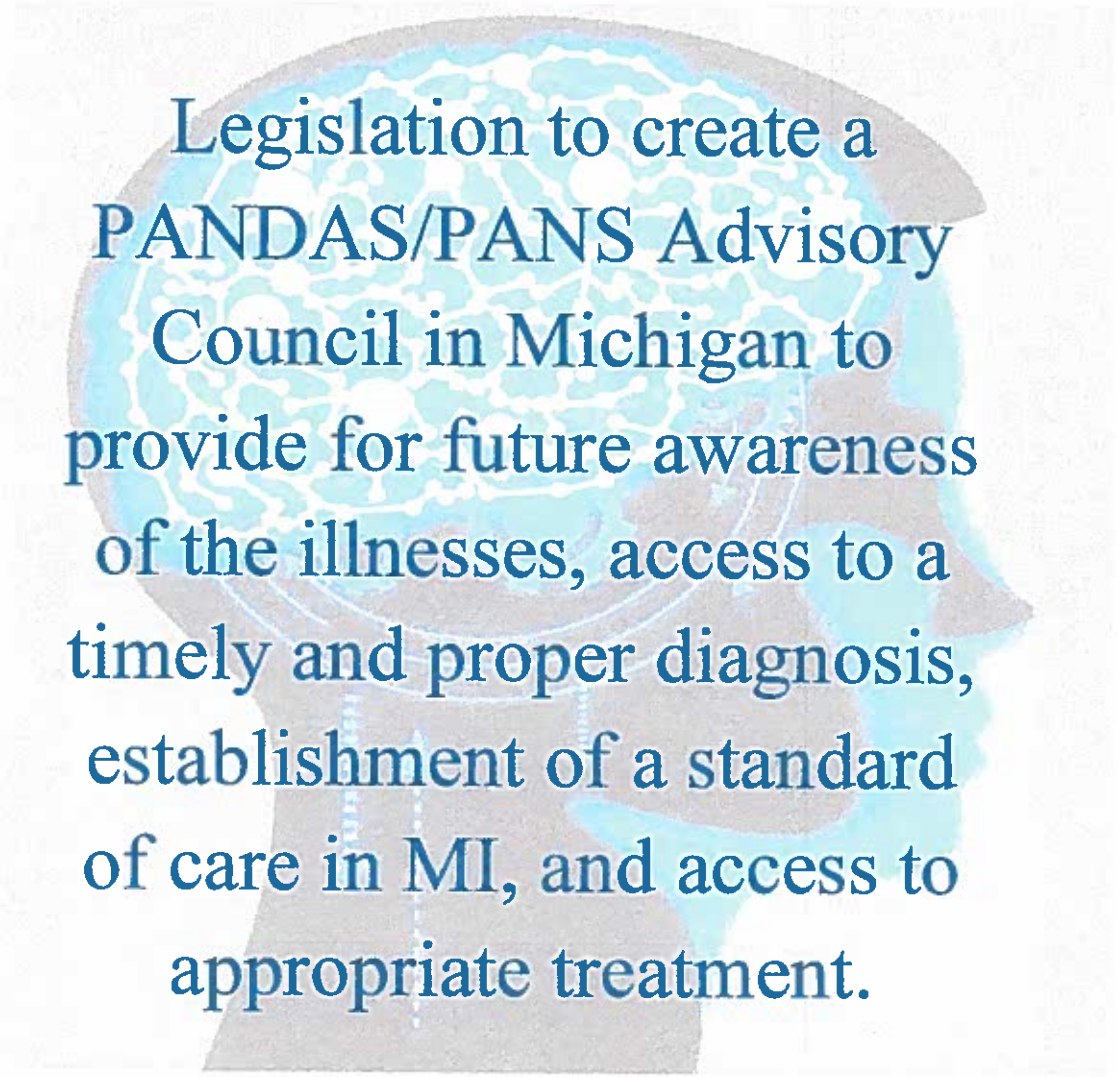
# House Health Policy Committee

September 26th, 2018 Hearing

**HB 5036**

Sponsors

Representative Aaron Miller, Representative Martin Howrylak, Representative Joseph Graves, Representative Jon Hoadley, and Representative Stephanie Chang



## Table of Contents

# Public Testimony in Support of HB 5036

1. Dr. Jame Neuenschwander founded the Ann Arbor Bio Energy Medical Center in 1988. Dr. Neu's philosophy is that we are designed to be well—illness results when something is preventing that wellness. "Dr. Neu", is board certified in Emergency Medicine, Integrative and Holistic Medicine, as well as Regenerative Medicine. He is a member of A4M, ACAM, and ILADS. He has been a DAN Practitioner since 2007, a member of Medical Academy of Pediatric Special Needs (MAPS) since its founding, and a MAPS fellow since 2014. He received his undergraduate, medical, and medical postgraduate training from the University of Michigan. For many years Dr. Neuenschwander has been one of the only doctors in the state of Michigan to treat individuals with PANDAS/PANS diagnosis due to the complexity in doing so. Dr. Neuenschwander will testify about the illnesses and why it is essential for the state to have an PANDAS/PANS Advisory Council to meet the needs of the children and adults living in Michigan with these often debilitating illnesses.

2. Mr. Joel Troyer is the father of a five year old son Landry who has been diagnosed with PANS and other medical conditions. He and his wife Anna live in Branson, MI with their three children, Landry, Cora, and Audra. Mr. Landry will testify to the challenges his family has encountered in obtaining an appropriate diagnosis for his son and access to the appropriate care due to having to travel outside of the state and even the country to do so.

3. Ms. Lindsay Liberman of Hudsonville, MI will share her family's story of two children living with the diagnosis of PANDAS/PANS. Lindsay's daughter is eleven years old and her son is six years old. She will discuss the struggles she and her husband have had in obtaining an appropriate diagnosis for her children; access to specialists in the field, and also affordable treatment her in Michigan.

4. Ms. Joanna Gauthier and her family reside in Ferndale, MI and she has a seven year old daughter who has been diagnosed with PANDAS/PANS. Originally misdiagnosed with Tourette Syndrome, Ms. Gauthier will share her three year journey and the challenges she faced while her daughter became more ill while she tried to obtain and proper diagnosis and access to appropriate medical care for her daughter.

5. Mr. and Mrs. Andrew Gammicchia live in Shelby Township, MI and have two adult sons. They will testify to their younger son's late onset diagnosis of PANDAS/PANS at the age of 25 and the almost three year battle they fought to obtain a proper diagnosis after their son being misdiagnosed. They will also discuss seeking care after obtaining a proper diagnosis and the long challenge of finding doctors who would treat their son while also getting insurance to pay for the treatment and services needed. They will also discuss their son's Medicaid Habilitation Supports Waiver services being cut improperly due to his illness.

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# TO THE HEALTH POLICY COMMITTEE REGARDING HB 5036

**09/13/2018**

*Chair Hank Vaupel*

*Vice-Chair Jim Teddar*

*Representative Joseph Graves*

*Representative Jason Sheppard*

*Representative Diana Farrington*

*Representative Pamela Hornberger*

*Representative Jeff Noble*

*Representative LaTanya Garrett*

*Representative Jim Ellison*

*Representative Kevin Hertel*

*Representative Daniela Garcia*

*Representative Julie Calley*

*Representative Roger Hauck*

*Representative Bronna Kahle*

*Representative Winnie Brinks*

*Representative Sheldon Neeley*

*Representative Abdullah Hammoud*

*Dear Chair Vaupel and honorable members of the Health Policy Committee,*

*My name is Joel Troyer and I am from Bronson, MI. My wife, Anna and I are the proud parents of three beautiful children, Landry, Cora and Audra who are ages 5, 4 and 1 respectively.*

*When our firstborn and only son, Landry was born on January 8th, 2013, it was the proudest day of our lives. He was born healthy and strong and was everything we imagined he'd be. When you sit and hold that child for the first time so many hopes and dreams for them flood your mind. We were envisioning little league games and teaching him how to field short hops in the back yard. We envisioned teaching him to bait his hook and landing his first fish. We envisioned the childhood our fathers gave us.*

*Early on, Landry was developing normally, and every check-up brought good news. We were vaccinating Landry according the CDC schedule, and we did notice that he was developing eczema and seemed to be sick quite often, but he continued to hit all his developmental milestones. He was crawling and walking by 10 months and by 1 -2 years he'd developed a 50 - word vocabulary. He loved his grandma and sitting on her lap being read to. He was counting to 3 and saying some of his ABC's. He'd point and laugh at the dog, and I vividly remember every afternoon when I'd come home from work, he was standing in the window waiting on me because he heard my truck coming down the road. He was always the first to greet me. Everything was as it should be.*

*Then in his second year we noticed some changes. He stopped developing new words. We wondered and asked other parents what could be causing this, and we were always given the same answer, "He's fine. They all develop at their own pace". Even his pediatrician thought nothing of it, so we continued with the CDC vaccine schedule. He became a hyper child and was nearly uncontrollable. We had difficulty going places because he was so out of control. He also stopped sleeping through the night. He'd wake up nearly every night at around 2-3 AM and would literally be jumping in his bed, laughing uncontrollably. We would take him to our living room and rock him, usually until around 7 AM when he'd finally fall asleep, while we had to begin our day on no sleep. These were ALL serious warning signs of much deeper underlying issues with his immune system. We simply didn't know.....and neither did anyone else.*

*In November of 2015 the severe onset began. It was basically overnight that he stopped looking at us, began chewing on everything (including himself), rocking back and forth, pacing in a circle for 45 minutes at a time, having small seizures, severe separation anxiety, loss of appetite, sensory and motor dysfunction, and he completely stopped responding to his name. All language he had was completely gone. We were completely devastated. We searched and searched online and the only answer that came up was "Autism".*

*HOW could a completely normal and healthy child regress in to a severe and debilitating developmental disability almost overnight? We asked his pediatrician and he checked for tumors on the brain. When that was negative his advice (and effort) disappeared. He simply shrugged his shoulders and said, "That's just how autism happens". Quite frankly, the worst answer to any question we've ever asked a doctor. We checked his hearing and it came back normal. We could not find a reason why this had happened. We were in a state of mourning and grieving at that time. Our son had disappeared before our very eyes and he'd become a shell of his former self.*

