

September 21, 2018

Chair Hank Vaupel  
Vice-Chair Jim Tedder  
Representative Joseph Graves  
Representative Daniela Garcia  
Representative Jason Sheppard  
Representative Julie Calley  
Representative Diana Farrington  
Representative Roger Hauck  
Representative Pamela Hornberger  
Representative Bronna Kahle  
Representative Jeff Noble  
Representative Winnie Brinks  
Representative LaTanya Garrett  
Representative Sheldon Neeley  
Representative Jim Ellison  
Representative Abdullah Hammoud  
Representative Kevin Hertel

Re; Bills HB 5035 and HB 5036

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

On March 17, 2015 our family was getting ready for St. Patrick's Day dinner. My 7-year old daughter, Claire, was helping by taking out recyclables before we sat down to eat. To do this she had to go down a flight of stairs to the back porch. I continued to get the family to the table and serve the food when I realized Claire hadn't come back yet. I went to check on her and found her climbing the stairs, up, then down, up, then down again. Over and over. She did it with a forced smile, with a frown, with a straight face, she had to touch the light switch, then the door knob. She had to do these repetitive behaviors because something was telling her that if she didn't, she would turn into a ghost and no one would ever see or hear her again, or that I would die in a car crash. This started at 6:35pm and went on until 10:30pm at which time she said she'd go to bed and sleep for a little while, then get up and do it some more.

Thankfully she slept through the night. The next day she couldn't get dressed or eat. She climbed the stairs for two hours. The not eating/dressing went on for four days. The climbing also continued on and off. Then the ticks started. Then the separation anxiety and rages started. She lost 4 lbs that week. This was a 42 pound kid who already didn't have an ounce to spare.

Our pediatrician had no idea about what was happening and referred her to a psychiatrist. The psychiatrist wanted to put her on anxiety medication. Luckily the friend of a friend heard about what was happening and suspected what we were dealing with was PANS/PANDAS. She referred us to her daughter's doctor, also a PANDAS kid, and we got a diagnosis right away. Claire started on antibiotics and ibuprofen and we saw marked improvement within three days. Unfortunately, it didn't last. A second antibiotic was added along with immunity boosting supplements, SSRI's and drastic diet modification. This all helped to keep her calm, but she still has paralyzing separation anxiety. She tried steroid treatment and this failed to keep her in school.

She got through first grade with separation anxiety slowly getting worse and she severely regressed in reading and writing. In second grade she missed the last two months of school. In third grade she never went back after the winter break, even though the school accommodated us and allowed me to remain at a desk in the hall outside of her classroom, to ease her separation anxiety. She had her tonsils and adenoids out in February, which was supposed to make a huge impact, but did nothing for her. Now, in fourth grade, she has yet to attend school. Her two best friends are in her class and she has the teacher she wanted. She

badly wants to go to school, but her separation anxiety keeps her home. She has unbearable fear. "Fear" tells her to do things or not to do things.

While this disease has ruined the past 3½ years of my beautiful, funny, loving, smart, talented, artistic daughter's life, it's had a devastating impact on the rest of the family also. My son isn't able to go play with his friends because she worries about him. It's always a fight to get her to let him go. She worries about him walking home from school, too. I own a business. I have been unable to work on my business because she needs to be with me 24/7. Because of this, we've lost the second income we relied on. Additionally, she sleeps with me, and if I'm not in the same room with her she yells for me throughout the house.

Her symptoms are regularly bad, but when she's sick, or a member of our family is sick she gets worse. Worse involves rages, incontinence, sensory issues and depression.

Our next course of action is IVIG. We have been on a waiting list since May, 2018 and expect to see the doctor in October. I don't know what to expect when it comes to paying for the treatment. Navigating this issue with our insurance company should not have to be complicated or worrisome. This should be covered, but people in the PANS/PANDAS community have forewarned me to not get my hopes up. This scares me. My bright, energetic child is missing out on an education, social events and simply being a normal child and this could be fixed by IVIG that may be out of reach for my family. Please ensure this doesn't happen!

It makes no sense to me that often insurance will cover rehab for addicts who made a choice to go down a drug/alcohol path, but not for kids affected by PANS/PANDAS who took no action to acquire this disease.

Please support us in establishing an advisory council for Michigan children. Currently, Illinois, Connecticut, Wisconsin, New York and Virginia have advisory councils in place or have bills currently pending to put an advisory council in place.

In five states, BCBS has PANDAS/PANS listed as a covered condition: Illinois, Oklahoma, Texas, Montana and New Mexico. Please work to ensure children in Michigan are covered for treatment for this devastating disease.

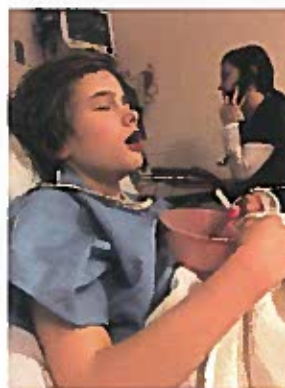
Meaghan McCann, Plymouth



Before PANS/PANDAS



In a rage



Tonsillectomy and  
Adenoidectomy



This is what Fear looks like

# *Smith Elementary School*

*Plymouth-Canton Community Schools*

1298 McKinley  
Plymouth, Michigan 48170

734-416-4850  
smith.pccs.k12.mi.us

September 22, 2018

Dear members of the House Health Policy Committee,

As a principal of an elementary school that has at least one family courageously striving every day to learn more about how to help their child thrive in while living with of a PANDAS/PANS diagnosis, I am writing in support of HB5036 to establish an Advisory Council on PANDAS/PANS in the state of Michigan. Better awareness for all is needed, but also access to diagnosis and treatment for those affected. Additionally I support HB5035 which will provide insurance coverage for diagnosis and treatment deemed to be a medical necessity for an individual suffering with this debilitating illness.

With much appreciation for your consideration,

Dana Jones  
1298 McKinley  
Plymouth, MI 48170

#### Bills info:

HB5036: Health; other; advisory council for pediatric autoimmune neuropsychiatric disorders; create.  
Amends 1978 PA 368 (MCL 333.1101 - 333.25211) by adding sec. 5145.

<http://www.legislature.mi.gov/.../billintroduced/House/pdf/20...>

HB5035: Insurance; insurers; coverage for certain pediatric autoimmune neuropsychiatric disorders; require.  
Amends 1956 PA 218 (MCL 500.100 - 500.8302) by adding sec. 3406u.

[http://www.legislature.mi.gov/\(S\(knx52tiuvakp4r3fyjn5axd3\)\)/mileg.aspx?page=home](http://www.legislature.mi.gov/(S(knx52tiuvakp4r3fyjn5axd3))/mileg.aspx?page=home)

Sincerely,



Dana Jones  
Principal



Sept. 22, 2018

Dear House Health Policy Committee members,

Thank you for taking a few moments to read my letter.

I'm writing you today as both mother of a 23-year-old, young man who has high-functioning autism and as an educational advocate for children with special needs. For 15 years, I've worked to bridge the gap between educators and parents, supporting children with disabilities.

Recently I've consulted with families whose children have PANDAS/PANS. What I've discovered in my process is that overwhelmed parents, the medical community, and the educational system have had limited to no information about this disability. There is so little information; the situation reminds me of when people in Michigan started to become more aware of autism. Michigan's Autism Insurance Reform legislation (PA 99 and PA 100 of 2012) went into effect on October 15, 2012. Only 6 years ago. Prior to that few services in Michigan were available to children on the autism spectrum. Those services that existed were paid for out of pocket from the families. Clients were literally losing their homes so they could help their child.

I support HB5036 and HB5035. The passage of HB5036 will establish an Advisory Council on PANDAS/PANS in the state of Michigan. We need to generate more awareness of how devastating PANDAS/PANS is to children and their families.

The importance of the passage of HB5035 can't be understated. It will provide insurance coverage for the diagnosis and treatment deemed medically necessary for those suffering with this debilitating illness. HB5035 will assist in promoting insurance coverage for appropriate diagnosis and treatment. Today that is almost impossible.

Thank you for your consideration.

Carla Baker Marymee  
CEO, Kids First Advocacy, LLC  
Special Needs Advocate, Parent Coach, IEP Consultant  
[www.kidsfirstadvocacy.com](http://www.kidsfirstadvocacy.com)  
mobile: 248-890-0584

## Melissa Weipert

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**From:** goudie143@charter.net  
**Sent:** Friday, September 21, 2018 5:56 PM  
**To:** Melissa Weipert  
**Cc:** 'gammicca@comcast.net'  
**Subject:** Support for HB5036

Dear members of the House Health Policy Committee,

I am writing in support of HB5036 to establish an Advisory Council on PANDAS/PANS in the state of Michigan. I am doing so because not only do we need better awareness, but access to diagnosis and treatment for those affected.

Additionally I support HB5035 which will provide treatment deemed to be a medical necessity for an individual suffering with this debilitating illness.

We have two Grandsons that are affected with PANDAS, one is 6 years old and one is 3 years old. They both have flares, ticks/ticking and inflammation. They both need to be able to receive treatment just like anyone is able to with any other disease. The financial part of this disease and trying to get treatment is a difficult struggle for my daughter and son-in-law. Another fear we have is that they will need further treatment that insurance won't cover and and my daughter or any of us simply won't have the funding to ensure that they have an opportunity to receive the treatment needed.

With much appreciation for your consideration,

Gary and Vicki Goudie  
6603 Bear Lake Drive  
Lake, MI 48632

**Bills:**

HB5036: Health; other; advisory council for pediatric autoimmune neuropsychiatric disorders; create. Amends 1978 PA 368 (MCL 333.1101 - 333.25211) by adding sec. 5145

HB5035: Insurance; insurers; coverage for certain pediatric autoimmune neuropsychiatric disorders; require. Amends 1956 PA 218 (MCL 500.100 - 500.8302)by adding sec. 3406u.

## Melissa Weipert

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**From:** Nicole <nicmacmillan07@yahoo.com>  
**Sent:** Saturday, September 22, 2018 1:26 PM  
**To:** Melissa Weipert  
**Cc:** gammicca@comcast.net  
**Subject:** HB5036

Dear members of the House Health Policy Committee,

I am writing to you in support of establishing a HB5036 Advisory Council on Pediatric autoimmune neuropsychiatric disorders associated with streptococcal infections (**PANDAS**) in Michigan. We are in need of better awareness and access to treatment and diagnosis of those suffering with this illness. Another reason for our support of HB5035 is that this will provide the needed insurance coverage for those affected.

Thank you for your time.  
Sincerely,

Ken and Nicole MacMillan  
43486 Stuart Ct  
Canton MI 48187

Sent from my iPhone

September 22, 2018

Dear Members of the House Health Policy Committee:

I am writing in support of HB 5036 to establish an Advisory Council on PANDAS/PANS in the state of Michigan. We undoubtedly need better awareness of this disease but we also need access to diagnosis and treatment for those children affected. Our precious granddaughter, Claire Leginza, is 10 years old and is one of the 10,000 children in Michigan who suffer from this debilitating disease. She was diagnosed over three years ago and suffers paralyzing anxiety which prevents her from attending school for months at a time. She takes two antibiotics and eight immunity boosting supplements 2-3 times daily. The next step of treatment for her and other children is prohibitively expensive. So I additionally support HB 5035 which will provide insurance coverage for diagnosis and treatment deemed necessary to treat a child with this halting illness.

Thank you immensely for your consideration of these important issues.

Sincerely,

Teri Stonerook  
13040 Dunn Ct.  
Plymouth, MI 48170

## **Melissa Weipert**

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**From:** Stamper, Eric <eric.stamper@pccsk12.com>  
**Sent:** Saturday, September 22, 2018 5:27 PM  
**To:** Melissa Weipert  
**Cc:** Claire / Meaghan McCann  
**Subject:** HB5036 Pandas/pans

Dear members of the House Health Policy Committee,

I am writing in support of HB5036 to establish an Advisory Council on PANDAS/PANS in the state of Michigan. I am an educator with a close relationship to a family dealing with Pandas/Pans. Claire, who is now in 4th grade, has been incredibly supported by her family but it has been a difficult task and has greatly impacted their dynamics. I support HB5035 which will provide insurance coverage for an individual (such as Claire) suffering from this illness.

With much appreciation for your consideration,

**Eric Stamper**  
Kdg/1st Grade Teacher  
Smith Elementary School  
Plymouth-Canton Community Schools



Alice McKeage  
612 W. Girard Ave  
Madison Heights, MI 48071

Sept 22, 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  
Hon. Representative Pamela Hornberger  
Hon. Representative Bronna Kahle  
Hon. Representative Jeff Noble  
Hon. Representative Winnie Brinks  
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).

This condition personally affects the family of a friend and former co-worker. The information they have shared with me indicates the symptoms that manifest are tics, most often associated with Tourette Syndrome. Raising awareness of the condition would assist families in obtaining a timely diagnosis and earlier treatment of the condition. It has been estimated that 25% of the children diagnosed with OCD and tic disorders may actually have PANDAS. Conservatively, the number could be 1 in 200 children.

Please support HB 5036. In doing so, you will support the healing of my friend's granddaughter and countless other children in the state of Michigan. As a former teacher, I support doing all we can to help children live their best lives. Thank you for your consideration.

Sincerely,

Alice McKeage

## Melissa Weipert

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**From:** Hattie, Kathleen <kathleen.hattie@pccsk12.com>  
**Sent:** Saturday, September 22, 2018 9:30 PM  
**To:** Melissa Weipert  
**Cc:** Meaghan McCann  
**Subject:** Support of HB5036 - PANDAS Adviosry Council

Dear members of the House Health Policy Committee,

I have had the pleasure of knowing the Leginza family for over 6 years. They are a loving, support group who have been severely affected by PANDAS. Their daughter, Claire, was once a vivacious, inquisitive, young girl who has steadily become more reclusive, insecure and compulsive in her daily life. PANDAS has affected the workings of this entire family, and all because of a common childhood infection.

Therefore, I am writing in **strong** support of HB5036 to establish an Advisory Council on PANDAS/PANS in the state of Michigan. Increased awareness, access to diagnosis and treatment for those affected by PANDAS is needed now.

Additionally I support HB5035 which will provide insurance coverage for diagnosis and treatment deemed to be a medical necessity for an individual suffering with this debilitating illness.

Thank you for your consideration.

Kathleen Flanigan Hattie  
6585 Norwood Drive  
Canton, MI 48187

JoAnne McFarland O'Rourke  
5786 Blue Jay Drive  
Kalamazoo MI 49009

September 23, 2018

Michigan House of Representatives  
Health Policy Committee  
Lansing MI 48933

Dear Committee Members:

I am writing as a mother and therapist in support of HB 5036, as I believe the advisory council for pediatric autoimmune neuropsychiatric syndrome (PANS) and related disorders is imperative to providing better care for those afflicted with this devastating condition in Michigan.

I am a clinical social worker with a practice in Kalamazoo through which I treat adults and children, including children with PANS. I am also the mother of a child who had a PANS diagnosis. Prior to starting my counseling practice full-time in 2016, I was Director of Research in the College of Health and Human Services at WMU and prior to that, I was a researcher and principal investigator at the University of Michigan for 16 years.

My son developed PANS in the summer of 2014, prior to beginning second grade. As I can best piece together what happened, he had two bee stings in June or July of that summer and then got a very serious bug or spider bite while we were on vacation in the upper peninsula in August. The bug bite was bad enough that I drove 40 miles to the nearest emergency department (ED). Thankfully, the ED doctor gave my son an antibiotic as a precautionary measure for the bite. Had he not prescribed the antibiotic, I believe my son's PANS episode would have been much worse. Within a month, my son developed obsessive-compulsive disorder (OCD). By the time school pictures were taken the third week of September, he was compulsively biting his lip such that there was always a red circle around his mouth and he had ritualistic behaviors characteristic of OCD. It is difficult to capture the impact OCD and PANS had on my then-8 year-old. My smart, witty, creative boy essentially "lost" second grade. Complicating factors included that my son changed school buildings within the same school district in second grade. We examined environmental factors (air quality, water) in the new school building, as we suspected that change caused his symptoms. The change was so dramatic that every possible factor was considered. All of this was before I even knew what PANS was.

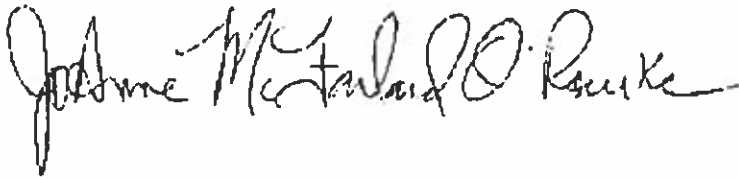
Though I am a person of substantial resources, it took months for a diagnosis and a couple of years to get my son's symptoms under control. I eventually took my son back to Ann Arbor and to a holistic medical practice where we treated when we lived in Ann Arbor and that that now treats PANS. I took my son there in the spring

of his second grade year – about 8 months after his symptoms began – and he was finally accurately diagnosed.

