

Melissa Weipert

From: HEATHER HULL <redwingheather14@yahoo.com>
Sent: Monday, September 17, 2018 8:39 PM
To: Melissa Weipert
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. 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,

340 Basket Branch
Oxford, MI 48371

Heather Hull
Redwingheather14@yahoo.com
248-818-0239

Melissa Weipert

From: Denise Skipinski <dmskipinski@yahoo.com>
Sent: Tuesday, September 18, 2018 12:07 PM
To: Melissa Weipert
Subject: HB5035 & HB5036

Dear members of house health policy committee,

Supporting bills HB5035 & HB5036 would help with diagnosing, treatment and needed awareness of those debilitating disease along with insurance coverage to help effected patients.

Thank you for listening.
Denise Skipinski

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 feel strongly about this because not only do we need better awareness, but access to diagnosis and treatment for those affected. I personally have a family friend who was diagnosed with PANDAS/PANS and I witnessed them go through many doctors and treatments because medical professionals were unaware of the disease and/or did not know how to treat it. I believe if they did this family would not have had to suffer the way they did. 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,

Rosie Randazzo

1714 Alsdorf

Rochester Hills, MI 48309

A handwritten signature in black ink, appearing to read "Rosie Randazzo", with a stylized, flowing script.

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...>

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\(reuvib1m05f0224o3s4kp1xb\)\)/mileg.aspx?page=GetObject&objectname=2017-HB-5035](http://www.legislature.mi.gov/(S(reuvib1m05f0224o3s4kp1xb))/mileg.aspx?page=GetObject&objectname=2017-HB-5035)

Andrea Koppa
7124 N. Kerby Rd.
Owosso, MI 48867
989-743-8367
atkoppa@hotmail.com

September 18, 2018

Re: Support of HB5036

Dear members of the House Health Policy Committee:

I am writing in support of the HB5036 to establish an Advisory Committee for PANDAS/PANS in Michigan. We are in need of more awareness for treating physicians and mental health providers for proper diagnosis of those affected by this illness.

I also support HB5035 which will provide insurance coverage with those affected by PANDAS/PANS. Insurance coverage is crucial for proper care and treatment of those affected.

Thank you for your time and consideration,


Andrea Koppa

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

From: L. Heugh <lheugh@yahoo.com>
Sent: Tuesday, September 18, 2018 4:23 PM
To: Melissa Weipert
Cc: denisechampine@yahoo.com
Subject: HB5035 & 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,

Larry & Judy Heugh
2046 Applewood Dr.
Troy, MI 48085

September 18, 2018

Dear members of the House Health Policy Committee,

I'm writing to you to express my support of bill HB5036 to establish an Advisory Council on PANDAS/PANS in this great state of Michigan. I'm doing so because as a special education teacher in one of the largest districts in the state of Michigan I believe I have a duty to help bring awareness, access, and effective diagnosing, and accessible treatment for all the children that have been afflicted with this terrible disorder. It has come to my attention that families and children are continually misdiagnosed within the health care and mental health communities in Michigan. I believe if the state forms an advisory committee many children will benefit from their research as well as medical and mental health care providers.

I would also like to show great support for bill HB5035 which would assist insurance companies in supporting the diagnosis and treatment of PANDAS/PANS with IVIG treatment which has direct medical studies that show its effectiveness. If you require further explanation regarding my support for either of these bills; please do not hesitate to contact me. Also, I have attached some links with a useful website with information on PANDAS/PANS and a journal article from the Journal of Child and Adolescent Psychopharmacology. Thank you in advance for taking the time to understand and support the necessity of both bills HB5036 and HB5035.

Sincerely,

Catherine Schreiber-Crottie

368 E. Baker Ave.

Clawson, MI 48017

248-259-2993

<http://www.pandasnetwork.org/understanding-pandas/pans/ivig/>

https://www.liebertpub.com/toc/cap/25/1#utm_source=ETOC&utm_medium=email&utm_campaign=cap

September 18, 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 Honorable Health Policy Committee Chair and members:

We need HB 5035 and 5036 to become law. My son Aubrey Sebastian Woodard, age 7, is a brilliant, sweet, creative, and funny little boy. I would put him in the car and he would say in his little boy voice, "Happy, happy!" His first joke, at age 2 went like this:

- "Aubrey, you are trouble with a capital T," said me, his mother, with a grin. "No I'm not!" he exclaimed. "I'm trouble with a lower case t."

He loved to climb, run, jump, and go to music classes. We would have full conversations about the planets and their moons. He would want me to read 4, 5, 6 books a day to him, and would correct us if we missed a word. He was reading by himself by three, and reading chapter books by age 5.

Everything about him changed after an illness in 2014. Our happy, curious, and sweet boy who would smother us with hugs and kisses became a very different child. The boy would wake up screaming in terror. He started hitting, acting out, becoming very angry. He stopped eating and lost weight. He was learning how to write and suddenly became very anxious about it. It took us a year to finally get a diagnosis: PANS. Pediatric Acute-onset Neuropsychological Syndrome. After our first bout with it, and five months of antibiotics, he started to come back to us. Then he got another illness around Thanksgiving and developed a debilitating bout of OCD in which he clenched his hands into fists and would chant "sluck-sluck-sluck/chchch from the time he got up in the morning until he went to sleep at night. He finally told us that he was afraid if he opened his hands, "something bad would happen to the family" and the chants were to "keep the evil away." Thousands of dollars we shelled out of pocket to try to find answers for him. Once we were able to beat that OCD, he developed yet another illness that settled into his olfactory nerve

and attacked his sense of smell. It was so acute, we could barely leave the house because everything was overwhelming to him.