*Because the pediatrician's answer didn't make sense to us, we began our fight. We found a doctor in Los Angeles, CA who treated Immune Dysfunction (NIDS) and immediately flew to L.A. to start treatments. We inundated ourselves with knowledge and learning that continues to this day. Our suspicions that Landry was injured through the CDC vaccine schedule were confirmed. The onslaught of vaccines was far too much for his little body to bear, and he was having issues detoxing the toxins and metals. His ANA titers were 1:640 (the highest possible reading) and he had retroviruses along with severe GI issues and candida overgrowth. We discovered that his immune system was attacking itself. Upon further testing through the Cunningham Panel of Tests (Not covered by insurance), we discovered Landry has what's known as PANS, or Pediatric Acute Onset Neuropsychiatric Syndrome. To discover this illness had a name was a source of relief for us. We also discovered just how many children have this who are going undiagnosed. Sadly, if our pediatrician would have simply recognized these symptoms immediately, our entire family could have been spared so much frustration and pain.*

*Our treatment consisted of going gluten and dairy free as well as no nuts, whole grains or red or blue colors. In an effort to avoid toxins we have gone completely organic and no longer vaccinate. Landry takes anti-viral medications as well as anti-fungals to control candida. He takes supplements to help his body maintain crucial vitamins and minerals and a slew of other meds to help deal with mitochondrial dysfunction, IgG deficiencies, autoimmune encephalitis and other issues involving his GI system. We eventually tried several different therapies including going to Panama City, Panama to do umbilical cord blood stem cells. Needless to say, the costs of doing this are astronomical. We have done MNRI Training and therapy as well as hired a speech therapist for him. Landry has improved tremendously over the*

*course of the last 2 years. We have "calmed" his immune system and he is doing much better. While his receptive language skills have greatly improved (we thought he was deaf and now he's our best listener), his expressive language still has a long way to go. He will allow us to read to him on occasion and his direction following and general cognition are much better than they were when he regressed. He's happy and playful again, but he's still far behind his peers socially. He makes wonderful eye contact now and even though we believe he's on the path to recovery, it's still very difficult to watch your almost 2 - year old begin passing your 5 - year old in many different developmental areas. As a parent, this is not a gift. This is not a blessing nor is it a different way of learning. This is an illness. This is frustrating for us and for Landry. He KNOWS he's behind, and we tell him every single day that none of this is his fault. He is very sick, and Mommy and Daddy are working tirelessly to make him better. No matter if it breaks us financially.*

*We eventually found a new doctor closer to home named Dr James Neuenschwander in Ann Arbor, MI. Dr Neu has tried several different treatment methods including MB12 injections and a few others. Since Landry hasn't responded to those we are going to have to look at getting IVIG for him after some more testing. His words to us regarding IVIG were, "Good luck in the state of Michigan". You can imagine our frustration at the lack of support from the medical community and insurance companies for treatments that are so desperately needed for our kids. But we've moved heaven and earth for Landry, and we will continue to do so.*

*And that is why Rep. Aaron Miller and others have sponsored this bill. It's because he understood we were speaking on behalf of our son. We are the voice that was stolen from him by PANS and the vaccine schedule that caused it. Landry may have lost his ability to speak, but his testimony is reaching other parents and helping other kids from coast to coast and even across oceans. Because we are speaking out, other kids are getting the help they need and overcoming this devastating illness. If Landry can give knowledge and understanding to other parents, why can't his story give knowledge and understanding to pediatricians who are in a position to stop this madness before it truly begins?*

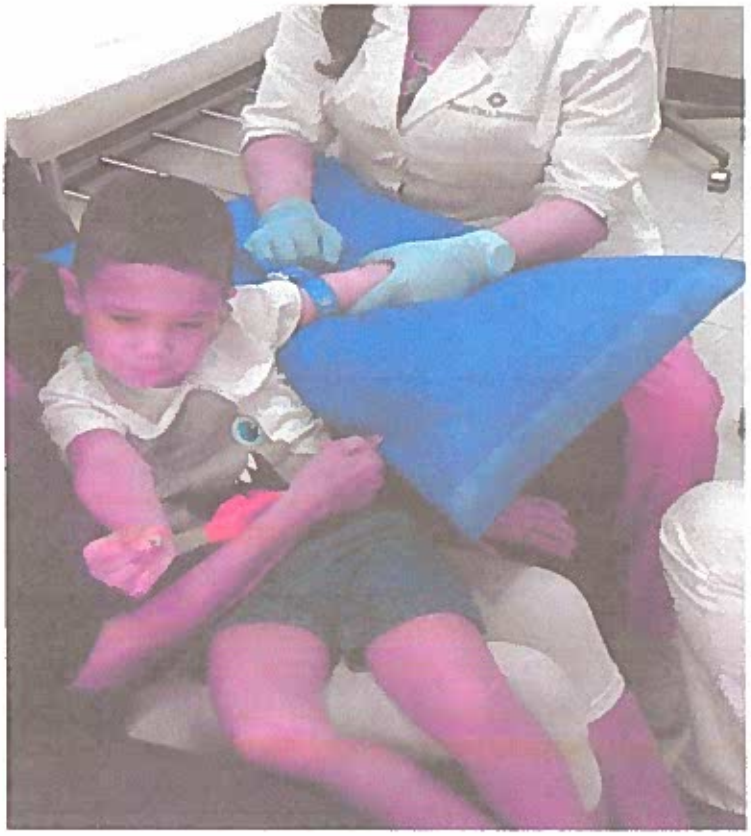
*To those reading this letter, we need you. Our son needs you. We are at a crossroads not only in MI, but nationwide. We believe healing and recovery is possible. We have watched our son slowly recover from this, and we do believe God has a powerful and ordained plan for Landry's life as well as so many other children across this great State. We must follow the steps of Illinois and Delaware and demand better for our children by giving them the opportunity to seek whatever treatments are needed for their recovery.*

*The time to act is now.*

*Sincerely,*

*Joel & Anna Troyer*

*Bronson, MI.*



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Dear Honorable Chair Vaupel and Honorable members of the Health Policy Committee,

When my daughter was 3 years old I had strep throat. She was placed on an antibiotic as a precaution but never tested positive for strep. The months following, she developed strange symptoms a few at a time. Fear of bugs, insomnia, frequent urination, night terrors, clothing preferences, lining up her toys, she would tell family she missed me (separation anxiety). The symptoms subsided a few at a time as quickly as they came (within a few months). We chalked it up to adjusting to changes and figured it was a phase. She had some mild clothing/sensory issues linger but in Kindergarten we noticed entirely new seemingly unrelated issues. She wasn't learning like the other children, even with extra help she was not progressing as expected. We got her tested and she was diagnosed with Depression and Generalized Anxiety Disorder and a borderline IQ of 82. Despite her sensory and some social issues, she did not meet criteria for Autism Spectrum and the psychologist did not feel that was what was going on.

We put her in therapy and for many years my daughter struggled with a variety of symptoms that have come and gone, waxed and waned, and changed over time but overall things only progressively worsened. As of right now her list of psychiatric diagnoses include: OCD, dysthymia, GAD, and neurodevelopmental disorder NOS in addition to sensory sensitivity, which currently holds no legitimate diagnosis of its own.

When she was 8 years old she got strep throat and was treated with a typical course of antibiotics. Following that she really struggled with worsening auditory and tactile sensory issues. I tried to figure out what was going on, but I was constantly sent back to therapy. We tried Neuro-Core, the Sensory Learning Center, occupational therapy, group therapy, individual and family therapy, and behavior plans at home: Nothing helped, nothing lasted. Both my daughter and I grew more and more hopeless.

In December 2016/January 2017 we experienced the most dramatic worsening of symptoms we have ever experienced. She quickly developed OCD and severe worsening of sensory sensitivity. In the middle of winter, she would only wear a summer nightgown. She couldn't go to school. She would not shower. I was desperate for answers and reached out to every professional who has worked with my daughter searching for answers. Some responded, some didn't but most again pointed me to the mental health system. Her doctor considered PANDAS briefly giving her an antibiotic which was not effective.

During the months following my daughter was tormented by the little sounds no one hears (markers, erasers, shuffling of feet, jackets). She would only wear skirts and tank tops with a little half sleeve sweater, so she had to stay indoors all day. She was tired, lethargic and it was difficult to get her out of bed. She was oppositional and often would refuse to get dressed and go to school. Severe anxiety and stomachaches prevented her from concentrating. When she was in school she would spend a lot of time in her "sensory spot" alone as she could not tolerate the sounds tormenting her and repeating in her mind. Her thinking seemed clouded and lacked reasoning. Sometimes she would hear voices. She regressed developmentally in play and school performance. She wanted to die and expressed wanting to kill herself. Even writing she wished she was dead on her desk at school.

Eventually, I found a doctor in pediatric neuro-immunology 3 hours away. We waited 3 months to get in; he prescribed a 5-day steroid burst to determine if her symptoms were in fact organic in nature rather than psychological. To my amazement she responded. She matured so much I felt like I had missed years of her life. I had my daughter back, and not just the daughter that I had lost in January but the daughter I lost years before! She was happy, goofy, she had energy and wanted to play and be active. She played age appropriately with friends. Her OCD diminished, and she could tolerate life and live. She wore some shorts instead of skirts. She went to school without anxiety and didn't need to use her "sensory spot". Most importantly she was happy again!

This, however, was short lived and symptoms slowly returned and new symptoms developed. New symptoms include: blurred vision, eye pain, and confusion. Her schoolwork declined. Her anxiety morphed into severe separation anxiety. She continued to miss some school. Her thoughts were riddled with fear and anxiety. The battle and rituals of showering took hours each time. She had emotional outburst over seemingly simple inconsequential things demonstrating her clouded mind and lack of reasoning. She continued to avoid fun normal childhood activities often saying, "I know it's fun and I want to, but I can't take it". Clothing continued to be difficult and she still cannot get herself to wear long sleeves or pants when we practiced. She would often say "I wish I was dead" or "I want to kill myself ".

The doctor diagnosed her with Autoimmune Encephalitis (PANDAS/PANS generally are believed to fall under this umbrella) and he recommended IVIG but insurance denied. We appealed with research, letters from those who witnessed her improvement on the steroids, school work examples, and I shared our story and our insurances denial of treatment everywhere I could. Eventually, insurance approved the treatment and my daughter has been improving with monthly IVIG. She is reading at grade level in both Spanish and English, her IQ has increased 13 points and she is catching up in school. Her separation anxiety, gone.