My son's PANS story has a happy ending. With an accurate diagnosis and proper treatment, nearly all of which I paid for out-of-pocket, his symptoms began to subside. I routinely see kids in my practice that I suspect have PANS and whom I refer to the few medical practices that I know of where I believe they can receive an accurate diagnosis. Insurance cost is an issue, as are travel cost and time away from work for the parents. This condition is overwhelming to the family and it is a challenge to get it diagnosed because so few practitioners even know what it is. When it is caught early, however, outcomes improve, and with proper treatment, kids and families can get their lives back. Our story is evidence of that.

So much needs to be done, and the advisory committee is needed in order to move forward in our state. Thank you for your efforts and attention to this issue to-date and thank you, in advance for your continuing efforts and persistence.

Very sincerely,

A handwritten signature in black ink, reading "JoAnne McFarland O'Rourke". The signature is fluid and cursive, with the first name "JoAnne" starting with a large 'J' and the last name "O'Rourke" ending with a long, sweeping horizontal stroke.

JoAnne McFarland O'Rourke, LMSW  
Kalamazoo Neurofeedback and Counseling Center

## Melissa Weipert

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**From:** Yvonne Bannon <bannon06@hotmail.com>  
**Sent:** Sunday, September 23, 2018 1:28 PM  
**To:** Melissa Weipert  
**Cc:** Meaghan.McCann@gmail.com  
**Subject:** support of HB5035 and HB5036

Dear members of the House Health Policy Committee,

I write this letter in support of HB5036 to establish an Advisory Council on PANDAS/PANS in the state of Michigan.

I do this because better awareness, access to diagnosis and treatment for those affected is needed.

I support HB5035 which will provide insurance coverage for diagnosis and treatment deemed to be a medical necessity for an individual suffering with this debilitating illness.

My childhood friend Meghan McCann and her daughter Claire have faced everyday with grace and strength, despite lack of availability of diagnosis or treatment options.

With much appreciation for your consideration,

Ardeth Bannon, Ludington, Michigan

Yvonne Bannon  
3763 s PM Hwy  
Ludington

KE8CLW  
231-690-2495

## Melissa Weipert

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**From:** Linda Pasternak <lindapasternak2@gmail.com>  
**Sent:** Sunday, September 23, 2018 6:52 PM  
**To:** Melissa Weipert  
**Subject:** PANDAS/PANS

This letter is to request proper diagnosis and treatment for PANDAS/PANS. Please help to pass the two bills introduced to our legislature to assist HB5036. I understand this bill will change our current health code to enable an advisory council to be established. HB5035 will assist in promoting insurance coverage for appropriate diagnosis and treatment.

My niece, Amy Kozlowski, is struggling to care for her son. Alex had to even be pulled out of school last year. He is too fearful to leave the house.

The state of Michigan needs an advisory council for PANDAS/PANS not only for better awareness, but access to diagnosis and treatment. I also support HB5035 to provide insurance coverage for diagnosis and treatment as a medical necessity for those suffering with this horrible chronic disorder.

Sincerely and with much appreciation for your consideration,

Linda Pasternak  
retired teacher  
3705 Duke Road  
Oakland, MI 48363

**Melissa Weipert**

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**From:** Emily Kline <emilyrandf@yahoo.com>  
**Sent:** Sunday, September 23, 2018 7:03 PM  
**To:** Melissa Weipert  
**Cc:** gammicca@comcast.net  
**Subject:** Support of HB5035/5036

Dear members of the House Health Policy Committee,

I am writing in support of HB5036 to establish an Advisory Council on PANDAS/PANS in the state of Michigan. I'm doing so because not only do we need better awareness, but access to diagnosis and treatment for those affected. Additionally I support HB5035 which will provide insurance coverage for diagnosis and treatment deemed to be a medical necessity for an individual suffering with this debilitating illness.

My friend has 2 sons with this medical issue and she and many like her need support from our great state.

With much appreciation for your consideration,

Emily Kline  
53281 Shawn Dr.  
Chesterfield, MI 48047

Sent from my iPhone

## Melissa Weipert

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**From:** Lori Piwok <tangsoodo73@live.com>  
**Sent:** Sunday, September 23, 2018 8:41 PM  
**To:** Melissa Weipert  
**Subject:** support of HB5036

Dear members of the House Health Policy Committee,

I am writing in support of HB5036 to establish an Advisory Council on PANDAS/PANS in the state of Michigan.

I am doing so because my 8-year-old son, Caden has been affected by PANDAS. The first signs and a somewhat diagnosis came at 4 years old. He had an onset of sudden OCD type behaviors followed by rage, ADHD and later came vocal and motor tics.

His motor tics have gotten so bad at times, he was causing damage in his neck and had to get therapy twice. His OCD would get to the point he would wash his hands till they were raw.

At night he would have to do pattern of movements over 20 times before he could settle down and hum his self to sleep. Most nights, I was lucky to get him to sleep by 2 am.

All these behaviors and many others came so quickly out of nowhere. It scared us as a family to watch our little boy go through all this and not knowing why or how to help him.

Some of the behaviors came and went. He was constantly sick, from strep or running fevers one minute and the next hour they were gone, they would come and go for days. It was like his little body was fighting something but was losing. He missed so much school from k-2 grade. I was forever taking him to the pediatricians trying to figure out what was wrong with him. I never received any answers. They had no idea what was going on with him.

They wanted him to see a psychiatrist to get on psych medication for the OCD, and the neurologist diagnosed him as OCD and Tourette syndrome and wanted to put him on other medication, that's when I hit the internet and researched and read night after night. I finally found a holistic doctors office. They ran many tests and found answers. They have now been treating my son for Pandas for the past year.

He has not made a total recovery but the improvement in my son is amazing. Most days the OCD is all but gone. The ADHD is by far better, His rage is pretty much gone. He still has Tourette Syndrome and suffers from vocal and motor tics, but they are hardly noticeable on most days. He still has "flares" but even then, it was nothing like he was. He is still going through treatments and under care for Pandas. I believe it maybe an on-going battle, but at the same time I am so happy to see how well my son is doing and to have him back.

Last month at my sons well visit, his pediatrician was happy to see so much improvement in my son. I told her everything we have been doing.

She said they finally have a PANDAS doctor they send kids too, and they are finally learning about PANDAS. She came out and told me "I am glad you took him somewhere else".

Everything we have done to help my son has been out of pocket. My insurance has not covered much of any of it. My credits cards have taken a beating. This is another reason I am supporting HB5035, which will provide insurance coverage for diagnosis and treatments. Most families like mine cannot afford the care and tests that PANDAS require. We need help.

With HB5035, I am hoping children will have an easier and faster diagnoses from doctors that are more aware of the illness. I pray that kids will not have to go through months and years with out a proper diagnoses and treatment. The faster they get treatment the less permitted damage they will endure.



It took me years to find a doctor to help my son, and months to get an appointment. During all that time my baby boy was suffering with something we just didn't understand. It caused him so much pain and frustration.

There were so many nights I held my son in tears, scared and wondering what was wrong with him, not being able to help your child is the worse feeling in the world.

I am begging you to help us parents and Doctors help these children.

We need more education on PANDAS/PANS. We need insurance to cover treatment and Diagnosis to stop these children from suffering another day.

We need more Doctors, so families don't have to wait months for an appointment or drive miles or even days to find a doctor that understands PANDAS/PANS.

Please don't let another family go through what we did and what many others have or are still going through right now.

Thank you for your time,

Lori Piwok

21956 Camille Ct.

Woodhaven, Mi

48183

## Melissa Weipert

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**From:** Heather Swan <heatherswan22@gmail.com>  
**Sent:** Sunday, September 23, 2018 9:12 PM  
**To:** Melissa Weipert  
**Cc:** gammicca@comcast.net  
**Subject:** For your consideration (HB5036)

Dear members of the House Health Policy Committee,

I am writing in support of HB5036 to establish an Advisory Council on PANDAS/PANS in the state of Michigan. With as many as 1 out of 200 children affected by this illness it should be a necessity for doctors to become educated on the diagnosis and treatment process. In addition we need to support HB5035 to provide insurance coverage for the diagnosis and treatment of this illness. Please help bring awareness to our state.

With much appreciation for your consideration,

Heather Swan  
44068 N Umberland  
Canton, MI 48187

## Melissa Weipert

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**From:** Donna P <ondon1951@gmail.com>  
**Sent:** Sunday, September 23, 2018 9:37 PM  
**To:** Melissa Weipert  
**Subject:** In support of HB5036

Dear members of the House Health Policy Committee,

I am writing in support of HB5036 to establish an Advisory Council on PANDAS/PANS in the state of Michigan. I'm doing so because not only do we need better awareness, but access to diagnosis and treatment for those affected.

My Grandson was Diagnosed with PANDAS/PANS awhile back. It has been a horrible thing to watch him go through.

The OCD behaviors, the rage etc. It was very heartbreaking as a grandparent, to watch your funny, outgoing, kindhearted grandson change into someone you know he isn't.

On top of all that, my poor baby was constantly going to doctor after doctor and never getting any answers.

The financial part of it has also taken a toll on my daughter.

So, I please ask you to support the HB5035 which will provide insurance coverage and diagnosis and treatment to many of these poor children and families suffering like ours.

With much appreciation for your time

Donna Piwok  
21956 Camille ct.  
Woodhaven, mi  
48183

September 23, 2018

Dear Members of the House Health Policy Committee,

I am writing in support of HB5036 to establish an Advisory Council on PANDAS/PANS in the state of Michigan. I'm doing so because I had a student in my classroom that suffered from this disease and it was hard to know how to help her in the classroom setting. Claire missed a major portion of 2nd grade because of her fears which were caused by her PANDAS. It affects her in so many ways and it makes it very hard on her parents too. It is hard to understand this disease until you have seen it first hand. Additionally, I support HB5035 which will provide insurance coverage for diagnosis and treatment for an individual suffering with this debilitating illness.

Sincerely,  
Julie Zinser  
2nd Grade Teacher  
Smith Elementary  
1298 McKinley St.  
Plymouth, MI 48116

## Melissa Weipert

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**From:** Jackie D. Igafo-Te'o <igafoteo@comcast.net>  
**Sent:** Sunday, September 23, 2018 11:17 PM  
**To:** Melissa Weipert  
**Cc:** gammicca@comcast.net  
**Subject:** Letter in Support of HB 5036 and HB5035

Dear members of the House Health Policy Committee,

I am writing in support of HB5036 to establish an Advisory Council on PANDAS/PANS in the state of Michigan. I'm doing so because not only do we need better awareness, but access to diagnosis and treatment for those affected. Additionally I support HB5035 which will provide insurance coverage for diagnosis and treatment deemed to be a medical necessity for an individual suffering with this debilitating illness.

I know a young man with this diagnosis whose quality of life could really improve from your positive action on these bills. Please help provide awareness, support and proper treatment for my friend and others just like him.

With much appreciation for your consideration,

Jackie D. Igafo-Te'o  
313 Randolph St.  
Jackson, MI 49203-4131  
517-812-8190  
[igafoteo@comcast.net](mailto:igafoteo@comcast.net)



Virus-free. [www.avast.com](http://www.avast.com)

**Melissa Weipert**

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**From:** Tom Brown <tbrown8436@yahoo.com>  
**Sent:** Monday, September 24, 2018 8:23 AM  
**To:** Melissa Weipert  
**Subject:** HB5036 to establish an Advisory Council on PANDAS/PANS

Dear members of the House Health Policy Committee,

As a practicing professional and a member of the PANDAS physicians Information and Referral Network, I am seeing more children with this complicated auto-immune disorder.

Many families run a gauntlet of roadblocks with their insurance carriers when they attempt to obtain treatment for their children. The effects of these auto-immune disorders is devastating.

I support of HB5036 to establish an Advisory Council on PANDAS/PANS in the state of Michigan. We need to work together to decide appropriate treatment and diagnostic information. I firmly support HB5035 which will provide insurance coverage for diagnosis and treatment deemed to be a medical necessity for individuals with PANDAS and PANS

Sincerely,

***Thomas A. Brown, M.A.,L.L.P.***

***Board Certified Professional Psychologist***

***Board Certified Clinical Psychotherapist***

***B.G. Tri-County Neurology and Sleep Clinic***

***MI.Warren,***

**<http://sleepquiet.com/>**

Melissa Weipert

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**From:** thoth <thoth16@yahoo.com>  
**Sent:** Monday, September 24, 2018 9:15 AM  
**To:** Melissa Weipert  
**Subject:** Diagnosis and treatment of PANDAS/PANS

Dear members of the House Health Policy Committee,

I understand that you are meeting on September 26th to discuss two critically important bills that if passed, will make a tremendous difference to individuals struggling to obtain appropriate and targeted treatment in Michigan.

I strongly support HB5036 that proposes an Advisory Council on PANDAS/PANS be established in the state of Michigan. Medical knowledge is not something frozen in amber -- it evolves with new documented observations and research to keep pace with the pervasive and invisible triggers for ill health that have become standard in our industrialized society.

Rather than living in denial of these new realities -- which implies tacit acceptance of a lifetime of suffering for those affected -- I welcome the establishment of an advisory body on a hitherto relatively unknown and poorly understood condition.

Furthermore, I also support HB5035 which will introduce insurance coverage for diagnosis and treatment for those affected by this difficult and debilitating condition.

I thank you very much for your consideration.

Sincerely,

Chitra Raman

654 Roslyn Road

Grosse Pointe Woods, Michigan 48236



Chair Hank Vaupel  
Vice-Chair Jim Tedder  
Representative Josep Grave  
Representative Daniela Gracie  
Representative Jason Sheppard  
Representative Julie Calley  
Representative Diana Farrington  
Representative Roger Hauck  
Representative Pamela Homberger  
Representative Bronna Kahle  
Representative Jeff Noble  
Representative Winnie Brinks  
Representative LaTanya Garrett  
Representative Sheldon Neeley  
Representative Jim Ellison  
Representative Abdullah Hammoud  
Representative Kevin Hertel

Dear Honorable Chair Vaupel and Honorable members of the Health Policy Committee, I am writing you to show my support for the bill HB 5036 and why it is crucial for so many kids.

2 ½ years ago when my son was 5 years old a monster came into our lives and stole him from us. That monster is P.A.N.S. ( pediatric acute onset Neuropsychiatric syndrome) P.A.N.S. is a thief that stole his mind and body. We had to watch helplessly as he first was overtaken by anxiety, and then lose his ability to write. Every day he was more closed off, within two weeks of onset he was talking to people who only he could see and hear and then came the tics. At first it was just his hands and arms but with each passing day they got more intense and over took his whole body. He could no longer control his body and needed assistance with doing basic things like sitting in a chair or eating. His pediatrician believed us that something very serious was happening but unfortunately our local children's hospital did not.

In one month our son had stopped talking to us and was going in and out of hallucinations and catatonic moments. One time he was hallucinating and was screaming, crying and begging for help because a bad guy was cutting his body in half. There was nothing we could do to comfort him or stop the hallucination. He had lost control of his bladder and for the first time in 2 years started wetting himself. He had stopped eating and drinking. Our son was gone and we were all helpless and suffering. We packed him up and drove 2 hours to the U of M Motts Children's Hospital. By the time we were admitted there he was in such bad shape they were preparing us for every parent's nightmare of losing our child. They gave him I.V.I.G. (intravenous immunoglobulin) IV steroids and medication for the catatonia. Within 3 days of starting this he started talking to us again, regaining some control over his

body and eating and drinking. We spent 13 days there, since they were out of network our insurance said we had to find an in network doctor to continue care. It would be another year and 3 months of suffering for him before we were able to find a doctor that understood and was willing to treat long term but it would take another 3 months of fighting with the insurance to cover it because at this point we had no money to spend out of pocket. Our son's life was completely in the hands of the insurance company. It took another 2 months to get approval for I.V.I.G. . Our son needs to get I.V.I.G. every month to be able to function and have a sliver of a normal life and each month we have to hope, pray and fight for approval. It is one of the worst feelings as a parent to watch your child suffer while knowing there are doctors and treatments out there to help them but because you are not rich you don't have access to them. Insurance companies should not be able to deny kids with P.A.N.S. And P.A.N.D.A.S their life. These children need your help; their lives are not only in the insurance companies hand but are now in yours.