I could tell you story upon story like this. We have been unable to consistently attend school. Every time he gets an illness, another symptom shows up. Currently, he is battling intrusive thoughts and cannot stop pacing the floor with his "great ideas."

We still see through the anxiety, rage, OCD, ODD, and Tourette's and see our little sweet boy who would say "Happy, happy!" and sing Paul Simon songs until he exhausted himself. Now he loves The Beatles. We are trying brick-and-mortar school this year, but the anxiety is already rearing its head, and we have low confidence if he will be able to continue in the long term. But every day we wake up and fight for this boy.

I haven't mentioned yet that we have another son. As of now, he has not developed PANS/PANDAS, but a neurologist we used to see said he has a similar immune profile and one illness could tip the scale.

I am writing that you fully support HB 5035 and 5036. Our sons' lives could very well depend on it.

Kind regards,
Jennifer Russell & Glenn Woodard
Detroit 48219



Melissa Weipert

From: Lisa Meyer <lisameyer1975@yahoo.com>
Sent: Tuesday, September 18, 2018 8:39 PM
To: Melissa Weipert
Cc: gammicca@comcast.net
Subject: HB5036

To House Health Policy Committee:

I am writing in support of HB5036, to form a state advisory panel related to diagnoses of PANDAS. This diagnosis is understudied and under diagnosed due to lack of research, and it is poorly treated due to a lack of health insurance companies covering the needed treatment. The passage of HB5036, along with its companion bill, HB5035, will ease the financial burden faced by families whose children have PANDAS as well as adults who suffer from the symptoms. I have a close friend who struggles to cover the costs of the treatments her sons need—and none of it is covered by her medical insurance. Thank you for your consideration of these bills.

Sincerely,
Lisa Meyer, LMSW
848 Mountview Rd
Lapeer, MI. 48446

Sent from Yahoo Mail for iPhone

Melissa Weipert

From: jacqueline martin-sebell <jacquelinemartinsebell@yahoo.com>
Sent: Tuesday, September 18, 2018 10:29 PM
To: Melissa Weipert
Subject: Letter in support of HB5035 and HB5036
Attachments: mikey sick.jpg; zack sick2.jpg

Dear members of the House Health Policy Committee,

I am writing to show my support of HB5036 which would establish an Advisory Council on PANDAS/PANS in the state of Michigan. I'm in favor of this because of several reasons; including better awareness of PANDAS/PANS, and also better access to diagnosis and treatment for those affected by the disorders. I want to show my support HB5035 as well, which will provide insurance coverage for diagnosis and treatment determined medically necessary for an individual suffering with one of these disorders.

As a mother to three children who have been diagnosed with PANDAS/PANS, I know firsthand the pain these disorders cause! My children are now 13, 14, and 18 and have spent many years suffering because of PANDAS/PANS. We have spent many weeks/months inpatient in the hospital, bedridden, and home bound because of the symptoms and illness due to PANDAS/PANS. We have spent months trying to get insurance coverage for things that have been shown to benefit my children, only for insurance to stop paying for it (for example, IVIG). Beyond the mental and physical pain these disorders cause, they cause many other things as well! The PTSD and emotional turmoil, the stress, and the financial burden these disorders bring; not just for the individual with the disorder but the entire family, is huge! This difficulty transfers to all areas of life; home, school, and the community!

Educating family, friends, community, and school has been very difficult, time consuming, and exhausting! Finding adequate care by medical professionals who understand the disorders is nearly impossible. Finding the money to pay for treatment, much of which has been shown through research to medically help individuals with PANDAS/PANS but which is still not often covered by insurance, is practically non-existent. Too often, kids (and adults) are left struggling on their own. One parent (and as a single mom, that means me) often have to stop working to care for the child full time. More and more kids are falling through the cracks. Untreated PANDAS/PANS can lead to a number of things due to the symptoms it brings. These can include a life time of mental and physical pain, jail time, and suicide. The difference in proper treatment/support vs none is incredible and too often the difference between life and death!

Families need help! These bills provide a great start to providing families in Michigan with this much needed help!

This links to a video of my youngest son, then age 11, in a PANDAS flare. Proper treatment for him is the difference between all over body (legs, mouth, vocal) tics/nonstop coughing/severe anxiety (unable to leave my side/homebound) and none of the above.