She continues to struggle with severe tactile sensitivity and is not able to wear pants yet. Symptoms like perception and emotional lability have improved but are not completely recovered. We hope to see these improve with continued treatment but at this time we are unsure if she will have any permanent damage due to going misdiagnosed and untreated for so long. Had my daughter received the proper diagnosis and treatment early on I am certain she would have improved 100% by now and be living a normal childhood. For now, she cannot go outside in the winter, she will not play in the snow with friends and she will continue to miss out on much of the winter fun.

In a way, though, my daughter is lucky. She is lucky we found a doctor who figured it out. She is lucky she is one of the few who got insurance approval for IVIG treatment. We went from believing my daughter would never be able to go college and questioning if she would even be able to have a job to her IQ skyrocketing up 13 points and her future looking bright. Had she not been treated I am certain she would have needed inpatient psychiatric services, and potentially residential treatment and a lifetime of mental health care.

I am certain there are many children, like my daughter, in Michigan who are misdiagnosed with a variety of mental health disorders who actually have PANDAS/PANS or other forms of AE. Finding help was not easy it required courage to stand up to powerful, educated people and not give up on finding my daughter an answer and effective help.

Children with this illness who go untreated will be accessing many mental health and social services throughout their lives including: psychiatric care, school services, and other social services. It is no secret that Michigan's mental health system is overwhelmed. Imagine if these children were identified early and promptly treated. It would largely eliminate their need for many social services in the future.

Sincerely,

Lindsay Lieberman, Hudsonville

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Vice-Chair Jim Tedder
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Dear Honorable Chair Vaupel and Honorable members of the Health Policy Committee,

My son was once fearless, happy, confident, and ready to try anything. No matter what we did he had fun. He approached things with curiosity, bravery and excitement.

In September/October of 2017 everything changed. My son at 5 years old had started wetting the bed again (even through a night-time diaper), he developed a sniffing tic, became more emotional, frequent stomach aches, he was not sleeping well getting up often and taking a long time to fall asleep. He would constantly ask the same questions. In general, he was not his happy self he was more anxious and fearful. His teacher approached me one day saying he was out of control in class and can't pay attention (he had 3-year-old school and pre-school full time the years prior, so in comparison I knew this was out of character).

Between the symptoms reported at school and what I was seeing at home I asked his teacher about strep throat and she said she was out with it earlier that week and several kids in his class had it. At that moment I knew. I had started learning about PANDAS a form of Autoimmune Encephalitis (AE) months before and immediately made the connection.

Two local pediatricians blew my husband and I off when we broached the subject with them. They minimized the teachers concerns and my son's symptoms and suggested ADHD testing. Meanwhile more symptoms started popping up. He had some auditory hallucinations and a few visual hallucinations and worsening insomnia. He was getting aggressive at school hitting other students. Our daughter's immunologist was not taking new patients. We knew his best chance was a specialist and the few treating doctors in Michigan have long waiting lists. We decided it was best to travel to a specialist who could see us soon and found one in Pennsylvania, a 6-hour drive, who could get us in the following week.

Our son was diagnosed with PANDAS encephalitis. He improved somewhat on antibiotics. He would have weeks of improved symptoms and weeks of increased symptoms. With the improvements my once self-proclaimed vegetarian started to eat steak and a hamburger for the first time in his life (at age 5). We realized that much of his previous strange eating habits were actually from this illness. We began to recognize how he probably had smaller flares prior to this with bouts of bedwetting, pinching/aggression and repeated questions. Symptoms continued to cycle with good weeks and bad weeks.

By December 2017 it was clear he struggled significantly with reading and writing. His teacher had been working with him one on one but reported at times his attention span was often less than 3-minutes. She advised we plan to repeat kindergarten.

In January 2018, with the continued ups and downs we tried a steroid taper. He suffered with side effects like insomnia and aggression. He, however, was thinking more clearly and improved in math. We were able to identify more OCD; he was having terrifying intrusive thoughts.

In May/June our son began having separation anxiety, taking me up to 30 minutes to get him into the classroom. After a year in school with 1:1 extra help he failed kindergarten as we expected, however the concerns noted on his report card were troubling. He still had not acquired the basic building blocks to learn to read and write even with the extra help. He did not know the alphabet, the sounds of letters, the concept of going left to right. Previous teachers from preschool had not had concerns regarding his ability to learn. With this information and the continued ups and downs we spoke to his specialist who decided to run some more labs but expressed that this is likely due to brain inflammation and IVIG would be the next step. His labs showed elevated coxsackie titers and we started a new medication however he continued to cycle with ups and downs and the doctor recommended IVIG.

We and his doctor were familiar with the difficulty of obtaining coverage for this treatment. We decided we would pay out of pocket rather than start a long and likely unfruitful battle with insurance that would ultimately delay treatment.

The IVIG cost us $7,000 out of pocket. We switched him to a private school that would accommodate him better with his symptoms, that was another $8,000. We, however, understand that we are the lucky ones. We had the means, with help from our families, to do what was best for our son's health and education.

We are unsure if he will need more treatments at this time but fear we may not be able to afford more treatments and will be left, like many, with insurance denials and going without further treatment. Many families do not even have the luxury to afford even one treatment and their children and families suffer. Our health system is failing children with this illness through misdiagnosis, lack of awareness and insurance denials.

This is the kind of emergency that breaks families and leads to financial ruin. What wouldn't you give for your child's health and future, for their ability to think clearly, learn and live without overwhelming anxiety? Your house? Your retirement? These are the decisions families dealing with this face.

I know we will get my son back with IVIG treatment in time. I pray every day for the families who do not have the recourses my family has relied on so heavily. Families who cannot travel out of state, who cannot pay out of pocket, who do not have extended families who can help them in a financial emergency. This is social injustice.

The legislation HB 5036 would work toward resolving this injustice and it could increase awareness among professionals leading to prompt accurate diagnosis and better access to treatment. Several states have already put in place an Advisory Council for PANDAS/PANS or have bills pending for one including: Illinois, Connecticut, Wisconsin, New York and Virginia.

Sincerely,

Lindsay Lieberman, Hudsonville

JOANNA M. GAUTHIER
946 Vester St.
Ferndale, MI 48220

September 19, 2018

Hon. Representative Hank Vaupel, Chair
Hon. Representative Jim Tedder, Vice-Chair
Hon. Representative Joseph Graves
Hon. Representative Daniela Garcia
Hon. Representative Jason Sheppard
Hon. Representative Julie Calley
Hon. Representative Diana Farrington
Hon. Representative Roger Hauck
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Hon. Representative LaTanya Garrett
Hon. Representative Sheldon Neeley
Hon. Representative Jim Ellison
Hon. Representative Abdullah Hammoud
Hon. Representative Kevin Hertel
HOUSE OF REPRESENTATIVES
HEALTH POLICY COMMITTEE

Re: House Bill 5036

Dear Chair Vaupel and honorable members of the Health Policy Committee:

I am writing you to request your support for HB 5036 of 2017, which proposes creating an advisory council on Pediatric Autoimmune Neuropsychiatric Disorders Associated with Streptococcal Infections (PANDAS) and Pediatric Acute Neuropsychiatric syndrome (PANS). PANS/PANDAS occurs when the immune system has a misdirected response to an infection, virus, or environmental toxin, which ultimately results in brain inflammation. The inflammation causes a variety of neurological and/or psychiatric symptoms that are life-changing and often debilitating.

My daughter (7), began exhibiting verbal and motor tics at the age of 4. She became cripplingly anxious about being away from me or our home. She began having meltdowns over little things that never bothered her before, like her stuffed animals being arranged "just so," being first on the stairs, or her pants having to match her shirt. She began refusing to wear socks, shoes, and underwear, and certain fabrics or textures drove her mad. She was now getting up multiple times during the night, afraid and anxious. She was clinging to me all the time. Over a short period of time, my happy, bright, adventurous child became anxious, depressed, and angry. She would say "I hate myself and my tics." We quickly became a family in crisis. During this time, the pediatrician said that tics are common in children and suggested that we should "wait and see" if the tics went away on their own. We returned to the pediatrician three times because the tics and ensuing behaviors did not diminish, but rather, continued to escalate.

It became clear after several months of this that we were losing our child – she was already a shell of her former self. By this time, there were days she could barely sit at the dinner table and use a

fork to feed herself. We thought she was having seizures, because she would sit and stare blankly into the distance while holding her fork. Despite professional opinions otherwise, this did not appear to be a medical condition that we could just "wait and see" about. Multiple visits with other specialists ensued, including an allergist, an ENT, a psychologist, and a neurologist. It was still suggested that we were dealing with "garden variety" Tourette Syndrome ("TS") and that medication would be the only option. So we medicated, for 9 days, during which time my daughter became even more lost to us due to side effects of the medication. The neurologist even recommended stronger medications, including an antipsychotic.


Unconvinced by the TS diagnosis, and dissatisfied with the limited treatment options for it, we set out on a different path. We turned to a certified nutritionist/licensed psychologist for help, who recognized signs of immune issues (specifically PANS/PANDAS). We searched for a knowledgeable MD, bringing an integrative practitioner onto our team. We also learned what other families were attempting, doing trial and error with supplements, and investing significant time and resources in changing her diet. And we've seen some improvement. Today, more than 3 years after the initial onset, my daughter is attending 2nd grade in a public school, learning karate, and attending playdates like many of her peers. But she continues to experience constant motor tics, accompanied by frequent associated physical pain, emotional outbursts, OCD, and bouts of anxiety.

I continue to be incredibly thankful a medical expert recognized that the "garden variety" TS behaviors were actually being caused by a misdirected immune response (PANS/PANDAS), and I also often wonder what would have happened if the other medical experts had been knowledgeable enough to recognize it at the beginning of this journey. Immediate treatment may have had a more profound effect. As it stands now, we don't know what the future holds for her.

The advisory council proposed by HB 5036 would be instrumental to understanding PANS/PANDAS and the practicalities of treatment. The advisory council could make recommendations on standard practice guidelines, develop mechanisms to increase public awareness, provide outreach to educators and parents, and increase the understanding of the burden on Michigan caused by this condition and its related conditions. All of these practices are crucial to ensuring proper diagnosis and treatment, as well as supporting the affected families and communities.

Please support HB 5036, and in doing so, support the healing of my child and other children in Michigan. Thank you for your consideration. If you have any questions, please feel free to contact me.