Sincerely , Michelle Root

Middleville MI.

**September 14, 2018**

Chair Hank Vaupel

Vice-Chair Jim Tedder

Representative Joseph Graves

Representative Daniela Garcia

Representative Jason Sheppard

Representative Julie Calley

Representative Diana Farrington

Representative Roger Hauck

Representative Pamela Hornberger

Representative Bronna Kahle

Representative Jeff Noble

Representative Winnie Brinks

Representative LaTanya Garrett

Representative Sheldon Neeley

Representative Jim Ellison

Representative Abdullah Hammoud

Representative Kevin Hertel

Our daughter is a highly intelligent, beautiful 13 year old girl who has encountered difficulties that she cannot control or understand. For years, she has dealt with repetitive rocking motions that we were told she would grow out of over time. For years she has dealt with constant strep infections which led to a surgery to remove her tonsils and adenoids in February of 2018. Following her surgery, various uncontrollable actions surfaced, consistent with OCD behaviors. We did have her evaluated when she was 10 years old as we could tell something was off. Her testing came back as the edge of ASD, with most behaviors testing outside of ASD. The diagnosis seemed manageable, but things continued to deteriorate gradually. We had decided to get on the waiting list for The Beaumont Centers for Exceptional Families before her tonsil surgery and after more than a year of waiting, she was finally evaluated at the Center and they identified many of our daughter's symptoms as consistent with PANS and/or PANDAS.

This diagnosis led to additional recommendations for treatment. She has been on various antibiotics, steroids and supplements and also trying to identify potential therapists for OCD and other issues. The medications have led to very minimal improvements and the recommended therapy has waiting lists of 12-18 months or more, if they are even accepting new patients on the waiting list.

As you will see from other stories, this diagnosis poses a number of problems:

- The onset and symptoms are different for each child. Some have a sudden onset, some are gradual. Some have violent symptoms, some have social symptoms, some need to

be home schooled, if that is even possible. Many need constant care and never know when and which symptoms are going to appear.

- Treatments work differently for each child. Antibiotics work for some, IVIG works for some, therapy works for certain children and certain issues. Some treatments will work temporarily and then symptoms will reappear.
- There are waiting lists for almost all professional services for these patients. In our case, we were on a waiting list to get a diagnosis and then there are new waiting lists to deal with, if you can even find professionals to help.
- Insurance coverage is inconsistent state to state and depending on the treatment and diagnosis codes. For the children going through this, there are obvious issues that need to be treated and this should be covered under insurance just as other medical issues would be covered.

Children who are treated properly at onset can return to full function within a few months and, in general, put PANDAS/PANS behind them. Children who go years without proper diagnosis and treatment and children who are hit particularly hard and have severe cases may need IVIG.

Families are going bankrupt trying to pay for IVIG for their children. Many children go without needed IVIG because their parents cannot afford it. The burden on schools and families is tremendous. We don't have to let children suffer and become debilitated from PANDAS/PANS when we know there are evidence based treatments.

Our daughter is 13 and will enter high school in one year. There, she will be expected to begin college prep courses. We need effective, covered treatment for her as soon as possible so we can get her back to a normal baseline and give our incredibly intelligent daughter the ability to get a good education and eventually support herself and be a contributing member of society. We cannot make that happen without the means to get her treatment in a timely manner and without insurance coverage.

We implore you to support us in establishing an advisory council for Michigan children. Currently, Illinois, Connecticut, Wisconsin, New York and Virginia have advisory councils in place or have bills currently pending to put an advisory council in place. In five states, BCBS has PANDAS/PANS listed as a covered condition: Illinois, Oklahoma, Texas, Montana and New Mexico.

Scott and Carrie Gedris

Chair Hank Vaupel

Vice-Chair Jim Tedder

Representative Joseph Graves; Representative Daniela Garcia; Representative Jason Sheppard;  
Representative Julie Calley; Representative Diana Farrington; Representative Roger Hauck  
Representative Pamela Hornberger; Representative Bronna Kahle; Representative Jeff Noble  
Representative Winnie Brinks ; Representative LaTanya Garrett; Representative Sheldon Neeley  
Representative Jim Ellison; Representative Abdullah Hammoud; Representative Kevin Hertel

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

In November 2007, our family began a journey that we did not know we were on. At a family event, our five-year old son began screaming and crying, complaining of an ear ache. We took him to the ER, where the doctor said that our son had a double-ear infection. We began a ten-day treatment of antibiotics. When the antibiotics were gone, the real illness became apparent.

Our funny, happy, boy who has a great imagination and a fabulous sense of humor, disappeared. He lost his ability to focus, his handwriting became illegible, and he lost his math skills. He began to have violent episodes, displayed OCD behaviors, exhibited tics and he started stimming - rocking and moving back-and-forth. Over the next couple of weeks, this behavior progressed into hitting his head on the wall and doors, striking out at others, and being oppositional and defiant. What had become of our son?

We were told by several doctors that he must have autism and possibly ADHD. This made no sense to us, so we began our quest to find out what was happening to our son. We wanted him back. It would take another four-and-a-half years – until July 2011 after visits to doctors in several states – before we obtained an accurate diagnosis of PANDAS.

Our neurologist and pediatrician recommended homebound school placement in January, 2011. This first of many homebound stays lasted for 13 months. Being homebound has impacted him socially and he has fallen behind academically. Our school district at first refused to provide tutoring services. Only after we hired an educational advocate were we able to get two hours of tutoring a week to offset the 35 hours of school he was missing each week. We couldn't afford additional tutoring because we were using our discretionary income to pay for lab work and medical treatments not covered by insurance.

Coming to a PANDAS diagnosis was neither easy or straight-forward. Prior to receiving the PANDAS and auto-immune encephalitis diagnosis, our son was mis-diagnosed and placed on medications that made him worse. ADHD medications made him anxious and hyperactive, and they worsened his ability to sleep. A constant-release Daytrana patch made him more impulsive and difficult to calm. We even had specialists disagreeing over whether he had a seizure disorder.

It wasn't until July, 2011 that our team of five doctors from three states decided together to look into the possibility of PANDAS. They placed our son on a 2-week program of Cephalexin 500 mg 3 times a day. By day 6, he was a different child. He was able to attend a 5-day summer day camp without the assistance of a 1-on-1 counselor. He now behaved well and interacted socially with other children at family functions. **Our doctors told us we had a textbook case of PANDAS.**

Unfortunately, our pediatrician refused to give us more than 15 days of antibiotics to treat him. Every time he was off the antibiotic, he would get sick and the ADHD, OCD, and autistic like behaviors would return. And each time that we took him off the antibiotic, it took longer for him to recover.

On December 2, 2011, our son had his first IVIG procedure, at the cost of \$3,800 - our portion after meeting our insurance deductible. The IVIG was a HUGE success. His tics and OCD behaviors all but disappeared and we had very few incidents or melt down behaviors after that for about six weeks.

In April, 2012, our son was placed on Straterra. He had a severe reaction to this medication – seemed to go completely out of his mind and had to be hospitalized for five days. Our portion of this stay was \$5,000. When he returned home, he stopped making death threats, but his tics ratcheted up and he continued to have almost daily melt downs. He would scream at the top of his lungs, throw heavy objects, turn over furniture, tear clothing, slam doors, break objects, and threw himself on the floor. We were concerned for his safety and ours as we tried to figure out how to best help him. This was easily the most horrific experience of our lives, because we finally knew what was wrong with our son, but the only treatment that had worked – IVIG – was expensive and not fully covered by insurance.

In Feb. 2014, my husband's job was eliminated and our son became eligible for Medicare. Losing our only income now made it possible for our son to receive the IVIG treatment he so desperately needed. He received nine IVIG transfusions, which greatly improved his ability to focus and control his behavior. From April 2016 to March 2018, we were able to get our son added to the Children's Special Health Care Services program and so he could continue to receive monthly IVIG and also get monthly plasmapheresis, which has also improved his focus, behavior and stamina, while helping his immune system to heal. And for the first time since second grade he was able to return to school for ALL of his ninth grade year.

Unfortunately, our neurologist, Dr. Mitchell Williams at Children's Hospital of Michigan, decided to stop treating PANDAS. Dr. Williams stated that PANDAS is too difficult to treat and he would no longer see PANDAS patients, even though the World Health Organization lists PANDAS in its most recent revision of its International Classification of Diseases (ICD-11).

PANDAS has been emotionally and financially devastating for our family, just as it has been for the nearly 10,000 other families in Michigan who have children with PANDAS. Leading experts now believe that PANDAS is the root cause for 25% of reported cases of OCD and 80% of reported cases of autism. Curing children with PANDAS will provide needed relief to our overtaxed health care system and to our school districts that now provide resources to families who have children with OCD and autism.

We and other families desperately need to have PANDAS covered by insurance. I ask that you take my letter, and other letters you will receive, into consideration as you vote to take the House Bill No. 5036 forward. Please make the decision to continue with this bill. It needs to pass – we need insurance to cover PANDAS in the state of Michigan. With 1 in 200 children being diagnosed with PANDAS, we are facing epidemic and the children and families of Michigan need your help! Thank you in advance for your consideration.

Sincerely,

Julie Cadman

CEO Healing Complex Kids

Dr. Diane P. Fleming  
Ms. Bern Merlo  
19722 Adrian Rd.  
Southfield, MI 48075

September 21, 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  
Hon. Representative Pamela Hornberger  
Hon. Representative Bronna Kahle  
Hon. Representative Jeff Noble  
Hon. Representative Winnie Brinks  
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:

As educators, we have seen a gamut of children with both physical and medical issues that impede their educational development and learning in an educational setting. With this in mind, we write this letter knowing that Grace's medical issues affect her learning. In our combined years in education(Over 70) we have only had the experience of a child only twice between us. Never have we knowingly had an experience with a child with Terets.

We have had the privilege of knowing Grace since birth. From the beginning, she was an active child that was happy and interested in learning. All of a sudden, while in Pre-school, her behavior, mood and overall actions with others changed. She was plagued by anxiety, crying and temper tantrums. She did not want to leave her mother to go to school. She was

hounded by physical tics that she was unable to control. She exhibited depression and moodiness. Her tics continue to make it difficult for her to establish and maintain friends.

These manifestations caused Mrs. Gauthier to seek medical treatment to assist her daughter. The psychotropic drugs that were prescribed as a means of therapy changed Grace's sparkling personality. We were saddened to see these changes.

When this was not a viable treatment for Grace, her mother tried alternative measures. Also, Grace's mom arranged to have guest speakers come to her daughter's school to help teachers and students to understand her daughter's health issues and the same issues that other children they meet might have.

We believe that it is crucial to support the advisory council proposal in HB 5036. We are available to speak with you if you need additional information regarding the changes in behavior.

Sincerely,

  
Dr. Diane P. Fleming

Ms. Bern Merlo



CC: Jeremy Moss



## Melissa Weipert

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**From:** maryann.baker79@gmail.com  
**Sent:** Monday, September 24, 2018 11:08 AM  
**To:** Melissa Weipert  
**Subject:** Letter of support

Good morning Melissa, and to anyone else it may concern, my name is Mary Ann Baker and I am writing you today in support of Landry Troyer. My hope and prayer is that Landry and children like him who may be suffering with PANS/PANDAS will be able to receive proper diagnoses and proper healthcare. I believe the HB5036 policy and introducing an advisory council for this is a necessity. I have another mom friend who has struggled for years to get a proper diagnosis for her daughter and has met nothing but dead ends in the medical community. Their family accepted a diagnosis of autism and have continued to struggle for the 8-9 years I've known them. I believe because of the Troyer family, Landry included, that many children are going to receive proper diagnosis and proper treatment in Michigan. Please be a part of this much needed movement. I also believe HB5035 is also a necessity. I cannot imagine needing treatment for one of my children, but not being able to afford proper care due to no help from insurance coverage. I'm thankful that the Troyer family is being so transparent with their struggles with this disease. Like I said, I believe it will reach and help countless families, and I urge you to be a part of this imperative need. Thank you for your time and consideration.

Sincerely,  
Mary Ann Baker  
18329 Featherstone Road  
Constantine, MI 49042

## Melissa Weipert

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**From:** Meghan O'Connor <meghanoconnor90@gmail.com>  
**Sent:** Monday, September 24, 2018 12:37 PM  
**To:** Melissa Weipert  
**Subject:** Letter of support for PANDAS/PANS

Dear members of the House Health Policy Committee,

I am writing in support of HB5036 to establish an Advisory Council on PANDAS/PANS in the state of Michigan. I'm doing so because the affects I've seen with my brother with pandas. Its hard seeing him go through this along with my family. Additionally I support HB5035 which will provide insurance coverage for diagnosis and treatment for the families the desperately need it with all the cost of the medical bills and medications.

With much appreciation for your consideration,

Josh Martin  
3700 Academy st. Dearborn, Mi 48124

## Melissa Weipert

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**From:** Ann Sobey <asobey9@gmail.com>  
**Sent:** Monday, September 24, 2018 2:01 PM  
**To:** Melissa Weipert  
**Subject:** support for HB5036 & HB5035

Dear members of the House Health Policy Committee,

I am writing in support of HB5036 to establish an Advisory Council on PANDAS/PANS in the state of Michigan. I'm doing so because not only do we need better awareness, but access to diagnosis and treatment for those affected, as my son has been affected.

Additionally I support HB5035 which will provide insurance coverage for diagnosis and treatment deemed to be a medical necessity for an individual suffering with this debilitating illness.

Regards,

Ann Sobey  
Rochester Hills, Michigan



## OAKLAND PEDIATRICS

100 North Pond Dr., Ste. E  
Walled Lake, MI 48390  
(248) 669-2273

9/23/18

Re: Formation of a PANS/PANDAS Advisory Council

To Whom It May Concern:

As a Pediatrician who practices in Walled Lake, I have treated many children with PANS and PANDAS over the past several years. It is for this reason that I am in favor of forming an Advisory Council to advocate for affected children and their parents. I feel that it is vital that there be greater public awareness of this health issue.

There are so many families in MI, who have children who are fine one day, but whose personality is transformed by the next day. These children are nearly incapacitated by overwhelming anxiety, OCD symptoms, and motor tics. This is due to an autoimmune process that causes inflammation in an area of the brain that manages a variety of functions.

In addition, children develop depression, school phobia, and intense fear. The majority of children develop some form of motor tic. Other symptoms associated with PANS/PANDAS are behavioral regression, handwriting regression, deterioration in school performance, severe food restriction/anorexia, sensory sensitivities, urinary tract symptoms, etc.

This is not a rare illness, as once thought by the medical community. My office has received calls from desperate parents from all over MI. We were receiving so many calls, on a daily basis, that we had to turn patients away. I wouldn't have room in my schedule for my established patients. We explained that I am not a PANDAS specialist, and that I only treat my established patients. However, I do work closely with Neurologists and Infectious Disease specialists, for those patients in need of IVIG.

There are very few physicians who can recognize this constellation of symptoms. Unfortunately, their patients aren't provided appropriate treatment.

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I have attached a chart, courtesy of the PANDAS Physicians Network, to clarify the differences between PANS and PANDAS.

**PANS is defined by the following criteria:**

Abrupt, dramatic onset of OCD or severely restricted food intake; symptoms are not better explained by a known neurologic or medical disorder; and the addition of at least 2 of the "accompanying" symptoms:

- Anxiety
- Emotional lability and/or depression
- Irritability, aggression and/or severely oppositional behaviors
- Behavioral (developmental) regression
- Deterioration in school performance
- Sensory or motor abnormalities
- Somatic signs including sleep disturbances, enuresis or urinary frequency

The onset of PANS may start with infectious agents other than strep. It also includes onset from environmental triggers or immune dysfunction.

**PANDAS is defined by the following criteria:**

Clinical diagnosis of PANDAS includes 5 criteria:

- Presence of significant obsessions, compulsions and/or tics
- Abrupt onset of symptoms or a relapsing-remitting course of symptom severity
- Prepubertal onset
- Association with streptococcal infection
- Association with other neuropsychiatric symptoms (includes any of the PANS "accompanying" symptoms)

More must be done to increase activity at the local, state and national levels. According to the literature, without appropriate diagnosis and treatment, PANS/PANDAS can become a chronic, life-long condition. Left untreated, permanent changes in the brain can ensue, requiring extensive care.

Lastly, health insurance companies will pay for strep screens, throat swabs for cultures, blood tests for ASO and DNase B Antibody titers. Health insurance companies often refuse to pay for the Cunningham Panel, which is a series of tests that can help determine whether a patient has an auto-immune condition, such as PANS/PANDAS, that is often misdiagnosed as a psychiatric illness. Regarding treatment, when antibiotics fail to resolve symptoms, IV Immunoglobulin therapy (IVIG) is warranted. We have had insurance companies decline coverage for this treatment in the past.