[https://video-ort2-1.xx.fbcdn.net/v/t42.1790-](https://video-ort2-1.xx.fbcdn.net/v/t42.1790-2/14246048_1202759919786239_2017395682_n.mp4?nc_cat=0&vs=ccc94d6a78819282&nc_vs=HBksFOAYJEdLQmcyUUQtMk1SZDUwVUVBT0lEUDNnOUFBQUFidjRHQUFBRhUAABUAGCRHRXBtMIFBdW9pOWI1MFVFOUdUUUN4OUFBQUFBYnY0R0FBQUYVAgBLAogPdXNIX2Rpc3RyaWJldGVkATAeZGJldHJpYnV0ZWRFY2h1bmtfZHVyYXRpb25fc2VjAjYwFOAAGA8xMDAwMDE1NjcyNzgxmTMWlq%2Fnwtz5ogQVAhkFGAJDMxgLDnRzX3ByZXZpZXccF0A5iTdLxqfwGClkYXNoX3YzXzEyODBFY3JmXzIzX2)

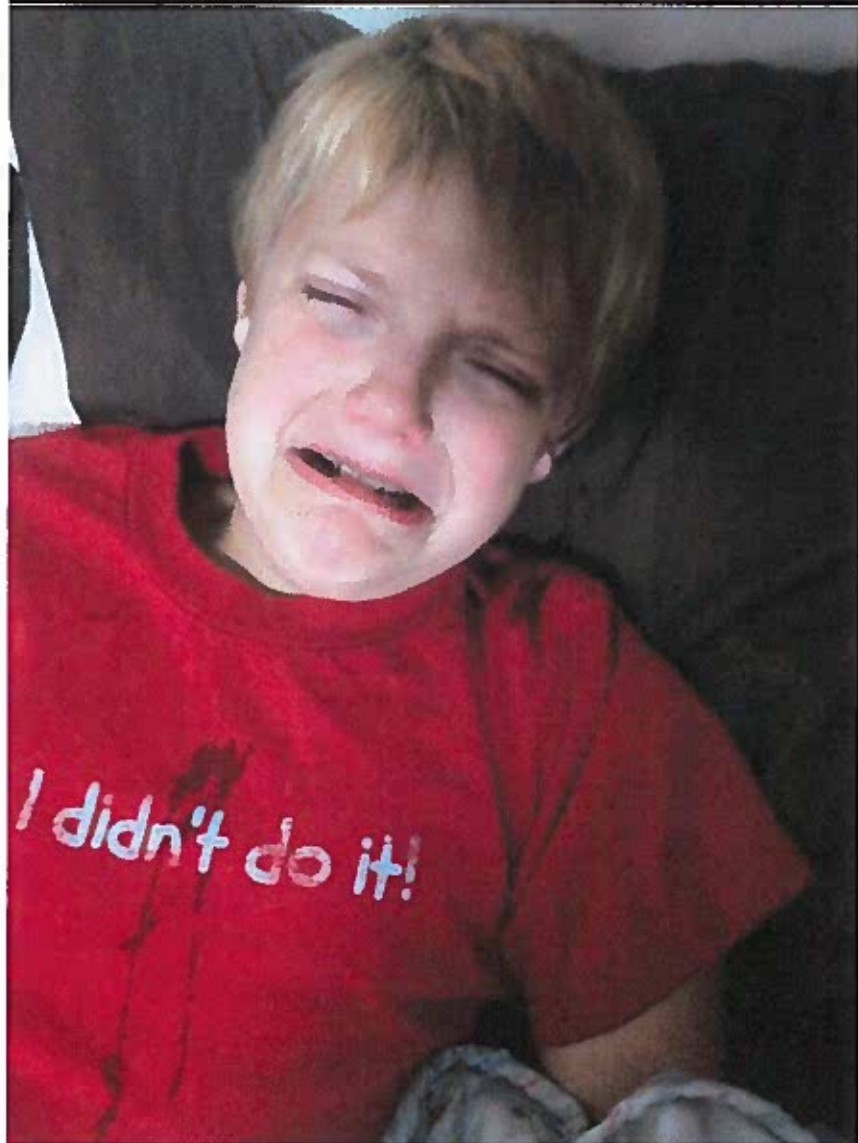
[2/14246048_1202759919786239_2017395682_n.mp4?nc_cat=0&vs=ccc94d6a78819282&nc_vs=HBksFOAYJEdLQmcyUUQtMk1SZDUwVUVBT0lEUDNnOUFBQUFidjRHQUFBRhUAABUAGCRHRXBtMIFBdW9pOWI1MFVFOUdUUUN4OUFBQUFBYnY0R0FBQUYVAgBLAogPdXNIX2Rpc3RyaWJldGVkATAeZGJldHJpYnV0ZWRFY2h1bmtfZHVyYXRpb25fc2VjAjYwFOAAGA8xMDAwMDE1NjcyNzgxmTMWlq%2Fnwtz5ogQVAhkFGAJDMxgLDnRzX3ByZXZpZXccF0A5iTdLxqfwGClkYXNoX3YzXzEyODBFY3JmXzIzX2](https://video-ort2-1.xx.fbcdn.net/v/t42.1790-2/14246048_1202759919786239_2017395682_n.mp4?nc_cat=0&vs=ccc94d6a78819282&nc_vs=HBksFOAYJEdLQmcyUUQtMk1SZDUwVUVBT0lEUDNnOUFBQUFidjRHQUFBRhUAABUAGCRHRXBtMIFBdW9pOWI1MFVFOUdUUUN4OUFBQUFBYnY0R0FBQUYVAgBLAogPdXNIX2Rpc3RyaWJldGVkATAeZGJldHJpYnV0ZWRFY2h1bmtfZHVyYXRpb25fc2VjAjYwFOAAGA8xMDAwMDE1NjcyNzgxmTMWlq%2Fnwtz5ogQVAhkFGAJDMxgLDnRzX3ByZXZpZXccF0A5iTdLxqfwGClkYXNoX3YzXzEyODBFY3JmXzIzX2)

hpZ2hfMy4xX2ZyYWdfMl92aWRlbnwAYGHZpZGVvcy52dHMuY2FsbGJhY2sucHJvZBkcFQAVvJkCABg
Gb2VwX2hkGBJWSURFT19WSUVXX1JFUVVFU1QbAYgTb2VtX3JlcXVlc3RfdGltZV9tcw0xNTM3MzEz
NzQ2NjQzAA%3D%3D&efg=eyJ2ZW5jb2RlX3RhZyI6Im9lcF9oZCJ9&oh=4a19fbfa25276a5a5206ce6b0707
3fb7&oe=5BA1AE4C&_nc_rid=e2735a7cbf80b1a&dl=1

Thank you for your consideration!