Sincerely,

Joanna Gauthier

Joanna M. Gauthier

Chair Hank Vaupel
Vice-Chair Jim Tedder
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September 24th, 2018

RE: House Bill 5036

Dear Chair Vaupel and honorable members of the House Health Policy Committee,

We are writing you today in support of HB 5036 in the hope that a PANDAS/PANS Advisory Council is created to ensure awareness of these illnesses, appropriate diagnosis, as well as access to appropriate treatment via a standard of care model that has assisted so many individuals toward a path to recovery.

As parents of a now twenty seven year old young man, we are sharing a synopsis of our son's story to illustrate to you all not only what he has been through, but what our entire family has experienced as well as thousands of other families are daily due to these debilitating illnesses. Our son has been through much in his life. Nicholas was diagnosed with severe autism in 1993 and we were told to concentrate on his older brother when the physician advised us that he would have to be institutionalized by the age of ten. He provided us neither resources nor hope for our beautiful two year old son who was born a healthy, happy child and regressed into an abyss of a neurological disorder when all speech, emotional connection, and the ability to self-regulate were lost. We've experienced nothing more difficult than losing our child, who was once advancing prior to developmental milestones measures and playing with his brother, to a child who

becoming self injurious, being unable to communicate, and aggressing toward his family and trying to elope daily which placed his life at risk.

As a family, we did not give up on our son. We looked for services, often having to leave the state for specialists because at that time we only had two doctors who treated autism in MI and we didn't even have a medical code for it for services. We also had to leave our jobs as Detroit Police Officers, due to residency requirements, and seek employment elsewhere so we could move to Macomb County to obtain better medical care and educational services for our son. We waited an entire year to get into one of those specialists. A month before that appointment, we were told that neurologist was taking a one year sabbatical and we were told we'd be seeing another doctor who was not a specialist. That pediatric neurologist, who first saw Nicholas in 1995, is still his neurologist today. She has supported him in obtaining medically necessary services and supports via a Children's Medicaid Waiver and a Habilitation Supports Waiver. Due to a team of medical professionals including a medical doctor, a neurologist, a psychologist, and a variety of therapists for speech, OT, Art/Music therapy, etc. our son was able to enter a general education class with supports and graduate high school on the honor roll and college on the Dean's List. As a family we advocated to create a standard of care for individuals with autism, worked over ten years to have bills introduced into legislation to ensure access to such care for others living with autism and to ensure an Autism Advisory Council was created.

In 2015 our son began to regress and exhibit symptoms he had never experienced before such as tics, deep obsessive thoughts on maintaining a schedule to the point it inhibited his daily life, being unable to regulate his anxiety, destroying property daily, and a loss of cognition. As an accomplished artist who dreams of becoming a storyboard artist and cartoonist, even his artwork became affected. He also showed physical symptoms of weight loss, hair loss, insomnia, periods where he appeared to be in a silent seizure and he would not be able to speak or process information. His medical team suggested a variety of tests including EEGs, an MRI, and looking at if this was a mental health disorder or metabolic disorder. In January of 2016 he was

diagnosed with Epilepsy after experiencing three seizures and close to 500 near seizures over a 72 hour period and placed on an anti-seizure medication. Within a week he became physically aggressive toward his family and unable to process information. He was removed from the medication and his blood worked showed his immune system was not functioning properly and it was in a sense attacking itself and also his brain. His doctor prescribed both antibiotics and antiviral medications over the next eight months and the viral overload would subside, but then return after the antibiotics were stopped. Nicholas began to also lose energy and become weak due to the extended use of antibiotics and his immune system not functioning. We again were losing our son, but this time to a medical condition that initially was not identified.

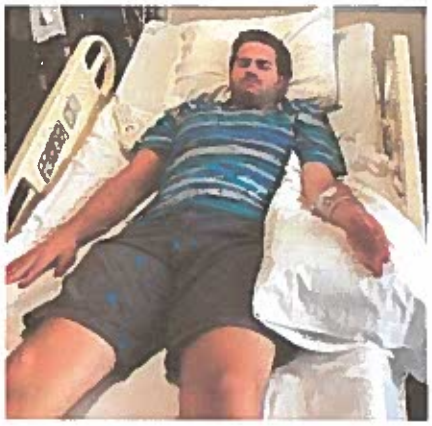
It took over a year of our son's declining health, and increase in challenging behaviors, for a diagnosis to be realized. After an emergency office visit with our son's neurologist to express our concern, due to our son's declining health and quality of life, she called us at 8pm and told us she felt our son had PANDAS/PANs and it was causing his brain to literally be on fire. She advised us we could seek either treatment via steroids or Intravenous Immunoglobulin treatment (IVIg) and explained what that would entail. She also referred our son to an Immunologist who initially thought the symptoms could be due to our son's autism because he didn't know him nor realize this wasn't his autism, despite his blood work that show a decrease in immune function. It took another year, as our son's health continued to decline and his services via Macomb County Community Mental Health (MCCMH) were being cut in part due to him being ill. The program he was participating in with as an artist asked that he leave due to property destruction and him being verbally inappropriate with others. His psychologist, who also has known him since he was a child, became increasing concerned as well due to his service cuts and his health decline. He advocated for him to maintain his services and MCCMH too did not acknowledge his medical diagnosis. Calls to the state went without assistance. It was like watching all over again what had transpired for him more than two decades before.

Once again his neurologist advised she had put forth a prior authorization for our son to obtain IVIg treatment and our insurance, Blue Cross/Blue Shield, denied the request. She appealed and it was again denied even after changing his diagnosis to Hypogammaglobulinemia which is an immunodeficiency. During this time our son's while blood count declined drastically as did his immune levels. He could hardly walk and was continuing to isolate himself due to his increased anxiety and OCD tendencies. The activities he loved, daily swimming, drawing, and being social with his family and friends he no longer desired. Light and sound became unbearable.

Again an effort was made to obtain our son's IVIg via both his immunologist and his neurologist and our son was finally approved, but not for the high dose amount his neurologist first suggested, but the low dose amount the insurance indicated they would cover which was half the amount. Additionally they advised us our son could only obtain the infusions, lasting up to sixteen hours, at home. We however could not find a provider to do so and we knew, due to our son's current challenges, that he would require hospitalization to do so. Again the doctors fought for our son to obtain access for the care needed and after four months we were able to obtain access to the IVIg our son needed. In that time however our son's much needed MCCMH

services were continued to be declined and the enhanced pharmacy that was keeping him healthy was being denied.

Our son's first IVIg occurred this past June in a room on the pediatric floor of a local hospital due to his neurologist and immunologist specializing in pediatric care. Though he barely was able to fit in the bed, and the Jimmy Neutron painting on the door hard for him look at as an adult, we were happy he finally had access to treatment. Seventeen hours and nine IVIg bottles later, our son had his first successful infusion, something that we had waited over two years to obtain while his health declined and he was denied Medicaid services he's had access to since he was a five year old child. We do however feel he should have been able to access this care and do so in a means that provides him with the dignity anyone of us would desire.



There is so, so much more we could share here, loss of employment, our older son having to return home to assist in his brother's care, as well as the consistent and constant battle we faced for over almost three years after having to struggle through what autism brought our son. Additionally, to obtain the proper diagnosis for our son, plan of care, and then treatment, should be something that all individuals living with these illnesses should be able to obtain. This should not be happening and misdiagnosis is continuing to cause children and adults in MI to be placed under an umbrella of mental health care that then denies access to appropriate care and much more harm physical and emotional harm.

That is why the citizens of Michigan deserve more. We should have access to the care needed and medical professionals supported in doing so. Several states are now addressing this and their residents obtaining needed medical care. We are asking for your support of HB5036 to do so with the establishment of a PANDAS/PANS Advisory Council with the direction being awareness of these illnesses, adequate diagnosis and a standard of care, and access to medical treatment.

With much appreciation in this matter,

Andrew, Carolyn, and Nicholas Gammicchia

7532 Nancy Lee Drive

Shelby Township, Michigan 48317

# PANS AND PANDAS AWARENESS

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:

- Emotional Liability 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.

- Using NIMH data, there are an estimated 12,000 children in Michigan with PANS or PANDAS.
- MI families with financial means are traveling to Illinois to seek medical treatment for PANS/PANDAS.
- Most children with PANS in MI are not receiving proper neuropsychiatric care because their condition remains unidentified and undiagnosed due to lack of awareness and education in MI.
- Astronomical amounts of money are spent on in-patient psychiatric care, residential treatment, and IEPs in the school system in MI despite the fact 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/PANDAS.
- The PANDAS Physician Network (PPN) is comprised of physicians affiliated with Harvard, Yale, Georgetown, Columbia, Stanford, and the NIMH. The PPN proves guidelines for diagnosis and treatment of PANS. Membership is open to Physicians, Nurse Practitioners, Registered Nurses, Physician Assistants, Psychologists, Social Workers, and Therapists.
- The PPN remains underutilized by Michigan Providers, most of whom are unaware of its existence.
- 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 University has been running a successful PANS clinic for over 5 years.
- 30 plus states are working on or have passed legislation related to PANS/PANDAS currently.
- Other states have developed advisory councils that raise awareness and make recommendations for doctors, therapists, and schools related to what can be done to identify ways to promote access to care and treatment.

# House Bill 5036

**Relating to an advisory council on PANS and PANDAS**

Pediatric Acute-Onset Neuropsychiatric Syndrome (PANS) and PANDAS (specifically associated with a strep infection) are clinically defined disorders characterized by the sudden onset of severe psychiatric and neurological impairment in children that can typically be treated effectively with antibiotics and anti-inflammatories.

**Why is this bill important?**

Based on the data from a lead NIMH researcher, there are at least 12,000 children in Michigan with PANS, but due to misdiagnosis, the numbers are probably closer to 35,000 children.
Children with PANS 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 Michigan are not receiving proper medical care because their condition remains undiagnosed due to lack of awareness and education in Michigan. This is a pervasive problem. Some parents are seeing up to 15 different doctors before being properly diagnosed. The human cost to taxpayers resulting from lack of physician awareness of the disorder is too great to ignore.

**What is the cost to taxpayers in Michigan?**

Astronomical amounts of money are spent on in-patient psychiatric care, residential treatment, and psychiatric medications for children with undiagnosed PANS funded by Medicaid. Using most conservative NIMH estimates, if each child on Medicaid in Michigan with PANS was spared one week of in-patient care (many spend far longer than that hospitalized) by being diagnosed promptly and treated with first line therapies, taxpayers would save over $27 million, This number is likely over $100 million.