Respectfully,



Regina Rizk MD  
Medical Director  
Oakland Pediatrics PLLC

## Melissa Weipert

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**From:** Barbara Browne <barbara-browne@att.net>  
**Sent:** Monday, September 24, 2018 3:05 PM  
**To:** Melissa Weipert  
**Subject:** Member of House health Policy Comm.Att: Melissa Weipert

Dear M. Weipert, I am writing in support of HB5036. in hope that the committee will establish an advisory council on PANDAS in the state of Michigan. This is a very debilitating disease. The families with children that have PANDAS encounter extreme medical bill . getting diagnosis as well as treatments The insurance co. should help support this illness the same as they do MD and MS and other debilitating diseases. Your consideration in this matter is appreciated as I am a Grandmother of a PANDAS suffer. Barbara Browne R.N.

## Melissa Weipert

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**From:** Wildman, Molly <molly.wildman@pccsk12.com>  
**Sent:** Monday, September 24, 2018 3:09 PM  
**To:** Melissa Weipert  
**Cc:** Claire / Meaghan McCann  
**Subject:** HB5036 Advisory Council

To Whom It May Concern, and especially the **House Health Policy Committee members**,

Please consider establishing an Advisory Council for House Bill 5036, or HB5036. I am an elementary school paraprofessional in the Plymouth/Canton Michigan school district I have seen first hand the debilitating effects PANDAS can have on students. Claire McCann (Claire-bear is what I always called her, when we said hello in the hall). was in my class for two years in a row. Some of her struggle began before she even entered the building EVERY day. Although many children struggle with transition times at school, Claire could only move to another part of the day with a strict routine, which isn't always possible with time constraints of a large class size. I have no medical training, but as a mom and Claire's teacher's helper I could see her struggle.

There is also Bill HB5035, which will allow insurers to cover medical expenses related to PANDAS for these families.

Claire is a bright and happy child, so won't you please consider helping her and her family?

HB5036: Health; other; advisory council for pediatric autoimmune neuropsychiatric disorders; create. Amends 1978 PA 368 (MCL 333.1101 - 333.25211) by adding sec. 5145.

<http://www.legislature.mi.gov/.../billintroduced/House/pdf/20...>

HB5035: Insurance; insurers; coverage for certain pediatric autoimmune neuropsychiatric disorders; require. Amends 1956 PA 218 (MCL 500.100 - 500.8302) by adding sec. 3406u.

[http://www.legislature.mi.gov/\(S\(knx52tiuvakp4r3fyjn5axd3\)\)/mileg.aspx?page=home](http://www.legislature.mi.gov/(S(knx52tiuvakp4r3fyjn5axd3))/mileg.aspx?page=home)

**Thank you so much for your kind consideration.**

Sincerely,

**Molly Wildman**

**42119 Woodcreek**

**Canton, MI 48188**

## Melissa Weipert

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**From:** Dorina Okroy <dokroy2002@yahoo.com>  
**Sent:** Monday, September 24, 2018 4:16 PM  
**To:** Melissa Weipert  
**Cc:** denisechampune@yahoo.com  
**Subject:** Support HB5036&HB5035

Dear members of the House Health Policy Committee

I am writing in support of HB5036. We need more awareness & we definitely need to support HB5035 for the insurance coverage. So many are in need for this. How terrible for the person suffering from this illness. Please pass these legislations.

DORINA OKROY  
44211 Ivory Way  
Sterling Heights, Michigan 48313

Sent from my iPhone



## Melissa Weipert

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**From:** Sandra Helinski <sjhelinski@sbcglobal.net>  
**Sent:** Monday, September 24, 2018 4:49 PM  
**To:** Melissa Weipert  
**Subject:** Re: Bill HB5036

Melissa,  
I'm e-mailing to express my support for Bill HB5036. Our family was deeply impacted by our grandson's medical struggles in finding and paying for care for his PANDAS condition. People shouldn't have to go through such struggles to access care. As a retired nurse I urge your committee to help these patients.

Sincerely,  
Sandra Helinski

## Melissa Weipert

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**From:** Julie Bruman <nursebruman@gmail.com>  
**Sent:** Monday, September 24, 2018 5:01 PM  
**To:** Melissa Weipert  
**Subject:** Fwd: HB5035/HB5036

----- Forwarded message -----

**From:** Julie Bruman <[nursebruman@gmail.com](mailto:nursebruman@gmail.com)>  
**Date:** Mon, Sep 24, 2018, 4:59 PM  
**Subject:** HB5035/HB5036  
**To:** <[mweipeet@house.mi.gov](mailto:mweipeet@house.mi.gov)>

To All Who Make These Decisions,

Please support and pass legislation on HB5035/HB5036 so children and their families have a fighting chance to live as normal life as possible without everyone going broke. I have personally watched my friend and her son suffer through absolutely horrible lives to get a proper road to follow that does not include understanding, acknowledgement, or any help in covering the expense of this disease. Please help these families as they have no other avenue to help their kids. As a nurse I have a deeper understanding of this issue and have seen the horrors families go thru. Please help them.

Sincerely,

Julie Bruman

## Melissa Weipert

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**From:** Abigail Samuels <abigail.m.samuels@gmail.com>  
**Sent:** Monday, September 24, 2018 8:21 PM  
**To:** Melissa Weipert  
**Cc:** meaghan.mccann@gmail.com  
**Subject:** We need your vote in favor of PANS/PANDAS advisory council

Dear members of the House Health Policy Committee,

I am writing in support of HB5036 to establish an Advisory Council on PANDAS/PANS in the state of Michigan. I'm doing so because not only do we need better awareness, but access to diagnosis and treatment for those affected.

Additionally I support HB5035 which will provide insurance coverage for diagnosis and treatment deemed to be a medical necessity for an individual suffering with this debilitating illness.

I am writing as a witness to my 10 year-old niece and her debilitating disease—PANDAS.

In March of 2015, my niece, Claire Leginza, had a sudden onset of extreme panic and inability to function with normal daily activity. One day she was just the average kid—like yours or mine—and the next day she walked up and down the stairs all night long turning the lights on and off and was overcome by a “fear” she could not explain. Her mother took her to Mott Children’s hospital—the gold standard of care in Southeast Michigan—where she was seen and sent home with no diagnosis, but a referral to see a child therapist. Within the next few days, Claire’s paralysis became more intense. I recall an evening during which her mother tried to gather her to take her back to Mott, but Claire could not put on clothes. After more than one hour, Claire’s mom, Meaghan, managed to wrap her naked seven-year-old body in a blanket, and drive her to Ann Arbor in the cold. That evening, they again left Mott with no answers and Claire cried—she told Meaghan and my mom that she thought the doctors would fix her. At that time, Mott / Michigan Medicine did not recognize PANS / PANDAS as a disease. Similar occurrences became the norm until Claire and her mother found a diagnosis.

I look back on the early days of Claire’s PANDAS and the days since then and carry sadness for her like the rest of our family. But, within our family I have an additional perspective. I also have a 10 year old daughter, Ryan—almost exactly one month younger than Claire. For the past few years, my daughter has continued to reach developmentally appropriate milestones like seeking more independence, wanting time alone with friends, and being embarrassed of her parents(!). As Ryan asks me to not walk her through the halls or to leave her home alone for short periods of time, the juxtaposition with her cousin Claire makes it more and more clear how paralyzing PANDAS/PANS is on a child and her family. Some examples include:

- At family gatherings, Claire’s mother Meaghan may not use the restroom without letting Claire know. If Meaghan forgets to tell Claire in advance, inevitably Claire has a momentary panic and yells, “MOM!” or her eyes bolt up from the current activity and she asks, “Where’s my mom?” Sometimes her mom uses the restroom with the door open to be able to answer her; if this is not the case, we are all prepared to say, “Your mom went to the bathroom.”
- For the last two years, Claire has struggled in school—needing to know the location of her mother at all times and needing her in close proximity. For months, Claire’s mother, Meaghan, sat at a desk in the hallway, doing her own work and volunteering correcting papers and doing projects for Claire’s classroom. Sitting in the hallway so Claire could see her allowed Claire the freedom to stay in school. This did not last, however, as Claire’s PANDAS would flare with any stress (even a common cold), the symptoms would intensify. Eventually Claire would need to be homebound / homeschooled as she could not focus in school and it became prohibitive to her peers’ learning as well.
- Claire’s brother, Andrew, is also limited. Claire’s brother—just one year older—must also remain close by. As Claire’s condition worsened, so did Andrew’s focus in school. During times when her symptoms are heightened, her

awake spells in the night would keep him awake. Andrew has suffered as Claire must also know his whereabouts, meaning he must often forgo playdates and sleepovers with friends and family members.

I admit that if Claire was not in my family I would probably not take this disease with such seriousness and I know it may seem distant for you too... a little girl flicking the lights on and off and needing to know when her mom is going to the bathroom just seems crazy and easy to ignore--our kids are "normal," right? But PLEASE DON'T ignore this! Please imagine:

- Your child or grandchild is going about their life—enjoying friends and school and all the fun six or seven-year-old stuff like playing on the playground with their friends;
- He gets strep throat after some kids in his class have it;
- BUT, he suddenly has severe and debilitating OCD tendencies;
- You or his parents cannot leave your home because this child can barely function;
- For days in a row you miss work as you go from doctor to doctor, hospital to hospital, hoping someone will listen or have an answer—perhaps you lose your job or you leave because you have no other option;
- Your other children / grandchildren begin to fall behind in school because the lights are flashing on and off throughout the night—keeping them awake and concerned. Maybe they are old enough to know you've been missing work and realize the financial impact this may have on your family;
- Your child / grandchild can no longer attend school on her own—you must sit in the hallway all day where they can see you;
- While you sit in the hallway and your child gets up and looks for you every few minutes, the parents of other student and the teacher are (rightfully) concerned that the disease (brought on by strep throat) is now interfering with the wellbeing of your child's classmates;
- Your child is eventually removed from school and you are home all day—explaining to your ten year old every time you need to use the restroom;
- You think—"How is this even possible—my child had strep throat—NOT CANCER!"
- You learn of a special diet—you try it; you try behavioral treatments; you try anything...
- As you find there are options for treatment, they are \$10,000+ (per treatment) and not covered by insurance;

*... You weigh the importance of continuing to pay off your mortgage against your child being able to attend school and continue to develop—what would you do?*

Thank you for your time and consideration. Please feel free to reach out to me if I can be of further assistance.

Abigail Samuels  
2914 Atterberry Court  
Ann Arbor, MI 48103

Bills info:

HB5036: Health; other; advisory council for pediatric autoimmune neuropsychiatric disorders; create. Amends 1978 PA 368 (MCL 333.1101 - 333.25211) by adding sec. 5145.

<http://www.legislature.mi.gov/.../billintroduced/House/pdf/20...>

HB5035: Insurance; insurers; coverage for certain pediatric autoimmune neuropsychiatric disorders; require. Amends 1956 PA 218 (MCL 500.100 - 500.8302) by adding sec. 3406u.

[http://www.legislature.mi.gov/\(S\(knx52tiuvakp4r3fyjn5axd3\)\)/mileg.aspx?page=home](http://www.legislature.mi.gov/(S(knx52tiuvakp4r3fyjn5axd3))/mileg.aspx?page=home)

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Abigail M. Samuels  
Mobile: 734.635.9015

September 24, 2018

Chair Hank Vaupel  
Vice-Chair Jim Tedder  
Representative Joseph Graves  
Representative Daniela Garcia  
Representative Jason Sheppard  
Representative Julie Calley  
Representative Diana Farrington  
Representative Roger Hauck  
Representative Pamela Hornberger  
Representative Bronna Kahle  
Representative Jeff Noble  
Representative Winnie Brinks  
Representative LaTanya Garrett  
Representative Sheldon Neeley  
Representative Jim Ellison  
Representative Abdullah Hammoud  
Representative Kevin Hertel

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

We are writing this letter in support of Bill HB5036 for an advisory council to be established. Our hope is to help our daughter Sophie (10yo) who has been diagnosed with PANDAS/PANS which manifests with very difficult behaviors.

Sophie is a ten-year-old fraternal twin and 1 of 4 kids. She is unable to focus and dress and do what most 10 year olds do in the morning to get ready for school. She screeches, spits, yells and stomps her feet like a two year old throwing a tantrum. We see this behavior increase as the day goes on. The facial tics and picking her clothes that touch her skin also increase. She needs clothes with out tags or seems. Fluffy socks are a must. She has fears and anxiety that keep her from going to the basement. She has OCD (Obsessive compulsive disorder) we need to do a ritual the same way every day. We have to repeat words like I love you over and over again before she will go to bed at night. Kiss-Kiss-Hug-Hug in that order. If out of order, we must do it again. If her routine gets messed up she will have a melt down.

At first my husband and I thought it was our disciplinary techniques so we took some classes at the school and search for online help. We took her to a psychologist thinking they would have answers. But to no avail most techniques do not work on her. We have three other children who have no problem with the way we discipline. All I can say is this monster that has taken over our Sophie needs to go. We have two other children with autoimmune disorders so this puts a lot of pressure on the family financially and mentally.

Sophie's issues were slow and gradual. Almost unnoticeable unless you knew what to look for. I noticed eye blink then the facial grimaces and screeching sound she made. Then the head twitches, arm movements and foot stomping started. The more stressed she got the more she would show symptoms. She would hold it together at school and come home and melt down. This made it difficult to do homework with Sophie. The harder we pushed the worse she got.

Sophie started falling behind in kinder garden could not grasp numbers and letters. We had to repeat kindergarten. Her penmanship was hard to read and each sentence blended together. We noticed she could not retain Math and her reading skills were falling behind in 1<sup>st</sup> and second grade. We had her tested in the second grade for an IEP but she fell just above the line. We had her tested for an IEP again in 3<sup>rd</sup> grade and she qualified. Yes, finally some help with homework. Homework was a nightmare. She had zero attention span. We got the ADHD, TIC and OCD diagnosis. This helped us get an IEP and 504 in place at school.

Finally we found a doctor summer of 2018 who recognized the diagnosis of PANS (Pediatric Auto immune Neurological disorder). The doctor confirmed with a scan and other tests that our daughter has inflammation in her front lobe of her brain. There were viruses and bacteria that had broken the blood brain barrier and were causing inflammation in her brain. She has adrenal fatigue and its like being in fight or flight all the time. We treated her with medicine for three months and unfortunately this protocol did not work on our Sophie.

Unfortunately, the treating doctor has shut down his practice along with all our records so we are looking for a new provider at this time. We have not found a doctor who treats PANS at this time.

We go through the day walking on eggshells hoping not to push or get Sophie upset so we can all live a normal life. We do what we can to keep the peace. We coddle her every need just like a toddler to get to the next day.

We are praying that the doctors and insurance providers will get on board with finding a cure for this awful DIS-ORDER!

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

Thank you for your time.

Michael and Melissa Luyckx

## Melissa Weipert

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**From:** Jennifer Lafer <j\_lafer@hotmail.com>  
**Sent:** Monday, September 24, 2018 9:23 PM  
**To:** Melissa Weipert  
**Subject:** Support of HB 5035 and HB 5036

This letter is being written to support HB5036 which will create an Advisory Council on PANDAS/PANS in the state of Michigan. We need to educate others on this disease and provide treatment for those who are currently affected. I also support HB5035, which will give those suffering from PANDAS/PANS insurance coverage for their medical appointments and medication.

Thank you for your consideration,

Jennifer Lafer

962 Hartsough St.

Plymouth, MI 48170

**Bills:**

HB5036: Health; other; advisory council for pediatric autoimmune neuropsychiatric disorders; create. Amends 1978 PA 368 (MCL 333.1101 - 333.25211) by adding sec. 5145.

<http://www.legislature.mi.gov/.../billintroduced/House/pdf/20...>

. 5036 HOUSE BILL No. 5036 - Michigan Legislature - Home

[www.legislature.mi.gov](http://www.legislature.mi.gov)

04241'17 EMR . 5036. 5036 HOUSE BILL No. 5036 September 27, 2017, Introduced by Reps. Miller, Howrylak, Graves, Hoadley and Chang and

HB5035: Insurance; insurers; coverage for certain pediatric autoimmune neuropsychiatric disorders; require. Amends 1956 PA 218 (MCL 500.100 - 500.8302) by adding sec. 3406u.