Jackie Martin-Sebell

2609 Vanness Street
Port Huron, MI
48060



Melissa Weipert

From: Sheri Camp <sheri.camp82@gmail.com>
Sent: Tuesday, September 18, 2018 10:55 PM
To: Melissa Weipert
Subject: PANDAS

September 18, 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,

Our son, Charlie, is 8 years old. He has PANDAS. He is a bright, funny, outgoing child, but PANDAS has taken a lot of that away from him. Our son's brain is inflamed.

He started with long meltdowns, OCD traits and defiance at age 2. At age 5, he began having tics in his face, chest & stomach. His level of defiance and anger became stronger. There were many days were I would have to pick him up from school because they did not have the resources or education on how to de-escalate him.

We are still in the middle of fighting PANDAS. He continues to have elevated Strep titers despite antibiotic treatment, as well as constant viral and sinus infections. He is constantly worn down, yet his body is in fight or flight mode most of the day. He most likely will need IVIG treatment to heal his immune system.

Our battle with insurance has been huge. The treatments and doctors that Charlie needs are not covered. A good portion of my day is spent communicating with insurance & doctors. In the meantime, our son isn't

getting the help he needs. A good portion of treatments, so far, have been an out-of-pocket expense for our family.

Please consider helping our children. We are all suffering due to this condition.

Thank you for your consideration,

Matt & Sheri Camp
Holland, MI



Sent from my iPhone

Melissa Weipert

From: Apryl Cherry <apryljcherry@gmail.com>
Sent: Tuesday, September 18, 2018 11:42 PM
To: Melissa Weipert
Subject: HB5036 Letter of Support

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 increased awareness, but access to diagnosis and treatment for those affected. I have a friend who has two children affected with this illness. Her oldest daughter struggled daily with horrible anxiety, OCD, sensory issues, severe separation anxiety, loss of academic abilities, social regression, and so much more for years. The only reason that this child was able to get a definitive diagnosis of PANDAS/PANS is because her mother never gave up on her. No matter what. Everyone was telling her that her daughter was beyond help. That she was just going to be this way and to stop fighting so hard for a reason why her daughter was different now than she was when she was much younger. All the family, friends, neighbors, teachers, strangers, and all health care professionals that told my friend that she was delusional, that her daughter's issues were my friend's fault, or genetics, or untreatable mental illness, or any other horrible thing that they could think of are wrong. Doctors need more education on this illness. After this child's first IVIG treatment, the change I saw was remarkable. Like a switch had been flipped and I could see everything change in this little girl. She still needs regular treatments since she went so long without proper treatment, but she is just like a normal little girl now. She has friends, which she had lost due to social regression. She leave the house without issue, full dressed, which was so hard with the illness causing sensory issues with clothes and separation anxiety to not be with her mother. She talks to me when I am there, which she never was able to do before. It truly is amazing what happens to people when their illness is treated with proper medication.

My friend dealing with all of these issues with her child(ren) everyday for years with almost no help, no support, no definitive diagnosis, and little hope was something that no mother, no parent, should ever have to deal with.

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. This illness is extremely expensive to treat without proper insurance coverage and affects children, who obviously cannot pay for this treatment on their own. This puts parents in a terrible position of either allowing their child to suffer and continually get worse, or to dive deep into debt to try and save their children's future. With early diagnosis, treatments can be minimized and therefore cost minimized. As the full scope of this illness is starting to come to light, all the people's lives that could be changed for the better will make today's fight for the future all the more important.

I can only imagine how long PANDAS/PANS has actually existed and how many people that are no longer in pediatric care, but are adults, could potential have this illness and not even know it. How many people are taking handfuls of medication everyday to treat a whole list of symptoms/diagnosis that could be treated for PANDAS/PANS and no longer be disabled and start to be full functioning members of society? Education and insurance coverage is the best way to continue to move forward and treat people. Everyone deserves a future.

With much appreciation for your consideration,

Apryl Cherry

Melissa Weipert

From: C Gonyer <cindygonyer@gmail.com>
Sent: Wednesday, September 19, 2018 8:54 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. I'm doing so because not only do we need better awareness, but access to diagnosis and treatment for those affected including my son. 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,
Cindy Gonyer
5892 Robinson Rd
Petersburg, MI 49270

Melissa Weipert

From: Jkekhousa <jkekhousa@gmail.com>
Sent: Wednesday, September 19, 2018 10:28 AM
To: Melissa Weipert
Subject: HB5035 & HB5036

Dear members of the House Health Policy Committee,

I am writing in support of HB5035 which will provide insurance coverage for diagnosis and treatment deemed to be a medical necessity for an individual suffering with the debilitating illness of PANDAS/PANS. Additionally I support HB5036 to establish an Advisory Council on PANDAS/PANS in the state of Michigan. I strongly support the People's right to increased awareness of medical conditions and access to diagnosis and treatment for those affected.

