept PANDAS/PANS as "real" and the lack of a sense of urgency needed to recognize, diagnose and treat it. I've heard other doctors refer to PANDAS as "controversial" or its treatments as "experimental." That is simply not the case. I was floored when one of my own colleagues, a child and adolescent psychiatrist, knew very little about this disease. She stated she hadn't treated any children with this disorder and added "I wish there was just some research to support the diagnosis!" I pointed out to her that our premier journal, *The Journal of Child and Adolescent Psychopharmacology*, had devoted two entire issues to PANDAS/PANS. First in 2015 and most recently, just two months ago in October, 2017. There are now decades of research from top national and international medical and research institutions supporting the diagnosis and treatment of PANDAS/PANS. If a practicing child and adolescent psychiatrist is uninformed of this disease, clearly, there is great need for education and advocacy. Countless studies show the benefits of early recognition and treatment. I've been amazed many times at the dramatic difference an antibiotic or steroid can make in a child's debilitating symptoms, all for just a few dollars. When treated early, kids who experience a sudden-onset of psychiatric symptoms following infection are able to recover and lead satisfying, productive lives.

Dr. Sue Swedo, the lead researcher at the NIH who first discovered PANDAS, put it best:

"It has been 30 years since we first discovered this disorder. Today, to see symptoms that are not being recognized and a child not being given appropriate care, that is the most frustrating and horrible part about all of this." Sue Swedo, M.D.

Many of my patient's families have gone online to educate themselves about this disease and continued to push for medical treatment for their child when they couldn't find answers. This leads to needless delays in treatment and increases the risk these neuropsychiatric symptoms will worsen or become permanent. As the disease progresses, simple medications like antibiotics, anti-inflammatories and steroids are no longer effective. Now treatments include IVIG, Rituximab or plasmapheresis. These medications can cost \$10,000 to \$15,000 a dose and carry a significantly increased risk of side effects.

If left untreated, these children will require significant psychosocial and medical interventions including inpatient treatment in medical and psychiatric hospitals, Intensive Outpatient Treatment for anxiety and OCD, individual therapy, occupational therapy and special education services at school just to name a few. Their families bear the brunt of severe financial and medical problems as these children often require round the clock care that precludes employment outside of the home. Parents and caregivers acutely feel the strain of this illness and they may require additional resources to cope.

I hope I have effectively communicated to you the seriousness of the lack of early recognition and treatment of PANDAS/PANS. So often I meet a new patient only to wish I would have met them years earlier, when this disease hadn't taken such a toll on their young lives and loved ones.

## Testimony in support of Assembly Bill 638/Senate Bill 535

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 reasearch 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.

Thank you for your time.

Joy Braund

#### Letter in support of Assembly Bill 638/Senate Bill 535

I am writing to you to consider passing the Assembly Bill 638/Senate Bill 535. 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/Senate Bill 535

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



Lisa Andreoni

290 Westfield Way Pewaukee, WI 53072

December 13, 2017

RE: Support for State of Wisconsin 2018 Assembly Bill 638/Senate Bill 535 - advisory council on PANDAS & PANS

Thank you for the opportunity to share why I whole-heartedly support Assembly Bill 638/Senate Bill 535 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.

December 12, 2017

RE: 2018 Assembly Bill 638/Senate Bill 535

To Whom It May Concern:

We are writing in support of Assembly Bill 638/Senate Bill 535, in order to create an advisory council to increase access to treatment for children with PANDAS/PANS by promoting awareness and education among medical professionals on the diagnosis and its treatment. In our experience medical professionals, this legislative effort to promote awareness of PANDAS/PANS is badly needed.

Our daughter had sudden onset of PANDAS/PANS symptoms, including near total developmental regression, and also of extreme, distressing, and uncontrollable behaviors. We scheduled an appointment with our daughter's pediatrician's office at UW Health East Clinic. Her regular doctor was not immediately available and because our daughter's symptoms were highly acute, we took the next available appointment with Dr. Plumb. We had read about PANDAS prior to the appointment and her symptoms were identical. She also was a carrier for strep for several months before the onset of PANDAS. When we stated we believed our daughter had PANDAS, the doctor dismissed the idea without consideration, "PANDAS was en vogue a few years ago." We asked the doctor what other diagnosis it could possibly be, she responded with perhaps our daughter had consumed alcohol or prescription drugs, perhaps she had been traumatized, or maybe it was an early onset of a psychiatric condition. We asked what psychiatric condition has an early onset at age four, and the doctor could not specify. She sent us away with a list of psychologists that we should contact.

Discouraged, we waited for the next available appointment with our daughter's regular pediatrician. He did a little research on PANDAS before our appointment. He admitted that he didn't know much about the diagnosis and was skeptical about treating PANDAS. We asked him for a referral to the UW Hospital Pediatric Neurology Department and he complied.

The referral described the symptoms, but did not mention our daughter's regular vocal ticks. The referral also mentioned PANDAS as a concern. The referral was rejected. To our very great frustration, we didn't find out for several weeks because the clinic informed the pediatrician's office, and they never informed us directly. All the while, our daughter's symptoms persisted; and eventually, after calling multiple times, we discovered the referral had been rejected. The reasons for the rejection included that the clinic does not treat PANDAS and that the referral did not note any "neurological symptoms" such as ticks. However, as noted earlier, our daughter had extreme developmental and behavioral regression.

Desperate, we scheduled an appointment with a PANDAS expert in Chicago, who promptly diagnosed our daughter with PANDAS. This appointment was out of network and therefore was not covered by insurance. Finally, we found a doctor in at the Wildwood Clinic in Madison who was able to have our referral accepted by the UW Hospital Pediatric Neurology Department. This appointment was made four months after our initial attempt to see neurology.

The neurologist discouraged the diagnosis of PANDAS. Based on the symptoms, our daughter was diagnosed with "unspecified developmental regression" and the doctor order several neurological assessments to rule out other possible causes. With no positive results of these assessments, the doctor suggested other possible diagnoses, including Autism and Rett Syndrome, both of which are obviously incorrect given the sudden onset, the wrong age of onset, and the incompatible symptoms. Being that I am a speech-language pathologist who has worked at the Waisman Center, I knew that these suggested diagnoses were incorrect and when explaining why, the neurologist agreed the diagnoses were unlikely. We persisted with the neurologist and, thankfully, she eventually prescribed the IVIG treatment that has so helped our daughter. She also successfully advocated for the treatment covered by our insurance provider. Since IVIG treatment, our daughter's development and behaviors have improved remarkably and she has almost recovered. The diagnosis of PANDAS was the correct diagnosis and the IVIG treatment was the correct treatment. It was a struggle to get a correct diagnosis and help for our daughter through the UW Health system, and we hope for better policies for treating PANDAS in the future.

Again, based on our personal frustrating experience with medical professionals in the state, we believe that this legislative effort to promote awareness of PANDAS/PANS is badly needed in order to support families who struggle with this condition. Assembly Bill 638/Senate Bill 535 is a great step in that direction and we support it wholeheartedly.

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

Sincerely,

Cassie and Matthew Wolfgram

Madison, Wisconsin