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 services throughout their time in school. Untreated PANS accounts for a significant number of emotional and behavioral issues in schools and places a tremendous burden on staff.

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

**Where does Michigan stand compared to other states in addressing this health crisis?**

At least 30 states are working on or have passed legislation related to PANS. Other states have developed advisry councils that raise awareness and make recommendations of doctors, therapists, and schools related to promoting access to care and treatment. Some advisory council bills passed unanimously in other states.

States who have advisory councils report that physicians are becoming more well educated and more aware about PANS and PANDAS and children are being diagnosed more quickly. This translates into fewer behavioral and emotional issues in schools, fewer special education services, a reduction in in-patient psychiatric care paid by Medicaid, and greater family and community stability. Of course, restoring a child to good mental health is priceless.

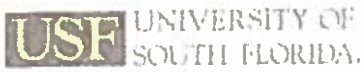
# Clinical Research Consortium

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

























# 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.

PACE
FOUNDATION

# PANDAS Physicians Network
# What are PANDAS & PANS?

## PANS

PANS ("Pediatric Acute-onset Neuropsychiatric Syndrome") is a clinically defined disorder characterized by the sudden onset of obsessive-compulsive symptoms (OCD) or eating restrictions, concomitant with acute behavioral deterioration in at least two of eight domains (please see the PPN PANS Diagnostic Guidelines). PANS does not require a known trigger, although it is believed to be triggered by one or more pathogens.

## PANDAS

PANDAS ("Pediatric Autoimmune Neuropsychiatric Disorders Associated with Streptococcal Infections") is a subset of PANS and was first reported by a team at the National Institute of Mental Health (part of NIH) in 1998. PANDAS has 5 distinct criteria for diagnosis, including abrupt "overnight" OCD or dramatic, disabling tics; a relapsing-remitting, episodic symptom course; young age at onset (average of 6–7 years); presence of neurologic abnormalities; and temporal association between symptom onset and Group A streptococcal (GAS) infection. The 5 criteria usually are accompanied by similar comorbid symptoms as found in PANS (please see the PPN PANDAS Diagnostic Guidelines).

## I. Is PANDAS Autoimmune/Autoinflammatory?

Autoimmune or Autoinflammatory Disease – Researchers hypothesize that simultaneous exposure to multiple infectious organisms can (i) override the natural immunological mechanisms which prevent the immune system from attacking self-antigen; and/or (ii) produce abnormal activation of the immune system, which then attacks neuronal cells. It is also possible that some people are genetically predisposed to these forms of dysregulated immune response.

## II. Why do some children get PANDAS after a Group A strep infection while others do not?

Science has not yet answered this question. Possible hypotheses include the following:

### Strain differences:

There are over 150 strains of Group A streptococci (GAS) and only 10–12 of these cause acute rheumatic fever and Sydenham chorea, the medical model of PANDAS. It is reasonable to hypothesize that only certain strains of GAS trigger symptoms of PANDAS. Geographic clusters of new cases of PANDAS have been reported, which would give credence to this possibility.

### Genetic vulnerability:

Defects in clearing Group A strep, resolving inflammation after group A strep, differences in neurocircuitry, cytokine receptors in the brain, or abnormal expression of neurosignaling molecules/receptors during infection are all hypothesized to play a role in neuroimmune disorders including PANS and PANDAS. No genetic marker has been determined as of today.



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### Location of Strep Infection:

Strep infections typically occur in the oropharynx, tonsils, and anus, and each area should be examined and swabbed for culture. Although "strep throat" infections are the most common trigger, PANDAS has been reported to occur in association with perianal strep infections. Additional sites may be involved; for example, animal research suggests that strep in the nasal cavity may enter or influence neuroimmune cells along the olfactory nerve, providing access to the brain through the third ventricle.

## III. Can a patient have PANDAS without having evidence of strep?

Yes, although documentation of a preceding strep infection is required to meet the criteria for PANDAS, cases in the community are often diagnosed on the basis of a history of exposure to known GAS infection (particularly in a sibling or overnight stay with a friend/relative). The strep bacteria which produce post-infectious sequelae, such as PANDAS, are often not symptomatic for pharyngitis; they produce minimal or no symptoms of sore throat, fever, abdominal pain, etc, so the infections go undetected and untreated for prolonged periods of time. Documenting a strep trigger may also be difficult because of the lag between the inciting infection and symptom onset (3–9 months in the case of Sydenham chorea).

Additional issues in locating the strep trigger include:

- Commercial serologic tests miss at least one-third of GAS infections; the ASO and anti-DNase B tests have a false negative rate of 37%. (In a 2003 study, children with GAS pharyngitis and positive throat cultures failed to produce anti-DNase B antibodies or ASO antibodies approximately 37% of the time.)
- GAS cultures can be difficult to obtain, and one must adequately swab the affected areas.
- GAS may reside in tonsillar crypts and may not be detected using routine throat swab.
- Rapid strep tests miss 15%-20% of infections, so overnight (or 48-hour) cultures must be done.

PANDAS is the only subtype of PANS that requires that symptoms be associated with a strep infection. PANS has been reported to occur in association with a variety of infectious agents, including influenza, varicella, and mycoplasma pneumoniae. Lyme disease has also been proposed as a trigger of neuropsychiatric symptoms, including those meeting criteria for PANS.

## IV. Additional Resources

### PANS Diagnostic Guidelines

www.pandasppn.org/ppn-pans-diagnostic-guidelines

### PANDAS Diagnostic Guidelines

www.pandasppn.org/ppn-pandas-diagnostic-guidelines



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PANDAS PHYSICIANS NETWORK

PPN

A DIVISION OF THE FOUNDATION FOR BRAIN SCIENCE AND IMMUNOLOGY

## WHAT IS PANDAS/PANS?

**PANDAS is an abbreviation for Pediatric Autoimmune Neuropsychiatric Disorders Associated with Streptococcal infections.** The term is used to describe a subset of children and adolescents who have Obsessive Compulsive Disorder (OCD) and/or tic disorders, and in whom symptoms worsen following strep infections such as "Strep throat" and Scarlet Fever. PANS is a newer term used to describe the larger class of acute-onset OCD cases.

**PANS stands for Pediatric Acute-onset Neuropsychiatric Syndrome** and includes all cases of abrupt onset OCD, not just those associated with streptococcal infections.

## PANDAS/PANS TREATMENT

Learn more about the treatment options that may be available for your child at www.pandasppn.org/treatment.

## FAMILY EXPECTATIONS

- Family education and support is critical, particularly in the early stages of illness. Obtaining material on treating and managing childhood OCD is an important step.
- PANS has a relapsing remitting course. Most children will experience at least one recurrence of symptom onset due to a PANS trigger.
- Communication with the school will help alleviate stress and establish a better understanding between faculty and student. Clinicians and parents might also volunteer to provide an informative lecture to class, parents, and teachers, and/or request a 504 Plan, IEP, or SST.
- Read more about setting medical and family expectations at www.pandasppn.org/SeeingYourFirstChild.

## FAMILY SUPPORT

Supportive and medical resources are available at www.pandasppn.org/parent-information.

**Children with PANDAS/PANS have an abrupt and dramatic onset of OCD or Restrictive Eating Disorder plus additional symptoms from at least 2 of the following categories:**