Thank you very much for your consideration.
Sincerely,

Joelle Kekhoua
1318 E Horseshoe Bend
Rochester Hills, MI 48306

Melissa Weipert

From: Kathryn Butler <kathrynvbutler@gmail.com>
Sent: Wednesday, September 19, 2018 10:30 AM
To: Melissa Weipert
Subject: HB 5036

Dear Ms. Weipert,

It is my understanding that the State of Michigan House Health Policy Committee will have a hearing for September 26 to begin legislative efforts to ensure that children with PANDAS/PANS will receive medical care and treatment.

Please consider this email as an expression of my support for HB 5036 which will allow the formation of a PANDAS/PANS advisory council to increase the awareness of this illness among a variety of professionals and help children receive accurate diagnoses in a timely manner.

Thank you.

Kathryn Butler
1555 Wandrei Court
Commerce Township, MI 48382

Melissa Weipert

From: Nicole.matta <nicole.matta@comcast.net>
Sent: Wednesday, September 19, 2018 10:46 AM
To: Melissa Weipert
Subject: HB5036

Good Morning-

I am writing in support of Bill HB5036. A formation of an advisory council to increase awareness of PANDAS/PAN with professionals and help children receive accurate diagnosis in a timely manner is of great importance; my neighbor's son was lucky enough to be diagnosed even when the illness was practically unknown and treatment has changed his life.

Thank you-
Nicole Matta

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

September 19, 2018

Hon. Representative Hank Vaupel, Chair
Hon. Representative Jim Tedder, Vice-Chair
Hon. Representative Joseph Graves
Hon. Representative Daniela Garcia
Hon. Representative Jason Sheppard
Hon. Representative Julie Calley
Hon. Representative Diana Farrington
Hon. Representative Roger Hauck
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). PANS/PANDAS occurs when the immune system has a misdirected response to an infection, virus, or environmental toxin, which ultimately results in brain inflammation. The inflammation causes a variety of neurological and/or psychiatric symptoms that are life-changing and often debilitating.

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

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

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



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

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

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

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

Sincerely,

A handwritten signature in cursive script that reads "Joanna M. Gauthier".

Joanna M. Gauthier

Melissa Weipert

From: Dorene Schulte <SchulteD@aktpeerless.com>
Sent: Wednesday, September 19, 2018 10:54 AM
To: Melissa Weipert
Subject: HB 5036

Good Morning Melissa,

I hope you are seriously considering to help pass HB5036. This would help children and their parents. It would spread the awareness of Pandas/Pan and to diagnose in a timely manner.

Thank you for your consideration on this manner.

Dorene Schulte
Senior Accountant

AKT Peerless Environmental
22725 Orchard Lake Road, Farmington, MI 48336
P (248) 615-1333 F (248) 615-1334
schulted@aktpeerless.com

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TO THE HEALTH POLICY COMMITTEE REGARDING HB 5036

09/13/2018

Chair Hank Vaupel

Representative Joseph Graves

Representative Diana Farrington

Representative Jeff Noble

Representative Jim Ellison

Representative Daniela Garcia

Representative Roger Hauck

Representative Winnie Brinks

Representative Abdullah Hammoud

Vice-Chair Jim Teddar

Representative Jason Sheppard

Representative Pamela Hornberger

Representative LaTanya Garrett

Representative Kevin Hertel

Representative Julie Calley

Representative Bronna Kahle

Representative Sheldon Neeley

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

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

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

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

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

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

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

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

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

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

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

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

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

The time to act is now.

Sincerely,

Joel & Anna Troyer

Bronson, MI.

Luke 3:5

Melissa Weipert

From: Catherine Crombez <cmcrombez@gmail.com>
Sent: Wednesday, September 19, 2018 11:29 AM
To: Melissa Weipert
Subject: Bill support from the community

Hello Melissa Weipert and the
State of Michigan House Health Policy Committee,

I am writing to you to assure my support for the bill HB 5036. I anticipate that the formation of a PANDAS/PANS advisory council will benefit patients, families, and health care providers so that awareness, diagnosis, and treatment can continue to improve. My own personal experience as a sibling of a child with PANDAS has given me the opportunity to recognize the need for patient's care to improve and the stress that must be placed on providers to properly treat and recognize this diagnosis.

Thank you for bringing this to the house so that this can be addressed and organized by validating the need for this advisory council in Michigan.

Best regards,
Catherine Crombez
Michigan resident and active citizen

Melissa Weipert

From: Sledheads Wifey <jolieswyrtek28@gmail.com>
Sent: Wednesday, September 19, 2018 11:51 AM
To: Melissa Weipert
Subject: HB5036
Attachments: IMG_20150604_131802.jpg; IMG_20160327_080754726.jpg; edited_IMG_20160402_174040.jpg; 20180803_130722.jpg; IMG_20160422_205758.jpg; 20180917_233411.jpg

Hi, my name is Jolie Swyrtek. This is why I support HB5036.