[http://www.legislature.mi.gov/\(S\(knx52tiuvakp4r3fyjn5axd3\)\)/mileg.aspx?page=home](http://www.legislature.mi.gov/(S(knx52tiuvakp4r3fyjn5axd3))/mileg.aspx?page=home)

Thank you for your consideration.



September 20, 2018

Chair Hank Vaupel  
Vice-Chair Jim Tedder  
Representative Joseph Graves  
Representative Daniela Garcia  
Representative Jason Sheppard  
Representative Julie Calley  
Representative Diana Farrington  
Representative Roger Hauck  
Representative Pamela Hornberger  
Representative Bronna Kahle  
Representative Jeff Noble  
Representative Winnie Brinks  
Representative LaTanya Garrett  
Representative Sheldon Neeley  
Representative Jim Ellison  
Representative Abdullah Hammoud  
Representative Kevin Hertel

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

My name is Mary Crombez. I live at 9615 Ingram St, Livonia, Michigan 48150.

I am writing in support of HB 5036. The establishment of a PANDAS/PANS Advisory Committee, as the bill ensures, would provide the public awareness children suffering from this horrific condition require in order to be properly diagnosed and treated with the medically necessary standard of care already established by the PANDAS Physician Network (<https://www.pandasppn.org/>) so that these children can overcome the debilitating and incapacitating symptoms this encephalitic condition causes.

Just how debilitating and incapacitating can this condition be? I can answer that as a mother of a child who has suffered for thirteen years.

“Mommy, Mommy, kill me, please kill me, please kill me now...I can’t live like this anymore!”

These were the words I heard my 11 year old daughter, Mary Rose, scream at the top of her lungs in February 2010. We had witnessed much of what we were seeing at the time four years earlier in February of 2006. At that time, she simply screamed...she had no way to put into words what she was able to express at the age of 11. At the age of seven our daughter was a vibrant, engaging, curious, active, musical, athletic, friendly, social butterfly. She excelled at school, she competed in gymnastics, and she played the violin in a youth symphony. And then, without warning or explanation, she could do none of these things. The more inflamed her brain became the more debilitated and incapacitated she became. You must understand her request to die was not borne out of suicidal ideation, far from it! Her request was the only viable option she could come up with when she could no longer fathom enduring the compulsions her brain demanded she complete. You see, not only did we lose our daughter...our daughter lost herself. Mind you, she was standing there in plain sight but the child we knew and the child she saw reflected in the mirror with each passing day--- the piano playing, soccer star; the violin playing, gymnast; the friend to all she met-- - disappeared over night and was replaced with a compulsion-driven, panicked, anxious, screaming, raging, out-of-control being who could accept no comfort, could find no solace, sought but discovered no relief from a misery that none of us will ever be able to comprehend. Our little girl couldn’t leave the house, she couldn’t go to school, she couldn’t eat or sleep. She urinated every 45 minutes during her waking hours. She couldn’t sleep more than 4-6 hours and remained awake for 36-72 hours at a time. There were periods during exacerbations that our daughter could not swallow her own saliva, wear clothing or eat any food that she witnessed someone prepare. She could not tolerate the sound of snow being shoveled outside, birds chirping in the trees, or the click that fingernails make on the keyboard of a smartphone. But most distressing of all, to both her and I, was her intolerance to touch...which

meant that she could not be held as she cried and screamed in pain and sorrow for the life that was slipping away from her....a life that was once filled with bliss and wonder only to be replaced by fear, anxiety, compulsions, uncontrollable body movements, and rage. She had every right to be enraged. The people she had always counted on, relied on, and believed in were utterly useless in bringing her aid despite endless doctor appointments. As time progressed it seemed her father, grandparents, and I were helpless in our efforts to find a physician in the state of Michigan. Our pediatrician tried to help but this was "out of her scope of practice". So with our pediatrician's blessing we traveled to Chicago, to a specialist. It was a sweltering hot spring day when we made the more than four hour trek to Chicago with our daughter screaming at the top of her lungs in 85 degree heat. But no relief from the heat would come despite our car being equipped with air conditioning because she could not tolerate the sound or feel of the air blowing in the car whether through the vents or from the windows being down...so we drove as our sweat pooled around us, as our child screamed in agony, and we prayed for an answer in Chicago.

Over the years our daughter would go to Chicago for three IVIg treatments. We would pay not only for the life-saving immune globulin (\$7,000 or more dollars based on her weight at the time of each infusion) but for the out-of-state office visits, out-patient facility fees and hotel costs simply because we could not locate a physician near us who had the knowledge and experience to treat our child here in our home state of Michigan. Countless days off of work for appointments, tests, and out-of-state treatment trips became our new way of life. IVIg treatments are costly but our daughter's brain function is worth any price. So is evidence-based diagnostic information. To satisfy the requirements for medical care and treatment in Michigan we have paid for many out-of-pocket medical tests. The Cunningham Panel was not commercially available when our daughter was significantly debilitated by this infectious-triggered faulty immune response so we paid \$400 to the University of Oklahoma to secure serologic evidence. This test determined our daughter's anti-neuronal antibodies and Cam Kinase II were nearly at the level of the established medical condition Sydenham's Chorea. But this was not enough evidence for Michigan physicians so we signed on to a clinical research study with Dr. H. Chugani at Children's' Hospital of Michigan and our daughter's brain activity was measured via a PET scan using the radioactive isotope PK11195. The activation shown in the test confirmed the hypothesis of PANDAS yet more tests ensued. MRI discerned bright, white hyper-intensities in her brain.

Yet, when given IVIg and antibiotics twice daily over months of time her debilitating symptoms would remit. She could be a child again...until the next infectious trigger and we would start again from scratch.

Our family has learned that the only way to help someone in the abyss is to climb into the black hole with them and through love, support, and the tenacity to never give up...the outcome can be positive. As a PANDAS support mama in Michigan I have willingly joined other parents as they have tried to navigate the abyss for their family. It is time that the Michigan Legislature sends a lifeline of support to families and enacts legislation to return children to health and wellness!

With what is now known about the condition, no other child in Michigan should ever suffer the way our dear, sweet, precious daughter did. You have the opportunity to save a childhood, to save a family, to protect the health and well-being of children today. Please vote to establish a PANDAS/PANS Advisory Council today...vote to save a child's life!

Thank you for your consideration on this matter and a vote to affirm the establishment of a PANDAS/PANS Advisory Council through HB 5036 and I look forward to working with you to establish medical insurance coverage as indicated in HB 5035 in the near future,

Mary Crombez

September 24, 2018

Dear Members of the House Health Policy,

I am writing this letter to express my support for HB5036 in order to establish a much needed and necessary Advisory Council on PANDAS/PANS for the state of Michigan. The majority of medical doctors and medical professionals are unaware of this condition, how to diagnose it and most importantly how to treat it. This is unacceptable and change is drastically needed. As an educator, I know of cases of PANDAS/PANS that were misdiagnosed as Aspergers/Autism. However, once the PANDAS was determined, the proper treatment alleviated the child's symptoms. How many similar cases went undiagnosed that have led to a lifetime of problems? With mental health issues on the rise, how many cases are actually undiagnosed cases of PANDAS/PANS that, with proper treatment, could have been resolved? How many cases have been misdiagnosed as a mental illness instead of an underlying and treatable health condition?

Changes cannot happen unless it is first recognized that there is a need. This letter is to attest to that need. The first step is the establishment of the Advisory Council. Second, HB5036 will allow a PANDAS/PANS diagnosis to be covered by insurance companies so that patients with the condition can be treated appropriately. A misdiagnosis could lead to a person mistakenly being placed on an unnecessary medication, which may be a life-long. Please support HB5036 and be the first step toward change in the right direction for those suffering from PANDAS/PANS.

Thank You!

Sheryl Melling  
57914 Grey Fox Glen  
Washington Township, MI  
48094

September 24, 2018

Dear members of the House Health Policy Committee

I am writing today in regard to help create an Advisory Council on PANDAS/PANS in the state of Michigan by supporting HB5036. This condition is so far from the public eye and we need to create better awareness and access to diagnose/treat these individuals accordingly. Additionally, I support HB5035 to provide insurance coverage in order to diagnosis and treat those deemed medically necessary suffering with this disease.

Thank you for your time and consideration on this very important matter.

Sincerely,

Fannita Menna  
18916 Newbridge Drive  
Macomb, MI 48044

Dear members of the House Health Policy Committee,

This letter is in support of HB5036 to get an Advisory Council established for PANDAS/PANS in Michigan. My son is affected by PANDAS and from the experience our family has endured, we have found that we need more efficient ways to diagnose, treat, and make others aware. Insurance coverage needs to be implemented so that individuals that suffer from PANDAS gets medical treatment needed.

Thank you very much for your consideration,

William Martin  
21956 Camille Ct.  
Woodhaven, MI 48187

## Melissa Weipert

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**From:** Lecia <leciabr@yahoo.com>  
**Sent:** Tuesday, September 25, 2018 1:08 AM  
**To:** Melissa Weipert  
**Subject:** Support for HB5035 and HB5036

Dear Members of the House Health Policy Committee,

I am writing to express my support of HB5036 to establish an Advisory Council on PANDAS/PANS in the state of Michigan.

Additionally I support HB5035 which will provide insurance coverage for diagnosis and treatment deemed to be a medical necessity for an individual suffering with this debilitating illness.

PANDA (Pediatric Autoimmune Neuropsychiatric Disorder Associated with Streptococcal infection) is an autoimmune condition initially triggered by strep infections, which disrupts a child's normal neurologic activity.

PANS (Pediatric Acute-onset Neuropsychiatric Syndrome) is associated with a variety of different infections.

All too often, children with PANS and/or PANDAS are misdiagnosed as having a psychiatric illness and may be treated solely with psychotropic drugs to manage their symptoms. Unfortunately, for PANS and PANDAS patients this does not address the root cause of the symptoms, which is an infection-triggered autoimmune condition. Studies have shown that when given appropriate anti-infective and/or immunological treatment, PANS and PANDAS patients experience symptom resolution, or their symptoms are dramatically reduced.

Obtaining a correct diagnosis can be challenging, because PANS and PANDAS symptoms can mimic other illnesses. There potentially may be a large number of children and even adults diagnosed with psychiatric illnesses who may unknowingly be affected by PANS or PANDAS and are misdiagnosed.

By establishing an Advisory Council (HB5036), steps can be taken to bring about better awareness, access to diagnosis and treatment regarding this illness. In addition, HB5035 will provide insurance coverage to help offer diagnosis and treatment for those affected.

Thank you for your consideration in addressing this very important health issue.

Sincerely,

Lecia Brunetti  
4022 Custer Avenue  
Royal Oak, MI 48073

email: [leciabr@yahoo.com](mailto:leciabr@yahoo.com)

## Melissa Weipert

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**From:** Tami Rozenboom <rozenbt@gmail.com>  
**Sent:** Tuesday, September 25, 2018 7:55 AM  
**To:** gammicca@comcast.net; Melissa Weipert  
**Subject:** Pandas/PANS

Dear members of the House Health Policy Committee,

I am writing in support of HB5036 to establish an Advisory Council on PANDAS/PANS in the state of Michigan. I know am familiar with 2family members/friends who have been diagnosed. We need to have better awareness in order to properly treat those who suffer! Additionally I support HB5035 which will provide insurance coverage for diagnosis and treatment deemed to be a medical necessity for an individual suffering with this debilitating illness.

With much appreciation for your consideration,

Tami Rozenboom  
1244 Tartan Lane  
Commerce, MI  
48390

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## Melissa Weipert

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**From:** Nicole Siemasz <nsiemasz12@gmail.com>  
**Sent:** Tuesday, September 25, 2018 8:50 AM  
**To:** Melissa Weipert  
**Subject:** HB5036 PANDAS/PANS letter

Dear members of the House Health Policy Committee,

My name is Nicole Siemasz, that parent of a child, Aiden who has been diagnosed with PANDAS.

After a year and a half of trying to find a doctor who saw all the symptoms my child was having as a whole. We found someone! He is doing so much better after starting treatment. Not all kids are as lucky. We need more awareness for our kids. So they can get treatment quickly so PANS/PANDAS doesn't have to be their end to a normal life.

I am writing in support of HB5036 to establish an Advisory Council on PANDAS/PANS in the state of Michigan. I'm doing so because not only do we need better awareness, but access to diagnosis and treatment for those affected. Additionally I support HB5035 which will provide insurance coverage for diagnosis and treatment deemed to be a medical necessity for an individual suffering with this debilitating illness.

With much appreciation for your consideration,

Nicole Siemasz  
35820 Booth  
Westland Mi, 48186



## Melissa Weipert

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**From:** Amy Fontaine <afontaine@miottawa.org>  
**Sent:** Tuesday, September 25, 2018 8:59 AM  
**To:** Melissa Weipert  
**Subject:** HB5036 Support

Dear Members of the House Health Policy Committee,

On behalf of my family, and the many Michigan families like mine who are suffering from the devastating effects of Pandas/Pans, I am writing to urge and encourage your support for HB5036, which will establish an Advisory Council on PANDAS/PANS in the state of Michigan.

This important and comprehensive Bill will promote awareness of Pandas among the health care community, so that those affected will receive a timely diagnosis and most importantly, prompt and effective treatment.

Additionally, the Bill will provide insurance coverage for the diagnosis and treatment for individuals suffering with this debilitating illness that they so deserve.

My darling daughter, Jolie, has suffered from Pandas—including devastating Tonic Clonic seizures—for over three years. We have been unable to find help or treatment in the state of Michigan, and we cannot afford to travel for expensive treatments in other states.

Please lend your support to this very important Bill, so that families like mine find the answers we so greatly deserve!

Thank you for your consideration and your efforts to help families affected by Pandas/Pans,

Amy Fontaine

17631 Tamarack Lane  
Grand Haven, Mi 49417  
616 402-2275

## Melissa Weipert

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**From:** Youssef M. Fawaz <ymfawaz@gmail.com>  
**Sent:** Tuesday, September 25, 2018 9:01 AM  
**To:** Melissa Weipert; AbdullahHammoud@house.mi  
**Cc:** lillerj@yahoo.com  
**Subject:** Support for HB 5036 of 2017

Re: House Bill 5036

Dear Chair Vaupel and Representative Hammoud:

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).

This condition personally affects the family of a friend and neighbor. The information they have shared with me indicates the symptoms that manifest are tics, most often associated with Tourette Syndrome. Raising awareness of the condition would assist families in obtaining a timely diagnosis and earlier treatment of the condition. It has been estimated that 25% of the children diagnosed with OCD and tic disorders may actually have PANDAS. Conservatively, the number could be 1 in 200 children.

Please support HB 5036. In doing so, you will support the healing of my friend's granddaughter and countless other children in the state of Michigan. As a new parent, I support doing all we can to help children live their best lives.

Thank you for your consideration.

Sincerely,

Youssef Fawaz  
23904 Wilson Avenue  
Dearborn, MI 48128

## Melissa Weipert

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**From:** smbrowning1979 <smbrowning1979@att.net>  
**Sent:** Tuesday, September 25, 2018 9:27 AM  
**To:** Melissa Weipert  
**Subject:** HB5036-HB5035

Dear members of the House Health Policy Committee,

I am writing in support of HB5036 to establish an Advisory Council on PANDAS/PANS in the state of Michigan. I'm doing so because we experienced this terrible illness with our friends son first hand, we saw the pain and constant doctor visits, We saw not only his suffering and the scare of the unknown but his whole families before being properly diagnosed.

Not only do we need better awareness, but families need access to proper diagnosis and treatment for those affected.

I also support HB5035 which will provide insurance coverage for the diagnosis and treatment to be a medical necessity for an individual suffering with this debilitating illness.

Thank you for your consideration,

Shannon Browning  
27355 Lorenz st  
Madison Heights Mi, 48071

### Bills:

HB5036: Health; other; advisory council for pediatric autoimmune neuropsychiatric disorders; create. Amends 1978 PA 368 (MCL 333.1101 - 333.25211) by adding sec. 5145.

HB5035: Insurance; insurers; coverage for certain pediatric autoimmune neuropsychiatric disorders; require. Amends 1956 PA 218 (MCL 500.100 - 500.8302) by adding sec. 3406u.

## Melissa Weipert

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**From:** Brandy Anderson <brandylee333@hotmail.com>  
**Sent:** Tuesday, September 25, 2018 9:53 AM  
**To:** Melissa Weipert  
**Subject:** HB5036 and HB5035

Dear members of the House Health Policy Committee,

I am writing in support of HB5036 to establish an Advisory Council on PANDAS/PANS in the state of Michigan. We need better awareness and access to diagnosis and treatment for those affected. Additionally I support HB5035 which will provide insurance coverage for diagnosis and treatment deemed to be a medical necessity for an individual suffering with this debilitating illness. My daughter was recently diagnosed with PANS. We have spent about \$20,000 out of pocket over the last three years for testing and doctor appointments looking for answers. We started some basic treatment protocols over the last few weeks and are already seeing big improvements. I have not been able to work for three years because I have had to take care of my daughter as no daycare would accept her and she was too sick to go to school or daycare. I just refinanced my house. Families need this support and children need to get better. It affects the whole family in major ways.