Anxiety

Emotional Lability/Rages

Depression

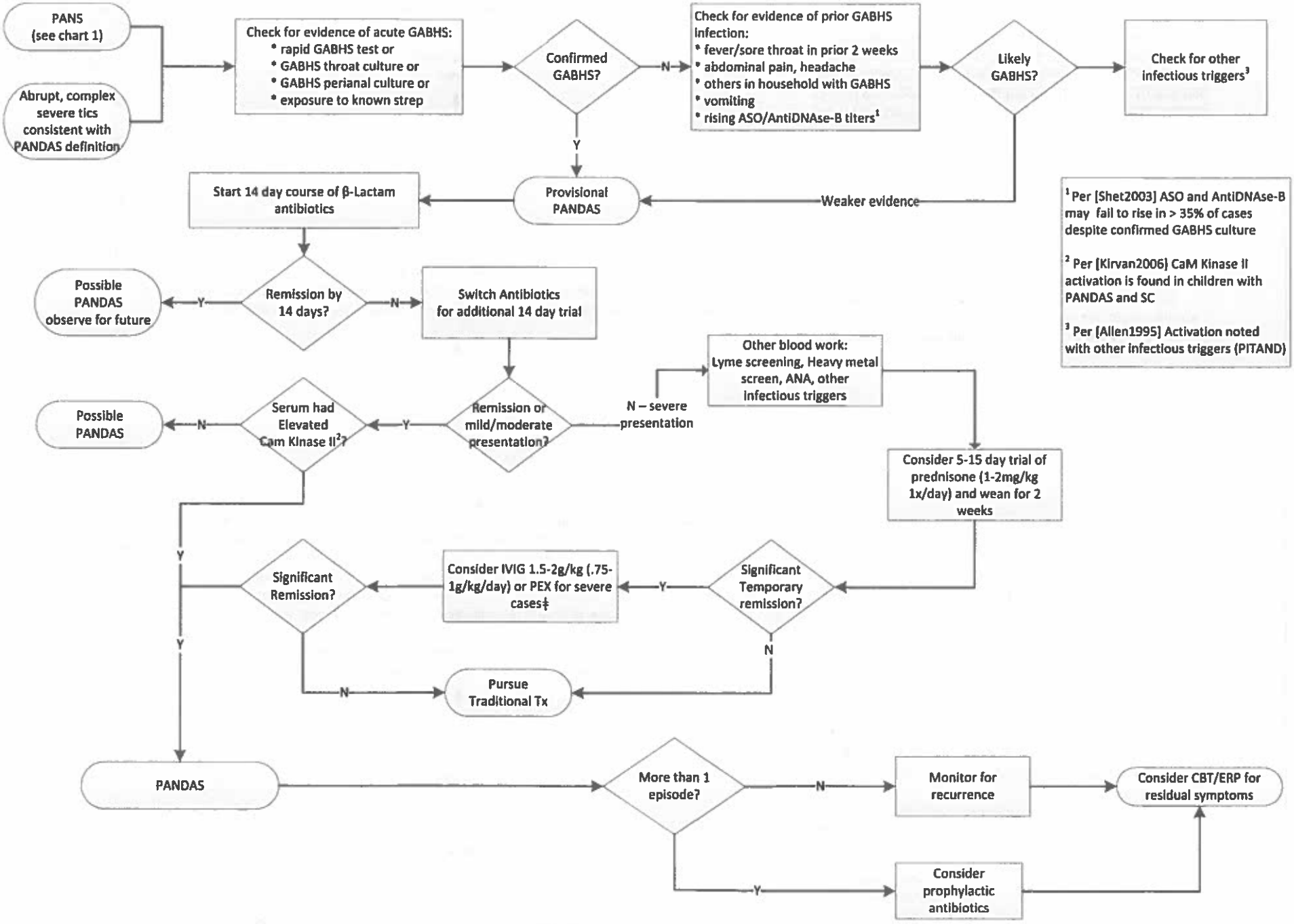
Behavioral Regression

Deterioration in School Performance

Sensory or Motor Abnormalities

Sleep Disturbances

Urinary Frequency

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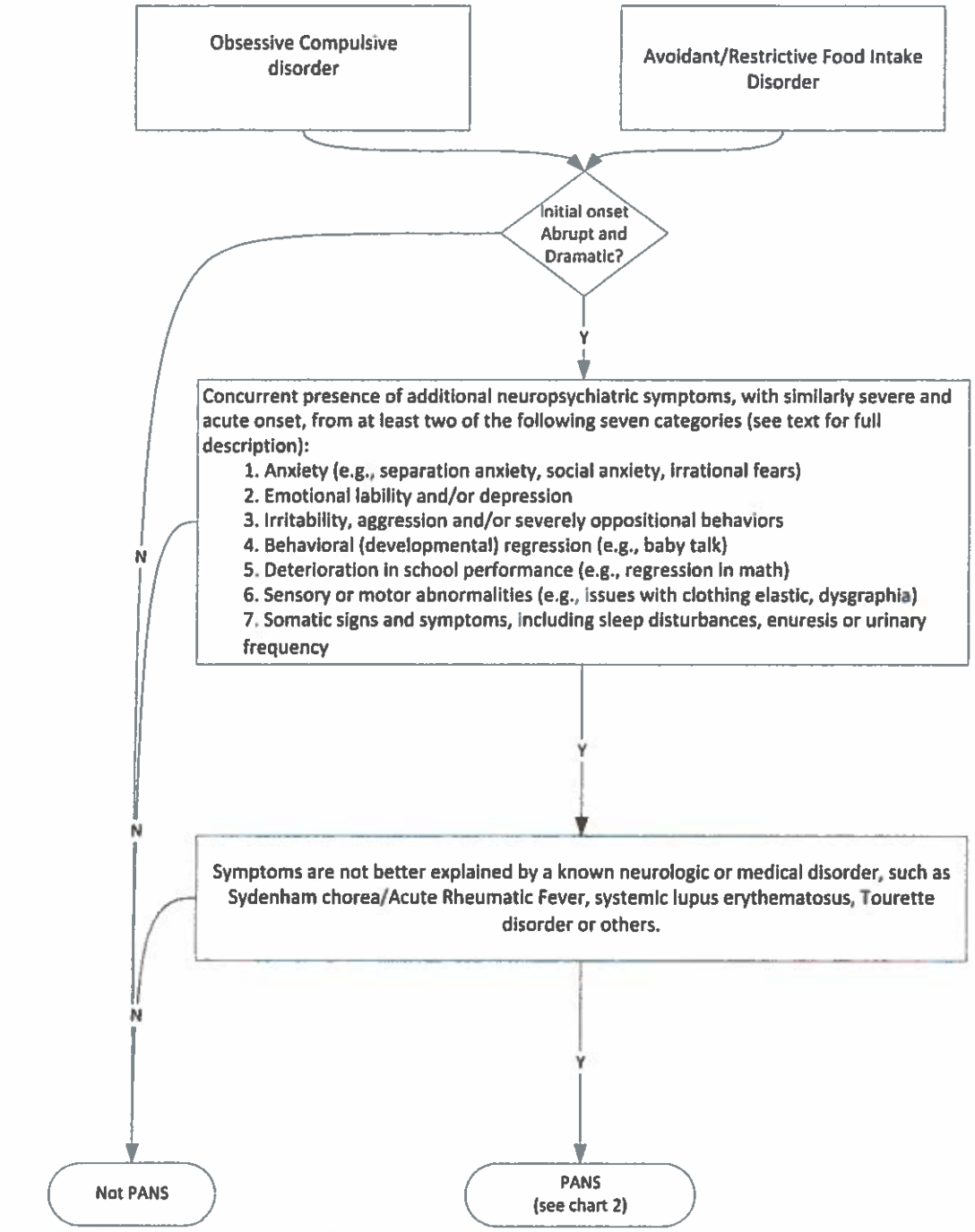


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Common Obsessive Compulsive symptoms in children are:

- Doorway rituals
- Contamination fears
- Compulsive hand washing
- Counting/Touching ritual
- Symmetry issues
- Excessive confessing

To be considered for PANS, the child must meet the DSM 5 criteria for OCD or be diagnosed with avoidant or restrictive food intake disorder.

Abrupt and dramatic onset is defined as significant behavioral change that is typically isolated to a particular day or week. Typical presentation has a shift of >16 pts in CYBOC scores. Unlike traditional OCD or ED, many parents can name the time/day when onset occurs in their child

In children, daytime urinary frequency (with no apparent UTI) is a common first clinical complaint.

The diagnostic work-up of patients suspected of PANS must be comprehensive enough to rule out these and other relevant disorders. The nature of the co-occurring symptoms will dictate the necessary assessments, which may include MRI scan, lumbar puncture, electroencephalogram or other diagnostic tests.

Swedo SE, Leckman JF, Rose NR. From research subgroup to clinical syndrome: modifying the PANDAS criteria to describe PANS (pediatric acute-onset neuropsychiatric syndrome). Pediatrics & Therapeutics 2012, 2:2. On-line article available at: http://dx.doi.org/10.4172/2161-0665.1000113

**Table and Text Excerpt from: "Treatment of Pediatric Acute-onset Neuropsychiatric Syndrome (PANS)"**
**SE Swedo (NIMH), J Frankovich (Stanford), TK Murphy (Univ S Florida)**
**In press, Journal of Child & Adolescent Psychopharmacology**

**Table 1. General principles for treating PANS[1]:**

1) Establish that PANS is the correct "diagnosis of exclusion" by completing a comprehensive diagnostic evaluation[2]

2) Provide symptomatic relief with psychiatric medications and behavioral interventions, prioritizing treatment of symptoms causing the greatest distress and interference[3]

3) Treat underlying infections and consider use of therapeutic or prophylactic antibiotics[4]

4) Treat symptoms resulting from neuroinflammation or post-infectious autoimmunity with anti-inflammatory or immunomodulatory therapies, dependent on symptom severity and disease trajectory[5]

5) Evaluate effectiveness of the treatment regimen at frequent intervals, making modifications as warranted by improvement or worsening of symptoms.

6) Treatment can be tapered downward or stopped when symptoms resolve. However, treatment may be necessary again at some point in the future, given the relapsing-remitting nature of PANS symptoms.

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"Immune therapies are the second cornerstone in the treatment of PANS, as detailed in Part II of the Guidelines: Use of Immunomodulatory Therapies.[5] Although immune treatments should be considered for all PANS patients, they are used only in cases where there is clear evidence of neuroinflammation or post-infectious autoimmunity as the underlying cause for the PANS symptoms (approximately 80% of patients). Such evidence might come from the physical examination, laboratory assays, or paraclinical assessments, as described in the PANS diagnostic guidelines.[2] The guidelines for use of anti-inflammatory medications and/or immune modulation in immune-related PANS are based on decades of experience with their use in the treatment of other post-infectious autoimmune conditions (such as asthma, reactive arthritis, and post-infectious encephalitis) and neuroinflammatory disorders (including neuropsychiatric lupus, cerebral vasculitis, and the neurologic manifestations of Sjogren's syndrome, among others). Anti-inflammatory and immunomodulatory therapies have proven useful for these conditions, even when the inciting infection has long since been cleared and biomarkers of inflammation are no longer found in blood or CSF. In such instances, the only evidence that there is ongoing neuroinflammation may be the therapeutic effects of anti-inflammatory and immunomodulatory interventions. However, their use is not without risks, and continued immunotherapy is warranted only when treatment produces clear and convincing symptomatic improvements. Clinicians should continually evaluate the impact of the interventions and stop therapy when the PANS symptoms no longer respond to the chosen immune intervention. If PANS symptoms fail to improve after intensive interventions, such as high-dose corticosteroids, consideration should be given to the possibility that the current symptoms represent damaged neural circuits, rather than ongoing neuroinflammation. In those cases, immunotherapy should be stopped, and therapeutic efforts redirected towards rehabilitation and supportive therapies." (Pp 1, 6-7 of Swedo SE, Frankovich J, Murphy TK; in press, JCAP)



ATTACHMENT

**Table 4: Corticosteroid-sparing agents (therapies used with/or to replace steroids) in PANS/PANDAS. Goal is to achieve remission with minimal steroid use.** (From Frankovich et al[5])

| | IVIG | TPE | Rituximab or MMF[a] |
|---|---|---|---|
| New onset | 1 – 6 monthly courses of IVIG in Moderate to Severe disease or in Severe-Extreme if TPE not available. | Use in Severe-Extreme cases | Patient has Moderate-Extreme impairment.<br>AND<br>Patient has proven responsiveness to corticosteroids, IVIG, or TPE.<br>OR<br>Patient has evidence of inflammation/ autoimmunity and objective signs of organic brain disease. |
| Relapsing remitting course | Consider repeated dosing of IVIG if:<br>1. Underlying immunodeficiency.<br>2. Frequent flares preceded by infections.<br>3. Deteriorating baseline. | Not indicated unless patient is in a Severe-Extreme flare. | Consider use if patient has a deteriorating baseline (i.e. each flare leaves the patient with permanent deficits) or frequent relapses.<br>AND<br>Patient has proven responsiveness to corticosteroids, IVIG, or TPE.<br>OR<br>Patient has evidence of inflammation/ autoimmunity and objective signs of organic brain disease. |
| Very delayed care, chronic-static or chronic-progressive course. | Trial of IVIG. If patient responds then symptoms recrudesce then patient is deemed immune therapy responsive, thus consider A, B, or C.<br>A. Monthly IVIG until patient is no longer having period of improvement after IVIG and recrudescence as IVIG effect wanes.<br>B. Rituximab, MMF, etc.<br>C. A + B. | Response to TPE may be transient. Consider concurrent rituximab or MMF if there is evidence of autoimmunity. | Patient has Moderate-Extreme impairment.<br>AND<br>Patient has proven responsiveness to corticosteroids, IVIG, or TPE.<br>OR<br>Patient has evidence of inflammation/ autoimmunity and objective signs of organic brain disease. |

[a] *Rituximab and MMF are generally used when the patient has demonstrated steroid/IVIG responsiveness, but the patient is steroid/IVIG dependent and there is a chronic course. Duration of therapy needed is unknown. For other inflammatory brain diseases, MMF is used for up to 5 years and rituximab is used for 1-3 years +/- additional years of MMF.*

*Abbreviations:* PANS, Pediatric Acute-onset Neuropsychiatric Syndrome; PANDAS, Pediatric Autoimmune Neuropsychiatric Disorders associated with Streptococcal infections.; IVIG, intravenous immunoglobulins; TPE, therapeutic plasma exchange; MMF, mycophenylate mofetile.