On March. 1,2016 just two days before turning 6, our son, Joshua, started acting very out of sorts. He went from a normal happy child attending kindergarten to having sudden onset of severe separation anxiety, fear of dying if he went to sleep, hallucinations, chest pain, and having vocal and motor tics. I took him to urgent care and was told it was probably reflux and sent home with pain meds. He was worse by evening... Dressing himself and begging to be taken to "mommy's work". I'm an RN at Hurley. He was sure he was going to die....the night before his sixth birthday and my son is crying tears for me to get him help because he's going to die. Being a nurse, I knew something was wrong, but no clue what a nightmare my life was turning into. ER diagnosed an asymptomatic strep infection. Yes, that's right no symptoms. No fever, no sore throat, no headache, no bellyache. He was given a shot in the leg of penicillin and sent home.

It took me hours to get him to sleep.... He looked up at me and said " Mommy will you stay awake while I sleep?" Of course I said I would. His next two questions will haunt me forever " Mommy if I stop breathing will you wake me up?" I reassured him that he wouldn't stop breathing and that I would stay awake all night to watch over him...his response " What if I do stop breathing, and you can't wake me up? Who will take care of me in heaven? " Why should any child feel this way? What is wrong with my son?

The next morning, his sixth birthday, he woke in pure panic. Hands clenched on his chest. Telling me he had to push on it to breathe. My first thought was rheumatic fever. So, back to the ER we went. Tests were done, blood was drawn, we spent the day and night of his birthday in the hospital. The following evening he was discharged with no answers as to what WAS wrong, but assured his heart was fine we were sent home.

I had googled "complications of strep" and started to read while we waited in the ER the day before. I came across Pediatric Autoimmune Neuropsychiatric Disorders associated with Streptococcal infection (PANDAS).

Fast forward to April 14th,2016. After three hospital admissions in the month of March and multiple antibiotics as well as IV steroids...we have a final confirmed diagnosis of PANDAS. I'm pretty sure this is a parents worst nightmare. Now I know you are probably thinking what about cancer? Well, unlike cancer, treatment for PANDAS is usually not covered by insurance unless the child has underlying immune deficiency, nor is the outcome predictable. Some kids need only one, some need multiple. To my knowledge our son does not have an underlying immune deficiency based on what tests have been done. We went to a doctor in Illinois who has been treating this for years....the cost \$9,870 just for the medication. Total out of pocket cost including travel, hotel, food, etc. Was just over \$13,000.

September 17, 2018 2 and 1/2 years of trying to heal our son's brain. He lost friendships and the ability to attend school. We did finally get IVIG covered by insurance which is unheard of in most cases. He was making a lot of improvements until the past few months. All of his symptoms returned just not as severe, and instead of being afraid of dying....wishing he would die. His treating neurologist has suddenly closed his practice leaving many PANDAS/PANS families without treatment.

We found strep A on Joshua's skin; finally the answer to why he was not doing well. In 2 weeks time he has seen 3 doctors at 2 different hospitals. During this time he has been fighting strep, shingles, and yeast. They keep changing his antibiotic, but we are back to step 1 looking for a specialist to assume his care. There are not many doctors to treat PANDAS and the most knowledgeable don't take insurance at all. We are back to sleeplessness, prayer, and desperation.

Before he started to decline he was doing well enough that I decided to enroll him in a fulltime online education program through our district. This means I am now full time mom, teacher and nurse for a child with special needs. I am missing more work than I can afford to...and bills are piling up. It is looking more and more like we will again need to travel and pay cash for his treatment. We also have other children....2 in Jr High and 1 in college.

Please help children like Joshua and Landry (son of Joel Troyer) by passing HB5036 so they can get the care/treatment they deserve.

- Pictures are
1. Before PANDAS
 2. At onset of PANDAS
 3. After 1st IVIG
 4. Recieving IVIG



Melissa Weipert

From: joyce sall <bjoyce.sall@gmail.com>
Sent: Wednesday, September 19, 2018 2:27 PM
To: Melissa Weipert
Subject: HB5036 & HB5035

Dear members of the House Health Committee,

I'm am writing in support of establishing an Advisory Council on PANDAS/PANS in the state of Michigan HB5036. We need increased awareness as well as access to diagnosis and treatment for affected children. I also am in support of HB5035. This much needed bill will provide insurance coverage for diagnosis and necessary medical treatment for children suffering with this debilitating disorder.

Thank you for your support!

Betty Sall
6093 16th Ave
Hudsonville, MI 49426

Sent from my iPhone

Melissa Weipert

From: Megan Zynda <megan.zynda@gmail.com>
Sent: Wednesday, September 19, 2018 3:37 PM
To: Melissa Weipert
Subject: Support for HB5036 and HB5035

Dear House Health Policy Committee:

I would like to support HB5036 to establish an Advisory Council on PANDAS/PANS in the state of Michigan. Also, HB5035 has my support so that families affected can obtain insurance coverage for diagnosis and treatment deemed to be a medical necessity.

Best,
Megan Zynda
25640 Dundee Road
Royal Oak, MI 48067

Melissa Weipert

From: Sandy Butler <sandy2882@comcast.net>
Sent: Wednesday, September 19, 2018 4:11 PM
To: Melissa Weipert
Subject: HB5036

Please support HB5036. I believe this bill is extremely important.