With much appreciation for your consideration,

Brandy Anderson

Sent from Outlook

## Melissa Weipert

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**From:** Linda Swan <mom@grandmaswan.com>  
**Sent:** Tuesday, September 25, 2018 10:16 AM  
**To:** Melissa Weipert  
**Subject:** PANDAS

Dear members of the House Health Policy Committee,

I am writing in support of HB5036 to establish an Advisory Council on PANDAS/PANS in the state of Michigan. I'm doing so because not only do we need better awareness, but access to diagnosis and treatment for those affected. Additionally I support HB5035 which will provide insurance coverage for diagnosis and treatment deemed to be a medical necessity for an individual suffering with this debilitating illness.

Thank-you for your attention to this matter

Linda Swan

9552 Rockland

Redford, MI 48239

## Melissa Weipert

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**From:** Kristen Misener <kristen0227@hotmail.com>  
**Sent:** Tuesday, September 25, 2018 10:52 AM  
**To:** Melissa Weipert  
**Cc:** Ragan Cudney; gammicca@comcast.net  
**Subject:** Support for House Bill 5036 & House Bill 5035

Dear Members of the House Health Policy Committee,

I am writing in support of HB5036 to establish an Advisory Council on PANDAS/PANS in the state of Michigan. It is time to create awareness about this health condition. Currently, there is no formal diagnosis for PANDAS/PANS leaving treatment options limited and parents of affected children, frustrated. Children with this condition are suffering. Health policy regarding this issue needs to be established through an Advisory Council so that we can move closer to developing a Standard of Care for proper diagnosis and treatment.

Additionally, I support HB5035 which will provide insurance coverage for diagnosis and treatment deemed appropriate for an individual suffering with this debilitating illness. I urge you to consider the families dealing with this and "get the ball rolling", so to speak, to help them be able to access the diagnosis and treatment they need. Your time and consideration is appreciated.

Regards,

Kristen Misener  
5149 Shay Lake Road  
Kingston, MI 48741  
Tuscola County  
(586)907-7624

## Melissa Weipert

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**From:** Casey <kcwangrud@chartermi.net>  
**Sent:** Tuesday, September 25, 2018 11:22 AM  
**To:** Melissa Weipert  
**Subject:** Support for HB5036 & HB5035

Dear members of the house health policy committee.

I'm writing to you in support of HB5036 to establish an advisory council on Pans/Pandas in the state of Michigan. My daughter was recently diagnosed with Pans. Due to the fact that insurance providers will not offer coverage for diagnosis or treatment of Pans/Pandas in Michigan my family has been debilitated financially in our efforts to help our daughter heal and thrive. These bills will not only bring about more awareness but also the insurance coverage that is necessary for proper diagnosis and medical treatment.

With much appreciation for your consideration,

Kenneth Wangrud  
4738 17th rd  
Escanaba, Mi. 49829  
Sent from my iPhone



UNIVERSITY OF MICHIGAN  
DEPARTMENT OF CHEMISTRY

Mark E. Meyerhoff  
Philip J. Elving Professor

September 25, 2018

House Health Policy Committee  
Michigan House of Representative  
Lansing, MI

**Re: Establishing State of Michigan Advisory Council on PANDAS/PANS**

Dear House Health Policy Committee,

As a parent who has a child who suffered from PANDAS/PANS from 2001-2006, and then again now as an adult from 2012-present, I am writing to recommend, in the strongest possible way, that you fully support the establishment of an advisory council on PANDAS/PANS for the State of Michigan (HB 5036). I also strongly support HB 5035 that will provide insurance coverage for children and young adults who are diagnosed with this very difficult to treat condition.

It is sad that so many families are suffering here in Michigan. Although Dr. Swedo at NIH first described PANDAS/PANS back in the late 1990s, many many MDs have refused to learn and recognize that infections by strep and other organisms (including mycoplasma) can cause an autoimmune type of encephalitis in the brain, that results in severe/paralyzing obsessive compulsive disorder (OCD) and many other issues with sudden onset for a significant number of children and young adults. I know firsthand the difficulties in finding care for such cases in the State of Michigan. Indeed, my son Joseph was doing great (even though he likely fell into the category of Aspergers Syndrome) until age 15 (in regular school and excelling). Then suddenly, two weeks after a strep infection, we were called by his high-school that he was completely stuck at his locker, doing highly repetitive things (neatening and straightening books in his locker). This first episode lasted 5 years---and we had to go out of state to get help, and much of the costs to get medical help for him were not covered by insurance. But eventually he recovered fully, and then was able to go on to college, etc. before the second episode of PANDAS/PANS started in 2012, which we are still dealing with. It is particularly upsetting to me, as a faculty member here at U of M for 40 years, that the U of M Medical School/Hospital did not have doctors who knew about this disorder back in 2001-2006 period, with the exception of one infectious disease person, Dr. Blackwood. My son's case changed things a bit, but it is still quite difficult for parents to find MDs who are know much about this disorder here at U of M and elsewhere in the State of Michigan.

It is imperative that the House act to help the many parents in Michigan who have children who fit into the PANDAS/PANS category. Stanford and Yale already have clinics to treat such children. Michigan needs to follow, and the first step is to make sure health insurances cover this disorder.

Sincerely,

A handwritten signature in black ink, appearing to read "Mark E. Meyerhoff".

Mark E. Meyerhoff  
Philip J. Elving Professor of Chemistry



## Melissa Weipert

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**From:** Julie Cucco <jucucco@gmail.com>  
**Sent:** Tuesday, September 25, 2018 11:48 AM  
**To:** Melissa Weipert  
**Subject:** PANDAS

Dear members of the House Health Policy Committee,

I am writing in support of HB5036 to establish an Advisory Council on PANDAS/PANS in the state of Michigan. I'm doing so because not only do we need better awareness, but access to diagnosis and treatment for those affected. Additionally I support HB5035 which will provide insurance coverage for diagnosis and treatment deemed to be a medical necessity for an individual suffering with this debilitating illness. I am a mother of a 34 year-old who has suffered from this debilitating illness since she was 12. We are in need of support that can help children through this horrible disease.

With much appreciation for your consideration,

Julie Cucco  
561-866-4884

## Melissa Weipert

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**From:** Dana Evans <danamevans@gmail.com>  
**Sent:** Tuesday, September 25, 2018 1:31 PM  
**To:** Melissa Weipert  
**Subject:** Support of HB5036

Dear members of the House Health Policy Committee,

I am writing in support of HB5036 to establish an Advisory Council on PANDAS/PANS in the state of Michigan. I'm doing so because not only do we need better awareness, but access to diagnosis and treatment for those affected. Additionally I support HB5035 which will provide insurance coverage for diagnosis and treatment deemed to be a medical necessity for an individual suffering with this debilitating illness.

I am a parent of a child who was diagnosed with PANS this year. Our lives were hell as our daughter became ill on December 20, 2017 and did not begin receiving treatment until May 2018. Our daughter suffered from physical pain, restrictive eating, OCD, a tic, extreme fatigue, weight loss, dizziness, separation anxiety and sever school avoidance. Thankfully, after discovering acute infections she was able to begin treatment (2 months of antibiotics and antivirals). I am happy to report that our daughter started school this year without a hitch. She is functioning as a typical 7th grader and our lives have begun to get back to "normal".

It is our hope that an Advisory Council can be formed in the State of Michigan to better guide parents and help children receive diagnosis and treatment sooner. So many children are suffering and families being destroyed by this awful illness. Please help families like mine get the support needed.

With much appreciation for your consideration,

Dana Evans

724 Greenbrier SE

Grand Rapids, MI 49546

## Melissa Weipert

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**From:** Pepper <pfair22@sbcglobal.net>  
**Sent:** Tuesday, September 25, 2018 2:09 PM  
**To:** Melissa Weipert  
**Cc:** Rep. Robert Wittenberg (District 27)  
**Subject:** Support for HB5036

To the members of the House Health Policy Committee:

I am writing to you today in support of HB5036 to establish an Advisory Council on PANDAS/PANs in the State of Michigan. I'm doing this not only because we need better awareness but also access to treatment and diagnosis for those that are affected. My niece, Grace, suffers from PANDAS and not receiving a proper diagnosis did not come in a timely manner or easily for her. Additionally I support HB5035 which would provide insurance coverage for diagnosis and treatment for an individual suffering with this debilitating illness.

With much appreciation-

Annette Fair  
410 Pearson St  
Ferndale, MI 48220

Sent from my iPhone

## Melissa Weipert

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**From:** Kolber, Katherine <KKolber@troy.k12.mi.us>  
**Sent:** Tuesday, September 25, 2018 2:16 PM  
**To:** Melissa Weipert  
**Subject:** Support of HB5036 and HB5035

Dear members of the House Health Policy Committee,

I am writing in support of HB5036 to establish an Advisory Council on PANDAS/PANS in the state of Michigan. I'm doing so because my son's best friend suffered with PANDAS during his young life. PANDAS was something I had never heard of before until his case but since then, I have known two more children who have suffered with PANDAS/PANS. There needs to be greater awareness for parents and doctors so appropriate diagnosis and treatments can be given. Additionally, I support HB5035 which will provide insurance coverage for diagnosis and treatment deemed to be a medical necessity for an individual suffering with this debilitating illness.

With much appreciation for your consideration,

*Katie Kolber*  
1st Grade Teacher  
Hill Elementary  
(248) 823-3522



## Melissa Weipert

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**From:** Amanda Muckenthaler <amuckenthaler@gmail.com>  
**Sent:** Tuesday, September 25, 2018 2:29 PM  
**To:** Melissa Weipert; Rep. Jim Ellison (District 26)  
**Subject:** HB5036

Dear Ms. Weipert and Mr. Ellison,

My name is Amanda Muckenthaler, and I am writing in support of HB5036 to establish an Advisory Council on PANDAS/PANS in the state of Michigan. We are personally affected by this autoimmune illness, as a dear friend of our's daughter has been diagnosed. We believe there needs to be increased awareness, as well as better access to diagnosis and treatment, and that this would greatly help many families in the state of Michigan.

I am also writing in support of HB5035 which will provide insurance coverage for diagnosis and treatment for individuals suffering from PANDAS/PANS. Our dear friend has spent thousands of dollars of her hard earned money on trying to help her daughter, and in a time when medical bills can sky rocket, it is important now more than ever that this be passed.

I truly appreciate your consideration.

Amanda Muckenthaler  
3502 Arbor Ave.  
Royal Oak, MI 48073

## Melissa Weipert

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**From:** Dan Riley <the\_riley\_5@hotmail.com>  
**Sent:** Tuesday, September 25, 2018 2:38 PM  
**To:** Melissa Weipert  
**Subject:** HB5035 support

Dear members of the House Health Policy Committee,

I am writing to you in order to show my support of HB5036. Families in Michigan need you to establish an Advisory Council on PANDAS/PANS.

We desperately need more awareness for this complicated health issue. It effects more children than most of us even know. I'm not sure how our road to recovery would have been different if we had access to diagnosis and treatment much sooner than what we did. My son was misdiagnosed with bipolar 1 at age 4. He has been prescribed countless psych meds which some carried a black box warning on them. Iv'e never had a problem with his private or State insurance covering these dangerous meds. However, the problem comes with mainstream doctors that don't know anything about PANS which was causing his neuropsych sypmtoms all along. We have gone to two different out of state physicians and paid completely out of pocket for his treatments for the past six years. Currently we are seeing a specialist in NYC. She understands and treats kids with PANS/LYME/AE. She does not take any insurance. This has been an extreme hardship financially for my family. What makes it worth it is that she has had tremendous success with her treatments and my son who is now 12, is doing well under her care.

I additionally want to support HB5035 which will provide insurance coverage for diagnosis and treatment deemed to be a medical necessity for any individuals suffering with this debilitating illness.

I would have loved to be at the hearing tomorrow but I just recently had knee surgery and cannot make the 3 hour trip. Please feel free to contact me if I can be of any help to you in understanding just what PANS kids and families go through in Michigan

With much appreciation for your consideration,

Colleen Riley  
the\_riley\_5@hotmail.com  
3901 Meadowbrook Ln,  
Hart, MI 49420

## Melissa Weipert

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**From:** Leslie Wilkins <lesliemcwilkins@yahoo.com>  
**Sent:** Tuesday, September 25, 2018 3:00 PM  
**To:** Melissa Weipert  
**Cc:** Meaghan.McCann@gmail.com  
**Subject:** Please support HB5036!

Dear House Health Policy Committee Members,

The purpose of this email is to ask you to support HB5036 in establishing an Advisory Council on PANDAS/PANS. I have a number of dear friends affected by this debilitating illness. Not only is it horrible for the actual patient, but it takes a terrible toll on their whole family and extended community. These families need better awareness, and even more importantly **access** to diagnosis and treatment. Another important aspect of HB5035 is that it will provide insurance coverage for diagnosis and treatment deemed to be a medical necessity for people suffering from PANDAS/PANS. Thank you for your consideration.

Regards,  
Leslie Wilkins, Ann Arbor, MI

September 20, 2018

Chair Hank Vaupel  
Vice-Chair Jim Tedder  
Representative Joseph Graves  
Representative Daniella Garcia  
Representative Jason Sheppard  
Representative Julie Calley  
Representative Diana Farrington  
Representative Roger Hauck  
Representative Pamela Hornberger  
Representative Bronna Kahle  
Representative Jeff Noble  
Representative Winnie Brinks  
Representative LaTanya Garrett  
Representative Sheldon Neeley  
Representative Jim Ellison  
Representative Abdullah Hammoud  
Representative Kevin Hertel

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

Six years ago in 2012, our daughter Claire started Kindergarten. We couldn't have been more excited. Claire was our oldest child and a very active, fun, smart, loving, and a silly girl. In March of 2013 Claire became very sick, which was the first time any of our kids had been sick for more than a day or two. She ran a high fever for over seven days and would not eat, drink and was very lethargic. Many times that week we called her primary care physician and each time they stated it was likely a viral infection and to keep monitoring her. We ended up taking her to urgent care but no test were completed and she finally started feeling better around day eight. That was the time things started to go downhill. Since that illness, Claire started having issues with behavior, anxiety, and aggressive behavior. Over the next two years from 2013 to 2015, we did counseling, dietary changes and journaling to see what could be causing these changes in personality and behavior. We thought we figured it out after a noticeable improvement with diet changes, however the symptoms still persisted intermittently.



In third grade (2015/2016) Claire was not doing well. We saw Sydenham Chorea movements, episodes where she couldn't walk saying "my legs feel like they are going to faint", hallucinations, low frustration level, rage, sensory issues, headaches, and separation anxiety. This was not our healthy daughter and we knew something was causing these signs and symptoms. We read, researched, asked questions and kept searching. Another family pointed us in the directions of PANS/PANDAS and that is when everything clicked together. The appropriate labs were requested and completed. The positive lab results plus clinical signs and symptoms gave us the diagnosis of PANS.

During the course of 6 years, we ended up seeing over 6 different doctors, having 3 visits to the Emergency Department for horrible headaches, belly aches, self-harm and uncontrollable rage. We spent over 30,000 dollars out of pocket related to lack of coverage from insurance and the uncertainty of physicians. We finally found a doctor that helped us treat the underlying infections and worked on building her immune system (February 2016). After 3 months we started seeing improvement, after 6 months she was able to participate in more activities with our family and after 9 months she was able to sleep in her own bed again rather than the floor in our room. It has now been over 2 years since we started initial treatment and the difference in our daughter is eye opening. Claire is still healing from this diagnosis but is an 11 year old who feels better, regularly plays with friends, travel softball, and actively participates in school. She has her loving, silly personality back and we couldn't be more blessed.

This diagnosis is very isolating. There are families that do not know where to go for proper diagnosis and treatment or are unable to pay for services if insurance does not cover. Early intervention can help prevent children from losing part of their childhood to PANS/PANDAS. We are asking for your support with this bill to establish an advisory council for Michigan. It is our hope to prevent other children from delayed diagnosis and treatment of PANS/PANDAS.