ATTACHMENT

## APPENDIX C: Use of corticosteroid-sparing agents in PANS (From Frankovich et al[5])

| | DESCRIPTION/BENEFIT | ADVERSE EFFECTS | DOSING |
|---|---|---|---|
| **Intravenous Immunoglobulin (IVIG)** | IVIG is derived from pooled plasma from human donors and processed using rigorous purification steps.<br><br>Several potential immunomodulatory roles including effects on Fc receptor activity (saturating FcR) and F(ab)2 activity (anti-idiotypic antibodies) and other mechanisms.<br><br>Benefit: Broadly impacts immune function and autoimmune responses and may help moderate the autoantibody responses.<br><br>Caution: The authors report rare cases of worsening PANS symptoms following IVIG when IVIG is given around the time of a new viral illness. | Common infusion related side effects include nausea, myalgia, fever, chills, rigors, chest discomfort, and hypotension (often dose related or due to rapid administration).<br><br>Post-infusion headaches (HA)[a] are common including aseptic-like meningitis. Aggressive hydration pre/post and half-way through IVIG infusion can help minimize HA. Use of OTC NSAIDs or corticosteroids during and after IVIG can also help prevent/manage HA.<br><br>A transient fever can be seen in the first 24 hours. Rarely, symptomatic hemolysis can occur and manifest up to 1-week post-infusion. Anaphylaxis can occur, especially in patients with IgA deficiency (if IgA deficient, use formulation that does not contain IgA). Other rare side-effects include renal failure, thrombosis (including sinus venous thrombosis), dermatologic reactions, hemolytic reactions, neutropenia, renal failure, transfusion-related lung injury, and seizures. | Induction: 1.5 - 2 g/kg, max dose 70 g/dose. If patient has clear improvement and then recrudesces, subsequent doses should be dosed at 1 g/kg. 2nd & 3rd doses have been given at 4-6 week intervals by PANS consortium members.<br><br>Some patients are treated with rheumatology protocols which utilize 2 g/kg monthly (max dose 70 g/dose).<br><br>If patient becomes dependent on IVIG to maintain good baseline, consider adding in or replacing with Rituximab or MMF. |
| **Therapeutic Plasma Exchange (TPE)** | Removes autoantibodies triggering immune responses leading to brain inflammation.<br><br>TPE is a process of separating blood components using centrifugation and a semipermeable membrane. This allows for disease promoting blood components to be removed while the remaining components are returned to the patient. Plasma proteins, including antibodies promoting disease, can be removed from the patient's blood.<br><br>Benefit: Rapidly removes antibodies from plasma and quickly eliminates autoreactive immune responses caused by antibodies. | TPE often requires an intensive care admission and this may be psychiatrically traumatizing to some children.<br><br>Related to IV access: pain, bleeding, infection, and, thrombosis. Risks of sedation. Risks of fluid shifts. Complications related to citrate anticoagulation/calcium chelating and replaced with albumin. Risks of exposure to blood products.<br><br>Syncope, pseudoseizures, and pain-amplification have been reported immediately following TPE.<br><br>TPE can cause hypogammaglobulinemia. | 1 volume therapeutic exchanges every other day for 10- 12 days (5-6 runs) (Perlmutter et al. 1999).<br><br>1.5 volume therapeutic exchanges over 3-5 days (3-4 runs) (Latimer et al. 2015).<br><br>As soon as TPE is stopped, autoantibodies will continue to be produced (if autoimmune disease present), thus adjunct therapy is recommended. In infection triggered PANS, TPE alone can be effective if infectious driver is eliminated. |
| **Rituximab** | FDA approved for use in microscopic polyangiitis, granulomatosis with polyangiitis (formerly Wegener's), and rheumatoid arthritis. It is frequently used in idiopathic thrombocytopenic purpura, lupus nephritis, and autoimmune encephalitis.<br><br>A chimeric antibody directed against CD20, a surface protein found on B-cells that leads to rapid B-cell depletion.<br><br>Benefit: B-cell depletion frequently occurs within 24-48 hours after infusion and can be sustained for 3 months to over 1 year. In chronic-static or refractory cases, benefits may not be seen for 6 months. | PANS patients can have escalation of psychiatric symptoms and pain symptoms after the first round (lasting 1-5 months), but the second round at 6 months is generally better tolerated.<br><br>Infusion reactions are frequent, especially with the first dose, but can be mitigated by slowing the infusion rate and premedication with corticosteroids, acetaminophen, and diphenhydramine. Serious infections have been reported but are rare. Reported infections following rituximab include: CMV related retinitis/colitis, progressive myelitis leukoencephalipathy (JC virus), pneumonia, empyema, etc. | Most autoimmune diseases are treated with the protocol used in rheumatoid arthritis of 750 mg/m2 (max dose 1000 mg) x 2 doses separated by 2 weeks. Although the effect can last up to a year, many patients relapse at the 6-month mark so most protocols aimed to treat chronic autoimmune disease require re-dosing at 6 month intervals. |

*IVIG related headaches generally respond well to steroids (1-2 mg/kg prednisone equivalent, max dose 60-120 mg/day) when given along with and/or 2-5 days after the infusions. For patients who do not tolerate corticosteroids, NSAIDS can be used (IV ketorolac or ibuprofen around the clock). Pre-medication with diphenhydramine (or other antihistamines) and acetaminophen can also improve tolerability. Nausea can be treated with ondansetron and it may be needed around-the-clock during and after the infusion. Some patients may need opiates to manage severe headaches.*

*Abbreviations:* PANS, Pediatric Acute-onset Neuropsychiatric Syndrome; OTC, over-the-counter; MMF, mycophenolate mofetil; IgA, immunoglobulin A; IV, intravenous; CMV, cytomegalovirus; JC, John Cunningham.



ATTACHMENT

**REFERENCES:**


1) Swedo SE, Frankovich J, Murphy TK. Treatment of Pediatric Acute-onset Neuropsychiatric Syndrome (PANS).
J Child Adolesc Psychopharmacology. In press, 2017.
2) Chang K, Frankovich J, Cooperstock M, Cunningham MW, Latimer ME, Murphy TK, Pasternack M, Thienemann M, Williams K, Walter J, Swedo SE. Clinical evaluation of youth with pediatric acute-onset neuropsychiatric syndrome (PANS): Recommendations from the 2013 PANS Consensus Conference. J Child Adolesc Psychopharmacology. 25:3-13, 2015.
3) Thienemann MM, Tanya K, Leckman J, Shaw R, Williams K, Kapphahn C, Frankovich J, Geller D, Bernstein G, Chang K, Swedo S. Clinical Management of Pediatric Acute-onset Neuropsychiatric Syndrome (PANS): Part I- Psychiatric and Behavioral Interventions. J Child Adolesc Psychopharmacology. In press, 2017.
4) Cooperstock MSS, Swedo S, Pasternack MS, Murphy TK, and Members of the PANS/PANDAS Clinical Research Consortium. Clinical Management of Pediatric Acute-onset Neuropsychiatric Syndrome (PANS): Part III- Treatment and Prevention of Infections. J Child Adolesc Psychopharmacology. In press, 2017.
5) Frankovich JS, Hernandez J, Dale R, Agalliu D, Williams K, Daines M, Hornig M, Chugani H, Sanger T, Muscal E, Pasternack M, Cooperstock M, Gans H, Zhang Y, Cunningham M, Bromberg R, Willet T, Bernstein G, Brown K, Farhadian B, Chang K, Kalamani G, Geller D, Kovacevik M, Sherr J, Shaw R, Leckman J, Murphy TK, Thienemann M, and Members of the PANS/PANDAS Clinical Research Consortium. Clinical Management of Pediatric Acute-onset Neuropsychiatric Syndrome (PANS): Part II- Use of Immunomodulatory Therapies. J Child Adolesc Psychopharmacology. In press, 2017.




ATTACHMENT

ILLINOIS PANDAS/PANS ADVISORY COUNCIL

# PANDAS/PANS Standards of Care Summit

## Wednesday, February 8, 2017

12:30 to 4:30 PM CT

DuPage County Health Department

111 N County Farm Rd, Wheaton, IL 60187

## Description

In 2015 the Illinois PANDAS/PANS Advisory Council was created by Public Act 99-0320 and commissioned to make recommendations concerning standard practice guidelines for PANDAS/PANS, develop mechanisms to increase clinical awareness of PANDAS/PANS, provide outreach to educators and parents, and develop a network of volunteer experts on PANDAS/PANS to serve as resources within the state.

This half-day conference will provide stakeholders with opportunities to be involved in implementing the commission of the Advisory Council. Breakout sessions will discuss progress and focus on developing action items creating framework for further education and standards development for health professionals and families alike.

Conference participants will have the opportunity to dialogue with advisory committee members and workgroup leaders about key issues related to the establishment and implementation of PANDAS/PANS standards of care in Illinois.

## Keynote Speaker

Dr. Susan Swedo, Chief Pediatrics & Developmental Neuroscience Branch at the NIMH

## Topics Covered

- Family and home
- Psychiatric manifestations: management and counseling
- Insurance coverage and treatment resources
- Educational issues

## Who Should Attend

- Physicians
- School nurses
- Social workers and school psychologists
- Public Health Professionals
- Risk and quality improvement professionals

## Objectives

At the end of the program you will be able to:

- Summarize the standards of care to date and understand the challenges affecting the ongoing development and implementation of a standard of care for the treatment of PANDAS/PANS.
- Describe opportunities to engage in educating and extending the understanding of the current diagnostic and treatment guidelines to help health professionals and family members in Illinois.