Sent from my iPhone

Melissa Weipert

From: Alyse Hays <alysehays@hotmail.com>
Sent: Wednesday, September 19, 2018 10:12 PM
To: Melissa Weipert
Subject: Our PANS story

Dear members of the House Health Policy Committee,

Our son, Jaedyn, was born in 2008 a healthy and delightful baby. He hit all of his milestones like a champ. He developed into a talkative, bright, and somewhat cranky toddler who we noticed had a touch of OCD. Jaedyn ate a pretty balanced diet up until around age 2. Then, quite quickly, he became an extremely picky eater who would only eat a handful of foods. When he was 3, Jaedyn started to have angry outbursts that were so hard for us to understand. He was angry way too often. He also began to refuse to wear certain types of clothing. He would become agitated about the tags in his shirts and insisted on wearing only soft, elastic waisted pants.

Jaedyn has always had an abundance of loving, supportive and involved family. He has two parents who work hard to provide everything he needs. We have always made sure he had a regular bedtime and plenty of healthy activities. His behavior just didn't make any sense to us.

At age 4, suddenly and without warning, he fell over and began to seize. I (Alyse) watched my son experience his first grand mal seizure. This was the beginning of a long journey of tests and specialist visits that ruled out many causes yet yielded NO answers. He had a total of three seizures while we tried to find the right medicine. His second seizure occurred at bedtime. His third seizure was in Wal-Mart. I can't fully explain the sickening and haunting wound that follows after witnessing your child convulse and go unconscious. Once we had the seizures under control, we left his med alone and waited. This was a terribly heartbreaking time for our family filled with so much fear and uncertainty about his future. During this time, we dealt with daily rage and oppositional behavior along with the food restrictions and OCD. During his rages he would often scream that he could not help it, that he needed help, and that he didn't want to be like this anymore.

I looked into therapy. More testing. We discovered he had many sensitivities and allergies. Again, no solid answers. We tried a mood stabilizer. An ADHD med. Nothing made a difference. Our son desperately needed help.

It wasn't until 2017 when we met Dr. James Neuenschwander that we learned about PANS/PANDAS. We could not believe that we finally had an answer and that there were so many other families living similar stories. When we looked into treatment, we realized just how much money we would need for appointments, labs and the treatments. Insurance would not cover any of it. We felt hopeless. After all of the years of suffering my family has endured while dealing with Jaedyn's issues, we simply do not know how we will regain quality of life unless we get him proper treatment.

Our son needed help six years ago. Now that we have a way to help him, we are facing financial strain. We were desperate for help back in 2012. It's 2018 and my son is now ten. He deserves to have the rest of his childhood free from the grips of PANS.

It is so very important that the medical community understands this debilitating and complicated disorder so that every child suffering can receive the treatment they need.

Thank you for your consideration.

Alyse Milliman
Jason Milliman
208 Susan Avenue
Sturgis, MI 49091

Jaedyn, age 5 ^

Jaedyn, age 7 ^

Sent from my iPhone

Melissa Weipert

From: Academic and Behavior Consultants MA ED <abc123achieve@gmail.com>
Sent: Wednesday, September 19, 2018 9:27 PM
To: Melissa Weipert
Subject: Insurance concerns for PANDAS

Dear members of the House Health Policy Committee,

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

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

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

I am an educational advocate and the pain and suffering that I have heard about from my families, and to add to the horrific drain of families, the lack of insurance support is just not acceptable.

With much appreciation for your consideration,

Brenda Mann

Academic and Behavior Consultants

(248)310-7700

--

Brenda Mann

Melissa Weipert

From: kathiewenz@aol.com
Sent: Wednesday, September 19, 2018 6:56 PM
To: Melissa Weipert
Subject: Support for HB 5036

Dear Ms. Weipert,

I am urging your support for HB 5036 that would enhance awareness of the devastating childhood illness: PANDAS/PANS, Pediatric Autoimmune Neuropsychiatric Disorder Associated with Streptococcal Infection or any infection.

I have witnessed the effects of this illness and worked with parents who have struggled to have their children treated appropriately.

Thank you for your concern and dedication.

Sincerely,

Catherine A. Wenz, MSN, NP
22316 Mylls Street
St. Clair Shores, MI 48081
586-419-8361 (cell)

Melissa Weipert

From: Kelly Fitzgerald <kfitzgerald823@yahoo.com>
Sent: Thursday, September 20, 2018 12:30 PM
To: Melissa Weipert
Cc: gammicca@comcast.net
Subject: PANDAS/PANS legislation

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,

Kelly Fitzgerald
1300 N 3rd Street
Kalamazoo, MI 49009

Smith Adult Foster Care Home
311 S. Clarwin Avenue
Gladwin, MI 48624
989-429-3272

September 19, 2018

House Health Policy Committee
Michigan Legislature
Lansing
Michigan

Attn: Clerk, Melissa Weipert

Dear Members of the House Health Policy Committee:

I am writing in support of HB5036 which would establish an Advisory Council on PANDAS/PANS in the State of Michigan. I am supporting this bill as I have a cousin that was diagnosed with this autoimmune disorder after his parents took him to many states meeting with several doctors. The disease was very difficult to diagnose and then took even longer to get a treatment plan in process. Treatment for the disease is very expensive and much of it is considered experimental and not covered by insurance. I am supporting this bill hopefully to get better access to diagnosis and treatment for those affected. I also support HB5035 which would provide insurance coverage for diagnosis and treatment necessary for a person with this debilitating illness. One in two hundred children are diagnosed with this disease and should have the opportunity to receive treatment without making it a hardship for the caregiver. Please help my cousin and the other estimated 10,000 children in the State of Michigan get insurance coverage for this disease.