Thank you for your consideration,

Lori and Ryan VanderWeele

Chair Hank Vaupel  
Vice-Chair Jim Tedder  
Representative Joseph Graves  
Representative Daniela Garcia  
Representative Jason Sheppard  
Representative Julie Calley  
Representative Diana Farrington  
Representative Roger Hauck  
Representative Pamela Hornberger  
Representative Bronna Kahle  
Representative Jeff Noble  
Representative Winnie Brinks  
Representative LaTanya Garrett  
Representative Sheldon Neeley  
Representative Jim Ellison  
Representative Abdullah Hammoud  
Representative Kevin Hertel

September 24<sup>th</sup>, 2018

RE: House Bill 5036

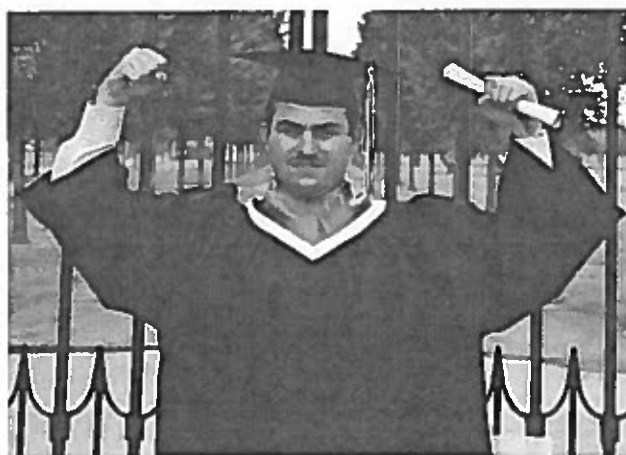
Dear Chair Vaupel and honorable members of the House Health Policy Committee,

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 work 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 increasingly 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 white 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

## Melissa Weipert

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**From:** Diane Adamick <dianemadamick@gmail.com>  
**Sent:** Tuesday, September 25, 2018 5:09 PM  
**To:** Melissa Weipert  
**Subject:** Support of HB5036

Dear members of the House Health Policy Committee,

I am writing in support of HB5036 to establish an Advisory Council on PANDAS/PANS in the state of Michigan.

I am doing this because we need not only more public awareness and treatment we need to provide for insurance coverage for these individuals who are suffering from this illness. Not only the patient, but their families are most certainly affected. Financially and emotionally. I hope you join me in your support.

Thank you for your consideration.

Diane Adamick  
9293 Tavistock Dr.  
Plymouth MI 48170

## Melissa Weipert

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**From:** Leslyn Rank <leslyna@gmail.com>  
**Sent:** Tuesday, September 25, 2018 5:12 PM  
**To:** Melissa Weipert  
**Subject:** Support for HB2036

Dear House Health Policy Committee Members,

The purpose of this email is to ask you to support HB5036 in establishing an Advisory Council on PANDAS/PANS.

This disease affects my family personally. I have a niece whom is Autistic as well as being diagnosed with PANS. This is a horrible diagnosis that is ruining my brothers home life. My niece has totally changed temperaments and is out of control. This started over 2 years ago and is not getting any better. All treatments take forever, if you can even find a neurologist to follow the proper protocol. My brother is going bankrupt and misses a lot of work.

Mine and all families need better awareness, and even more importantly **access** to diagnosis and treatment. Another important aspect of HB5035 is that it will provide insurance coverage for diagnosis and treatment deemed to be a medical necessity for people suffering from PANDAS/PANS.

My niece would certainly benefit from having some of these treatments covered by insurance and also awareness in the medical community. You should read the book, "Brain on Fire, my Month of Madness" by Susannah Cahalan. The author was one of the first to present with PANS symptoms. The book was recently turned into a Netflix movie.

Thank you for your consideration.  
Hopefully

-  
*Leslyn*  
*Plymouth, MI*

## Melissa Weipert

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**From:** Cindy Beller <cindy\_beller@yahoo.com>  
**Sent:** Tuesday, September 25, 2018 5:36 PM  
**To:** Melissa Weipert  
**Subject:** PANDAS

Dear Members of the House Health Policy Committee,

I'm contacting you to ask for your support of HB5036, which would establish an Advisory Council on PANDAS, and HB5035, which would provide insurance coverage for the diagnosis and treatment of children affected by PANDAS.

My close friend's 7 year old daughter has been battling this debilitating illness for several years. I've seen, first hand, the unbelievable challenges the family has faced and the lengths to which they have had to go to find help for their daughter, mostly at their own expense. I cannot imagine what it would be like if it was my child or grandchild.

Please, we must have better awareness and access to diagnosis and treatment for those dealing with PANDAS.

Thank you.

Cynthia Baldwin Beller  
344 Ely Drive North  
Northville, MI 48167

Sent from my iPhone



## Melissa Weipert

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**From:** tolaugh2003 <tolough2003@yahoo.com>  
**Sent:** Tuesday, September 25, 2018 5:51 PM  
**To:** Melissa Weipert  
**Cc:** megan.mccann@gmail.com  
**Subject:** support of bills HB5035 and HB5036

Dear member of the House Health Policy Committee,

I am writing in support of HB5036 to establish an Advisory Council on PANDAS/PANS in the state of Michigan. I'm doing so because not only do we need better awareness, but access to diagnosis and treatment for those affected. Additionally I support HB5035 which will provide insurance coverage for diagnosis and treatment deemed to be a medical necessity for an individual suffering with this debilitating illness.

With much appreciation for your consideration,

Lucy Janson

## Melissa Weipert

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**From:** Lisa Pasternak <lisampasternak@yahoo.com>  
**Sent:** Tuesday, September 25, 2018 6:35 PM  
**To:** Melissa Weipert  
**Subject:** HB5036: Health; other; advisory council for pediatric autoimmune neuropsychiatric disorders; create. Amends 1978 PA 368 (MCL 333.1101 - 333.25211) by adding sec. 5145

Dear members of the House Health Policy Committee,

I am in support of HB5036 to establish an Advisory Council on PANDAS/PANS in the state of Michigan. I'm write because not only do we need better awareness, but access to diagnosis and treatment for those affected. Additionally I support HB5035 which will provide insurance coverage for diagnosis and treatment deemed to be a medical necessity for an individual suffering with this debilitating illness.

With much appreciation for your consideration,

Lisa Pasternak

## Melissa Weipert

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**From:** marybesson <marybesson@yahoo.com>  
**Sent:** Tuesday, September 25, 2018 7:04 PM  
**To:** Melissa Weipert  
**Subject:** HB 5035 and HB 5036

September 25, 2018

I am writing to support HB 5035 and HB 5036. I have personally met and spent time conversing with Claire McMann while she visited her grandmother Dee Payment.

Claire's mother Megan McMann must always be in Claire's vision field or Claire will panic while she frantically searches for her mom. Claire will speak but not in detailed and long sentences and appears to be easily distracted.

Claire is a BEAUTIFUL young girl who unfortunately suffers from PANS and her life would dramatically improve with proper research and new treatments.

I support HB 5035 and 5036 and hope you will also support it and the possible changes it can make in lives of people with PANS.

Thank you,

Mary Besson

Sent from my Verizon, Samsung Galaxy smartphone

## Melissa Weipert

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**From:** Chrissy Thibodeau <cmt1607@yahoo.com>  
**Sent:** Tuesday, September 25, 2018 8:36 PM  
**To:** Melissa Weipert; gammicca@comcast.net  
**Subject:** PANDAS/PANS

Dear Members of House Health Policy Committee -

I am writing in a desperate support of HB5036 to establish an Advisory Council on PANDAS/PANS in the state of Michigan. We need awareness, but also much better quality in care to diagnosis and treatment options. Many are affected by this auto immune disorder and it needs to be set forth and acknowledged, as many individuals are suffering.

Additionally, I support HB5035 which will provide insurance coverage for proper diagnosis, along with any/all treatments deemed to be of medical necessity for any and all individuals suffering with this debilitating illness. Individuals have a right for their illness to be properly acknowledged and treated without prejudice.

I appreciate your consideration, many youths and adults are suffering.

Christine Gregoire  
12815 Sycamore Apt.1  
Southgate, MI 48195

## Melissa Weipert

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**From:** Wally P <wl\_adju47@hotmail.com>  
**Sent:** Tuesday, September 25, 2018 9:01 PM  
**To:** Melissa Weipert  
**Subject:** I am writing in support of HB5036

Dear members of the House Health Policy Committee,

I am writing in support of HB5036 to establish an Advisory Council on PANDAS/PANS in the state of Michigan.

My Grandson was affected by Pandas/ Pans . He is currently being treated for it. It has been hard to watch my grandson go through it.

It has affected him physically and mentally. It also has taken years for him to be diagnosed and treated. It's painful to know he has been suffering needlessly because of the lack of education on Pandas and insurance coverage.

Please consider supporting HB5035I which will provide insurance coverage for diagnosis and treatment deemed to be a medical necessity for an individual suffering with this debilitating illness.

Walter Piwok

21956 Camille Ct.

Woodhaven, Mi

48183

## Melissa Weipert

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**From:** Aarti Toth <aarti.toth@gmail.com>  
**Sent:** Tuesday, September 25, 2018 9:51 PM  
**To:** Melissa Weipert  
**Cc:** Meaghan McCann  
**Subject:** PANDAS/PAN

Dear Members of the House Health Policy Committee,

I am writing in support of HB5036 to establish an Advisory Council on PANDAS/PANS in the state of Michigan. The children and families affected by this horrible illness deserve proper access to diagnoses and treatment. Furthermore, I support HB5035 which will provide insurance coverage for diagnosis and treatment. PANDAS/PANS is a disease that requires treatment so children and their families can live a normal life. If a person has diabetes, insurances covers the tests that lead to diagnosis and life long treatment. So why should a child with PANDAS/PAN be denied proper access and treatment?

I have seen this debilitating illness affect my daughter's friend, Claire Laginza and her mother's life tremendously. Since the onset of PANDAS/PAN, Claire's life has been turned upside down and her childhood has been ruined. She has been unable to attend school on a regular basis, sometimes missing months at a time, lives in fear that something awful will happen to her family and has to be in the presence of her mom at all times due to fear of harm. She has missed out on the childhood experiences of sleepovers and "hanging" out with friends. Her mom, Meaghan McCann has been an amazing advocate for her daughter and others suffering from PANDAS/PAN. However, she has given up her life due to the effects it has had on Claire. She is no longer able to work, go out with friends or be away from Claire for any amount of time.

Thank you for your time and your consideration,

Aarti Toth  
Plymouth, MI

## Melissa Weipert

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**From:** larry secord <shamroc2@att.net>  
**Sent:** Tuesday, September 25, 2018 10:01 PM  
**To:** Melissa Weipert  
**Subject:** Pandas

I understand there is a hearing today in regard to Pandas/Pans I have a granddaughter who suffers from this and our family would greatly appreciate any help from the legislators to pass this bill. Sincerely Carol Secord, 50 Lisa Circle, White Lake, MI 48386

## Melissa Weipert

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**From:** KATHY DOUGHERTY <mrsdonut@comcast.net>  
**Sent:** Tuesday, September 25, 2018 10:13 PM  
**To:** Melissa Weipert  
**Subject:** Letter to House Health Policy Committee

Dear Members of the House Health Policy Committee,

I am writing to you because I have met several Michigan parents who have a child diagnosed with PANDAS/PANS. I strongly support and urge you to support HB5036 that would establish an advisory council in Michigan for these pediatric disorders. I also support HB5035 that addresses insurers and insurance coverage for certain pediatric disorders.

This legislation would really help families with PANDAS/PANS patients. Sometimes these families have to travel out of state for therapy and medical treatment. They almost always have to pay out of pocket to get care for their children.

Thank you for your consideration,

Kathy Dougherty  
2477 Waltham Dr  
Troy, MI 48085  
248-457-0449



September 24, 2018

Dear members of the House Health Policy Committee,

I am writing to you on behalf of my family, specifically on behalf of my 5.5-year-old son Simon, in support of HB5036 to establish an Advisory Council on PANDAS/PANS in the state of Michigan. We support this bill as Simon suffers from a neurological disorder that resembles PANDAS/PANS in both presentation and treatment. We also want to express our support for HB5035 to help families access the proper diagnosis and treatment for their children and to ensure that insurance will cover these life-saving treatments and diagnoses. I hope you will take the time to read my son's story to see why these bills are so crucial for the children of our state.

Simon was born a healthy, perfect little boy. The first two years of his life we watched him achieve all of his milestones and even excel in some of them. He had a slight speech delay, however his pediatrician seemed entirely unconcerned. It wasn't until age 2.5 when we became concerned that he was able to say something one day and the next day he couldn't. We involved our local Early On program and they determined that Simon had a mixed expressive-receptive speech delay and we started speech therapy. He was making steady progress until December 2015, when he was one month shy of turning 3. Our world came crashing down as seemingly overnight our sweet little boy began to change. He stopped sleeping, he couldn't make eye contact anymore, wanted to be alone all the time, stopped making any attempts at verbal communication, and stopped playing with his toys appropriately. He was hyper, impulsive, lacked focus. The words he had left turned to stutters and then turned into gibberish. Over a period of ten months our 3-year-old boy regressed into moderate to severe autism in front of our eyes. We got him diagnosed with ASD, started therapy as suggested, and nothing helped. We were heartbroken.

In January 2016, when Simon turned 4, we finally got into see a local neurologist who heard Simon's story and suggested an alternative diagnosis of Landau Kleffner Syndrome. This diagnosis is characterized by regressive aphasia in children or the loss of language. It is a devastating syndrome and has no known cause. Shortly after hearing this possibility Simon had his first overnight EEG and we discovered that he had one of the primary characteristics of LKS, a pattern known as ESES or electrical status epilepticus of sleep on his EEG for approximately 65% of the night. This meant that for over half the night, our little boy's brain was seizing while his body appeared to be sleeping. As a pediatric nurse, I know what a seizure in a child looks like. I couldn't believe that as a mother, I didn't see it in my own child. It was devastating news for our family.

We began to treat the ESES with the recommended medication from our doctor and his EEG began to improve, however our son wasn't doing any better cognitively. He continued to regress in front of our eyes. The little boy that once loved books and the alphabet, couldn't even look at a book properly anymore. He remained completely nonverbal and was still struggling to sleep properly. He looked malnourished with dark bags under both eyes and had actually lost weight over the time period of regression. I began to speak with parents of children like Simon all around the world via a family support group on Facebook and discovered the best results were being obtained through a treatment combination of anti-epileptic medication, high dose steroids, and a medication known as IVIG or intravenous immunoglobulin. Interestingly, this treatment contains two of the main components of the

treatment for PANS/PANDAS and it is essentially the same treatment as AE or autoimmune encephalitis. As it turns out, many of the kids with ESES who struggle to see improvements are now being treated as if they have AE.

We begged our doctor to adjust treatment and we finally convinced her to start the high dose steroids. Our son began to improve! We realized that he understood every word we said and we began to see glimpses of the little boy we lost at age 3. It wasn't enough to bring back his speech and we were referred to one of the best epilepsy centers in the world, Cleveland Clinic. They started a new anti-epileptic medication and he improved even more, but once again the speech didn't come. Our new neurologist, a leading expert on ESES and LKS said our boy needs IVIG and it was ordered this past summer. I know from speaking with other parents that this is the med that changed their families lives. That for some kids (not all) it was the sole treatment that bought back language. But just like that, our hopes have been dashed yet again. Just last week I spoke with the insurance company who explained that our request was denied after the third appeal as it is still considered experimental by the FDA. I feel like the insurance company is giving up on my child. I understand the cost of IVIG is incredibly high, but the cost of lifelong care for a nonverbal individual is significantly higher. Once again, we are completely devastated in this journey. Our country is in dire need to recognize the importance of treating children like my Simon and all the other kids out there like him. Our stories are all different and yet they are all the same. Every parent deserves the opportunity to watch their child succeed in life. Please allow Michigan to become one of the leading states in helping children like mine.