## For More Information & Registration

Limited, **NO COST** registration and additional information is available by clicking the Brown Paper Tickets link below:

**http://bpt.me/2727320**

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ILLINOIS PANDAS/PANS ADVISORY COUNCIL

# PANDAS/PANS Standards of Care Summit

## Thursday, October 4, 2018

12:00 to 5:00 PM CT

John R. Block Building

801 E. Sangamon Ave., Gate 11, State Fairgrounds, Springfield, IL 62702

## Description

This afternoon conference will provide stakeholders with opportunities to learn about the history and current standards of care for diagnosing and treating Pediatric Autoimmune Neuropsychiatric Disorder Associated with Streptococcal Infection (PANDAS) and Pediatric Acute onset Neuropsychiatric Syndrome (PANS).

Conference participants will have the opportunity to dialogue with Illinois PANDAS/PANS Advisory Council members and world-renowned experts on the latest in diagnostics, the development of treatment protocols, and issues related to the establishment and implementation of appropriate care models for the children of Illinois.

## Keynote Speaker

Dr. Susan Swedo, Chief, Pediatrics & Developmental Neuroscience Branch of the National Institute of Mental Health (NIMH)

## Topics Covered

- History & Current Research
- Diagnostics
- Treatment Guidelines
- Insurance Coverage and Treatment Resources
- Educational Issues
- Excerpt from PANDAS/PANS Documentary Film

## Who Should Attend

- Physicians
- Social Workers and Psychologists
- Public Health Professionals
- Risk and Quality Improvement Professionals
- Hospital Administrators
- School Administrators, Nurses, and Educators

## Objectives

At the end of the program you will be able to:

- Summarize the standards of care to date and understand the challenges affecting the ongoing implementation of a standard of care for the treatment of PANDAS/PANS in Illinois
- Understand the necessary components to ensure a smooth insurance process for your patients and your office
- Partner with the family and the school system to suggest appropriate educational accommodations for your clients and patients

## For More Information & Registration

Limited, NO COST registration and additional information are available via Brown Paper Tickets:

**https://ipac-summit-2018.bpt.me**

**CLICK HERE TO REGISTER**

This program was developed in cooperation with the Illinois State Board of Education, an approved provider of continuing nursing education for Illinois nurses under Illinois Nurse Practice Act Rules, Section 1300.130, Continuing Education, c)1)P). Contact hours are to be determined.

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# Pans, Autism, and the Immune System: An Interview with Expert Neurologist Dr. Richard Frye

*9/3/2018 - Dr. Richard Frye is a pediatric neurologist and Chief of The Division of Neurodevelopmental Disorders at Phoenix Children's Hospital. He's recognized as an expert on the treatment of autism.*

**Could you summarize the results of your recent study, "Intravenous Immunoglobulin For The Treatment Of Autoimmune Encephalopathy In Children With Autism"?**

Our study recently published in *Translational Psychiatry* showed that a subset of children with autism spectrum disorder (ASD) who did not respond to standard interventions had autoantibodies in their blood targeting brain tissue which might qualify them for the diagnosis of autoimmune encephalopathy (AIE). The majority of children with ASD had elevated levels of autoantibodies measured by the Cunningham Panel™ (Moleculera Labs, Oklahoma City, OK) along with an elevation in the activation of calcium calmodulin dependent protein kinase II (CaMKII). A few patients had other brain targeted autoantibodies associated with AIE, such as voltage-gated calcium channels autoantibodies.

Some of the patient qualifying for the diagnosis of AIE were treated with intravenous immunoglobulin (IVIG) and their symptoms were monitored with two widely-used validated behavioral questionnaires, the Aberrant Behavior Checklist (ABC) and the Social Responsiveness Scale (SRS). Overall, IVIG was found to improve scores on both the ABC and SRS questionnaires and the great majority of parents reported improvements in additional symptoms related to ASD. The majority of patient experienced side effects from the IVIG treatment but most of the time these were mild and limited to the time around the infusion period. We were also able to divide the patients who received IVIG into those that demonstrate a positive response on the behavioral questionnaires and those that did not. This allowed us to determine if autoantibody titers of the Cunningham Panel™ collected prior to IVIG treatment could predict which individuals would response to IVIG. We found that, overall, the Cunningham Panel™ could predict which individuals would response to IVIG treatment with over an 80% accuracy rate and that the anti-dopamine receptor D2L and anti-tubulin antibodies were particularly sensitive to predicting response to IVIG treatment.

**What initially led to your interest in considering immune-mediated factors in autism?**

I have built my clinical practice with a vision of discovering new treatments for children with ASD. Some children with ASD do not respond to standard treatments or even new novel treatments and many times a standard medical workup does not reveal any additional obvious treatment targets. Such patients need to be investigated further to determine if there are other factors preventing them from developing skills or causing disruptive behaviors. For me, integrating an investigation of immune factors into my practice was the next step for further determining treatable factors for children with autism.

Do you have a sense for the percentage of children with autism who also have AIE?

The study describes 82 patients that were screened for AIE. This was about 8% of the patients seen in

my autism clinic during the study period. 60% of these children were believed to probably have AIE, or about 5% of the children seen in my autism clinic. The percentage of the other 92% of patients seen in my autism clinic that might also have AIE is not known but it is very likely that a significant percentage of these children may have AIE. Many of these children were not investigated further because of various reasons including insurance coverage of testing, parental preference and/or difficultly in drawing blood. Further studies that systematically evaluate the general ASD population for AIE so we have a better understanding of the number of children with ASD that may benefit from treatment for AIE.

**While acceptance of post-infectious autoimmune encephalopathy and pediatric acute-onset neuropsychiatric syndrome (PANS) continues to grow, there seems to be a bias within the medical community against considering PANS in children with autism. Would you agree or disagree with this statement and do you have a sense for why this might be?**

I believe that the idea that there are physiological abnormalities underling ASD which can be treated is novel concept that is faced by significant skepticism. Also many are skeptical that children with ASD can recover from their disorder at all. This skepticism, I believe, it based on an old concept of children with neurodevelopmental disorders having a "static encephalopathy" in which it is believed the brain is damaged and cannot improve. As new research connects neurodevelopmental and neurobehavioral disorders such as ASD with abnormal physiology and treatments that target these physiological abnormalities, evidence will become more compelling. As treatments are shown to improve function in disorders which previously had few effective treatments, I believe more people in the medical community will embrace treatments that help children with neurodevelopmental disorders.

**Some physicians have questioned the validity of the Cunningham Panel due to the fact that many children with autism have positive results. The conclusion by some is that this means the test is producing false positive results. How would you respond to this?**

In our study 57% of the children we tested were positive for the Cunningham panel as we defined a positive test. We set a more stringent criteria as compared to others. For our clinical practice, the Cunningham panel is considered positive when one or more autoantibodies are elevated AND CaMKII is elevated. One of the reasons we examined the predictability of the Cunningham panel is too validate and refine the accuracy of the Cunningham panel. Our study points to two particular autoantibodies which appear to predict response. Since the components of the Cunningham panel have been developed based on converging animal and human basic research, it is very clear that these components are very likely to be very meaningful. It is likely that different components (or combination of components) will identify different subgroups of neurobehavioral, neuropsychiatric and/or neurodevelopmental disorders. Further studies are needed to further refine the most accurate use of interpreting the components of the Cunningham panel.

**Do you ever treat children who did not have an abrupt or acute onset of neuropsychiatric symptoms, and if so, do they respond similarly to children who did have an abrupt onset?**

Abrupt onset of neurological, behavioral or psychiatric systems as well as abrupt loss of previously acquired skills are red flags for an underlying metabolic or immunological disorder. All three cases described in our recent paper had abrupt onset of symptoms and approximately one-third of children with ASD are estimated to have neurodevelopmental regression. However, there are children without a

history of an abrupt onset of systems who also respond to immune and metabolic treatments that target medical abnormalities usually associated with an acute onset of disease. Thus, I do not usually use the history of abrupt symptoms onset to guide my workup. Treatments I prescribed are guided by biomarkers.

**What is your approach to managing children with autism who develop neuropsychiatric symptoms? How does this differ from your approach to those without autism?**

I have found that many children with neuropsychiatric symptoms without ASD have similar metabolic and immune abnormalities as those with ASD. I use the same approach for such children and have had successes in improving their symptoms and ability to function.

**Is there any research you're working on currently that you'd be willing to tell us about?**

At this time I am working with several collaborators on the interaction between metabolism and the immune system. Emerging research demonstrates connections between the immune system and metabolism, both mitochondrial disorders and oxidative stress. We have recently published a review article on mitochondrial dysfunction in autism which discussed this (https://www.ncbi.nlm.nih.gov/pubmed/30039193) and previously Dr Rossignol and I published a review article outlining the evidence for connection between these abnormalities in the brain of children with ASD (https://www.ncbi.nlm.nih.gov/pubmed/24795645). I think this is a promising area of research which may pave the way for new treatment targets.

**You've published "Autism Spectrum Disorder in The Emergency Department: Looking Beyond Behavior." What should ER physicians, primary care providers, and specialists be considering when a patient with autism presents with acute behavioral or neuropsychiatric symptoms?**

It is very important to consider that there may be medical issues that can be driving behavioral decompensation. These medical abnormalities do not have to be complicated immune and/or metabolic abnormalities but may be more basic problems such as sleep disruption, gastrointestinal disorders and/or anxiety which may need to be evaluated and addressed. There may also be other underlying more complicated metabolic and/or immune disorders, so it is important to consider referring the child to a practitioner experienced in looking into these treatable abnormalities. Most importantly, it is important to have a vision of try to treat the underlying biological cause of the symptoms rather than just treating the behavior with medications to suppress it. Indeed, disruptive behavior may be signaling that something that is not obvious needs to be addressed and suppressing this signal may simple make a untreated medical problem worse by allowing it continue and progress without appropriate treatment.

*-The Foundation For Children With Neuroimmune Disorders thanks Dr. Richard Frye for taking the time to allow FCND Founder and President Anna Conkey to interview him.*

*Link: http://www.neuroimmune.org/frye/pans-autism-and-the-immune-system-an-interview-with-expert-neurologist-dr-richard-frye*