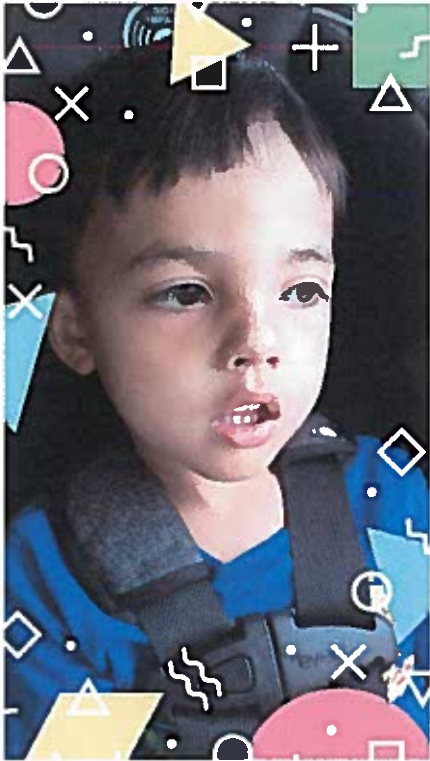
Sincerely,

Amanda Valenzuela

805 Forestdale Road

Royal Oak, MI 48067

582-258-8930



## Melissa Weipert

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**From:** Joe Ferullo <joeferullo@gmail.com>  
**Sent:** Tuesday, September 25, 2018 10:34 PM  
**To:** Melissa Weipert  
**Cc:** gammicca@comcast.net  
**Subject:** HB5036

Dear members of the House Health Policy Committee,

I am writing in support of HB5036 to establish an Advisory Council on PANDAS/PANS in the state of Michigan. Additionally I support HB5035 which will provide insurance coverage for diagnosis and treatment for an individual suffering with this debilitating illness. I vote in every election, and i will be paying attention to the voting record on this issue.

With much appreciation for your consideration,

Joe FERULLO  
25991 Rogell  
New Boston, Mi 48164

## Melissa Weipert

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**From:** Mom Argy <stefargy@gmail.com>  
**Sent:** Wednesday, September 26, 2018 12:08 AM  
**To:** Melissa Weipert  
**Subject:** Letter to support HB5036

Dear members of the House Health Policy Committee,

I am writing in support of HB5036 to establish an Advisory Council on PANDAS/PANS in the state of Michigan. I'm doing so because not only do we need better awareness, but access to diagnosis and treatment for those affected. Additionally I support HB5035 which will provide insurance coverage for diagnosis and treatment deemed to be a medical necessity for an individual suffering with this debilitating illness.

With much appreciation for your consideration,

Stefanie Argy

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Stefanie Argy

## **Melissa Weipert**

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**From:** Lori Barnes <lorilou2121@yahoo.com>  
**Sent:** Wednesday, September 26, 2018 5:36 AM  
**To:** Melissa Weipert  
**Subject:** Pandas/Pans Bill

Melissa Weipert

I have a family member - grand daughter - formally diagnosed with Pandas! She is struggling to get better. It is so very important this bill is passed . Thank you so much Sent from my iPhone

## Melissa Weipert

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**From:** Jamie Richey <jamiem1205@gmail.com>  
**Sent:** Wednesday, September 26, 2018 6:08 AM  
**To:** Melissa Weipert  
**Subject:** Please support HB5036 and HB5035

To The Members of the House Health Policy Committee,

I would like to ask that you please support HB 5036, we do and this is why it is important for an Advisory Council to be formed.

I would like to begin by telling you a little bit about my son. Born in December of 2004, Kaden has always been a loving, interesting, smart little boy. As a child he spent most of his time playing with Trains, watching Thomas the Tank Engine, and playing outside. In his grade school years he had some difficulties with social interactions and cues, which led to a diagnosis of Asperger's syndrome. Health wise, Kaden suffered from childhood asthma, numerous environmental allergies, and endless cases of bronchitis. As he has grown, much of these issues have disappeared. Asthma subsided when he was around 11 years of age, although the environmental allergies continued. In the summer of 2017 (age 12), we decided to try allergy injections for Kaden. He had three injections once a week for around 20 weeks, without much reaction to them until towards the end, when he began to develop small welts from them. In early October 2017, he got his annual flu shot, which we have never had a problem with before. Around two weeks later, Kaden complained of a sore throat. I took him to our family physician as I had always done, they swabbed him for strep, it was negative. The culture they ran was also negative, so treatment was not given for Kaden's sore throat.

On October 27th, 2017 our lives were turned upside down. Kaden's counselor at his school called and stated that Kaden had told another student that he wanted to kill himself. I thought there must be some mistake...my son has never expressed any of these types of feelings, even in a joking manner...they must have the wrong kid. I immediately went to the school and picked him up. They recommended us to take him to the ER, for further evaluation. We went to the ER, where my son continued to express thoughts of wanting to slit his throat, write letters to his friends to say goodbye, he didn't feel like he should be alive anymore. Consequently, my son spent 5 days inpatient at a psychiatric hospital. Upon his release, we had an appointment with his physician at the center where he was being followed for his Autism diagnosis. The nurse practitioner there promptly asked if he had been sick. I mentioned the sore throat he previously had, and you could see a light bulb go off. She ordered labs and put Kaden on an antibiotic. She explained to me what PANDAS is, and said she believes this is what happened to Kaden. (When the labs returned, Kaden's streptococcal titers were very elevated, indicating he did in fact have a recent strep infection). We also added some supplements and vitamins to help with Kaden's immune system.

Over the next few weeks we had ups and downs with Kaden. School was a huge struggle, he refused to attend his classes (which had never previously been an issue), he hid in the bathroom for large lengths of time, and still expressed some suicidal thoughts here and there. We spent days and nights on edge, we locked up every knife and possible item he could harm himself with, we barely slept for fear he would wake in the night and be alone. I missed days and days of work due to school refusal, and the difficulties he had staying in classes and completing work. He spent another 9 days in an outpatient psychiatric program. He had severe irrational thoughts, he worried about starving to death, he worried about people coming into our home and killing him in the middle of the night. There were nights where he cried to me, mom please take me back to the hospital, I don't want to feel this way anymore, I just want to end it all. He could not explain WHY he felt the way he did, he just did. As a parent, it was the most heart wrenching awful thing to watch...and there was nothing I could do to help him. After 3 months of ups and downs, we ran more blood work which showed his strep titers had actually elevated instead of decreasing the way they should have. We changed antibiotics and added a steroid burst to help with the inflammation on Kaden's brain. Slowly but surely, the suicidal and irrational thoughts began to disappear. My son became happier and more able to function.

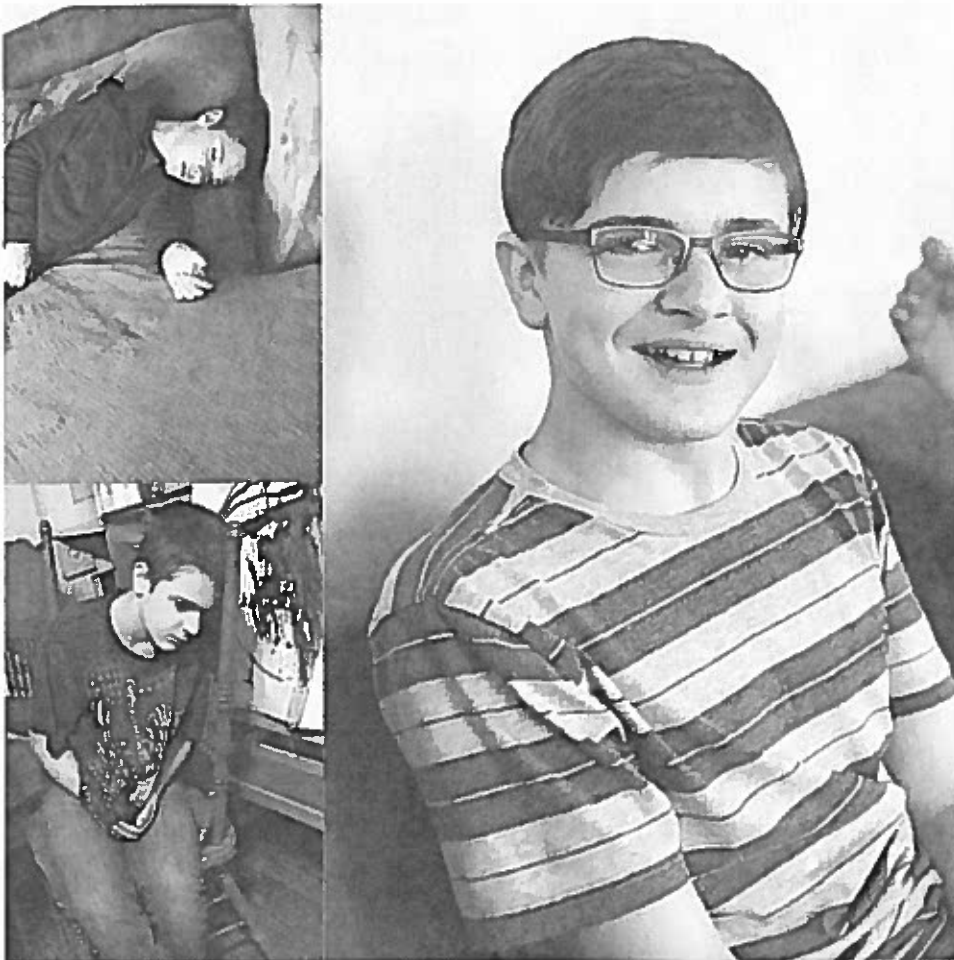
Today, almost 1 year post PANDAS diagnosis, I look back and think how lucky we were that Kaden was diagnosed and treated as quickly as he was. I can only imagine how badly things could have turned out had he not been. I could have lost my son because of the suicidal thoughts caused by the inflammation on his brain. I cringe to think how many children the world HAS lost due to inflammation on their brains, which went

undiagnosed. How many people in psychiatric hospitals actually had an infection that went untreated and caused their mental illness? What if my son was only treated with psych meds and continued to get worse? We could save so many people, if we open our minds and think about the possibility of bacterial and/or viral infections causing damage to the brain. Strep can cause rheumatic fever which is inflammation of the heart, blood vessels and joints...why is it so hard to believe that it can cause inflammation on the brain as well? This illness is real, and the world cannot wish it away. People are suffering and dying because of it. My son happens to be one of the success stories of what the outcome can be for a child diagnosed and treated quickly. Kaden has absolutely no thoughts of suicide or self harm anymore, the only thing he worries about is when he can play his xbox or call his friends again. He is a healthy, happy, 13 year old boy who has the rest of his life ahead of him!!!! And I owe that in full to the nurse practitioners and doctor who believed, and followed their gut (and the science) and treated my son for brain inflammation. I pray that other physicians will do the same, and save many many other children from this awful illness.

Thank you for taking the time to read this. I have enclosed some photos of my son before and after our journey through PANDAS.

Sincerely,

Jamie and Eric Richey





September 24, 2018

Chair Hank Vaupel  
Vice-Chair Jim Tedder  
Representative Joseph Graves  
Representative Daniela Garcia  
Representative Jason Sheppard  
Representative Julie Calley  
Representative Diana Farrington  
Representative Roger Hauck  
Representative Pamela Hornberger  
Representative Bronna Kahle  
Representative Jeff Noble  
Representative Winnie Brinks  
Representative LaTanya Garrett  
Representative Sheldon Neeley  
Representative Jim Ellison  
Representative Abdullah Hammoud  
Representative Kevin Hertel

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

My name is Mary Rose Crombez, and I am writing in support of HB 5036. I was diagnosed with PANDAS/PANS when I was 7 and I have been struggling with the chronic, lifelong symptoms ever since. Throughout my time actively dealing with PANDAS/PANS, my symptoms have worsened, improved, and changed in many ways, but daily symptoms still remain. I have done many different treatment methods, diet changes, life style accommodations, etc. to help and nothing individually or combined have gotten my symptoms down to baseline and nothing probably ever will. PANDAS/PANS is something that I will live with, deal with, fight, and cope with every day for the rest of my life. Not a day goes by where I don't struggle, where I don't think about what PANDAS/PANS has taken and will take away from me. For years, I was so sick that I could not go outside of the house, could not wear clothes, could not/didn't eat, didn't sleep, and had to live with constant anxiety, OCD, depression, sensory sensitivities to touch and sound, muscle pain, joint pain, fatigue, body weakness, and foggy brain and cognitive issues. In the past 5 or so years, I have gotten to the point where I can cope with my daily symptoms and live a fairly typical life of a 20 year old, but each day comes with symptoms and struggles, not necessarily less than what they once were, but controllable based on

the abilities I have gained over the years and the want to fit in and live as much of a normal life as possible.

My past struggles with PANDAS/PANS is not something that I like to relive in order to bring awareness to what can be but doesn't have to be such a debilitating chronic illness. It took me weeks to bring myself to write this letter because of the heartache it puts me through to have to remember what my brain has purposely forgotten. I don't remember about 3 years of my life because my brain blocked those memories from being formed in the first place and some of it, I have chosen to forget. So rather than going over the past impact that PANDAS/PANS has made on my life, I am focusing on the present and future. I could easily write you a sob story about how PANDAS/PANS is an awful condition that takes away children's childhoods, teens' will to live, and many adults' full potential. I could make you cry and feel and be amazed at what I have gone through to get to the capable, functioning point I am at now but I can't personally do that. Not because the story does not exist but simple because it is too horrendous for me to think about, write down, and put myself through again.

Rather, I would like you to know that these children, with proper treatment and care can relieve their symptoms enough and learn the proper coping skills to handle their chronic illness in day to day life and become active members of society. Without access to proper testing, treatment, and acknowledgment that PANDAS/PANS exists and it is not all in their head, these children will need additional, lifelong care, potentially never being able to function on their own.

Another thing that the medical community, government, and families have not yet addressed is the chronic impact that these children will have on society in the future. Even though the symptoms can be managed and greatly reduced, we have no knowledge of what will happen as these children age, start their own families, and then eventually enter the elderly population. This is something that will need to be considered and addressed. However, the current need is for proper diagnosis, care, and treatment of these children while young and when first presenting with symptoms, as it seems that the quicker the diagnosis and starting treatment, the quicker the recovery and greater ability for the child to have less complications and return to baseline abilities. Proper treatment and care will in turn lessen the negative effect of these children on the medical system, economy, and overall community. Once awareness and acknowledgement of PANDAS/PANS exists, and proper diagnosis and care is given to those living with it daily, we can then address the long term effects and how best to manage them. But for now, please help us support awareness and treatment of PANDAS/PANS and the families affected by it by supporting HB 5036.

Sincerely,

Mary Rose Crombez

## Melissa Weipert

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**From:** Dino Caverson <caversons5@sbcglobal.net>  
**Sent:** Wednesday, September 26, 2018 8:21 AM  
**To:** Melissa Weipert  
**Subject:** HB5036

Dear Members of the House Health Policy Committee,

I am writing to express my support of HB5036 to establish an Advisory Council on PANS/PANDAS in the state of Michigan. I am doing so because better awareness and access to diagnosis and treatment is crucial for those who are impacted by PANS/PANDAS. I support HB5036 as it will provide insurance coverage to cover diagnosis and medically necessary treatment for individuals battling this terrible illness.

Thank you for your time and consideration!

Sincerely,

Heather Caverson  
32086 Avondale St.  
Westland, MI 48186

## Melissa Weipert

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**From:** AMY KOZLOWSKI <amyjkoz@gmail.com>  
**Sent:** Tuesday, September 25, 2018 9:23 PM  
**To:** Melissa Weipert  
**Subject:** HB5036 & HB5035  
**Attachments:** Screenshot\_20180925-211505\_Facebook.jpg; IMG\_5807.3gp

Dear members of the House Health Policy Committee,

My name is Amy Kozlowski and my son Alex at the age of 10 was a very outgoing child, lots of friends, enjoyed school and of course gym was his favorite class and played basketball. That winter he was severely sick with pancreatitis and strep throat and has never been the same. He's now been diagnosed with severe depression and anxiety with suicidal ideation. His hair has fallen out and he picks at himself. He's unable to shower only once a week. Only eats double hamburger with ketchup from McDonalds everyday which is something because many children have to have a nasal gastric tube for nutrition. I had to pull him from school in 5th grade because he was unable to leave the house which is still the case. I had no support from school only threats. No one even knew of this disorder. I was being blamed for his behavior not only by school officials but also from family. He just turned 12 and should be in 6th grade however remains at home. He has regressed significantly in his math and ELA. His psychiatrist has officially diagnosed him with PANDAS just this 9/11. I'm a single mom who is an RN. I'm writing in support of HB5036 to establish an Advisory Council on PANDAS/PANS in the state of Michigan. I'm doing so because not only do we need better awareness, but access to diagnosis and treatment for those affected. Additionally I support HB5035 which will provide insurance coverage for diagnosis and treatment deemed to be a medical necessity for an individual suffering with this debilitating illness. Without insurance coverage I will not be able to financially receive treatment for Alex and I want my Alex back!

With much appreciation for your consideration,

Amy Kozlowski, RN  
2465 Johnson Mill Rd  
North Branch, MI 48461

The 1st picture is before illness playing basketball. The 2nd is a 35 sec video of Alex following his strep illness. Please say you see a need for help for us parents.



100% 9:15 PM



Crop

DONE

To:  Public