Please consider my request for the support of HB5036 and HB5035

Thank You.

Sincerely,

LaVel Smith

LaVel Smith
Smith Adult Foster Care Home

September 13, 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 to express support for HB 5306 to establish an Advisory Council for PANDAS/PANS. We believe that the establishment of this entity is critical to children in the State of Michigan, to bring further awareness of the disorder, standardize treatment guidelines and advocate for treatment coverage by insurance companies.

Our son, Carter, was a bright, bouncy, easy going baby who met and exceeded all his milestones and brought boundless joy to our lives. However, around age 3, we began seeing strange symptoms following illnesses - unusually long tantrums, separation anxiety, clothing sensitivity and then facial tics. We brought our concerns to the pediatrician, who chalked it up to "adjustment to the new baby brother" and sent us on our way.

By age 6, these behaviors had been coming and going for some time and we sought out the assistance of a child psychiatrist. Initially diagnosed with Generalized Anxiety Disorder, the psychiatrist astutely changed his diagnoses to PANDAS, after observing our son suddenly develop OCD, crippling separation anxiety, food restriction, nighttime enuresis and school refusal - all of which followed a relapsing, remitting course that coincided with 7 - yes 7 - strep infections in one year's time. Carter was lucky to have a pediatrician who collaborated with his psychiatrist, aggressively treated his strep throat and recommended tonsillectomy.

Carter recovered, and we naively thought this was a chapter that could be put behind us. But in 2007, he developed a severe stomach illness with fever. He complained of severe stomach pain for months, and his psychiatric symptoms returned and worsened. He developed panic attacks, new separation anxiety, school refusal and became suicidal - all at age 12. He did NOT test positive for strep this time, and so no medical treatment was given. He was psychiatrically hospitalized twice, put on medicines that caused rapid weight gain, missed 3 months of school, saw his reading level regress back to 1st grade, and was only able to return to school under a Special Education certification.

Carter's symptoms worsened again in 2009 following several sinus infections and a bout with H1N1 flu. This time, he developed full body tics and violent rage/terror attacks that would last for hours, several times a day. Desperate, we traveled out of state to consult with experts in Maryland and New Jersey, which ultimately led to a PANS diagnosis - before the term had even been acknowledged. Lab results indicated multiple levels of infections we never even knew were there, and a lowered immune system. We were lucky enough to get Carter into a clinical trial at Detroit Children's Hospital, where inflammation of the basil ganglia and thalamus portion of his brain were confirmed via PETscan. He was also able to become a part of the research going on at the University of Oklahoma, which confirmed an elevated CAMkinase activity in his brain close to that of patients with Sydenham's Chorea. We had **PHYSICAL proof of a MEDICAL condition**, and IVIG was ordered. But despite this proof, and consult

with the Chief of Pediatric Neurology at DMC, **our insurance company denied coverage**. Desperate to give our son a fighting chance at a future, we found an infusion company that would sell us the IVIG at wholesale cost, took out a home equity loan and **paid \$12,000 for ONE infusion**. Within a week, the violent rages and terror attacks became a thing of the past, and within a month, the nighttime enuresis that had plagued him on and off for a decade was gone. Other symptoms remained, and the neurologist recommended another infusion, however, refused to write a script for it knowing we would have to pay out of pocket and take out further loans. We were denied a choice in the matter.

Carter continued to heal following IVIG, although quite likely much slower, and less comprehensively than if he had been allowed to continue the infusions. Because of insurance denial, he was not given the choice or the chance. He has had to continue with antibiotic, antiviral treatments, and we have paid countless dollars for continued consults and therapies and tutoring in the last 8 years. He continues to battle episodes of depression and anxiety. He missed out on a LOT of his childhood, and his teen years that he will never get back, but his healing has continued.

I am proud to say that he is now a 22 year old college senior studying Environmental Studies and Sustainability at Michigan State University who is excelling academically and socially. Where he was once crippled by separation anxiety, he now lives independently, and has participated in environmental studies and research in Hawaii and Florida, and volunteered in California installing solar panels for low income families. The kid who was 5 years behind in his grade level reading in high school, is now writing research papers and has a 3.6 GPA. The child who had such severe school anxiety he could not even enter the school building, now is talking about possibly attending graduate school. He was selected to be a part of the MSU Glassen Scholar program this summer and is currently working as a Student Assistant for the State of Michigan DNR Trails Department.

Carter's story shows that the healing from this disorder IS possible, but it also shows how much needless suffering was endured by delayed, incomplete diagnosis and treatment. It is our hope that with passage of this bill, no other child will be denied proper diagnosis and medical treatment, and that their healing will come much quicker than it did for our son, allowing them to have the childhood they deserve.

Thank you for your consideration,

Rachel and Mark Helinski



Carter – age 22 (present)



Carter – age 14 pre-IVIG



Carter – age 7 pre-tonsillectomy

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

Re: House Bill 5036 to establish a PANDAS/PANS Advisory Council

I support House Bill 5036 to establish a PANDAS/PANS Advisory Council. My son suffers from PANDAS/PANS, a form of autoimmune encephalitis since he was five years old. He is now 14 years old and a freshman in high school.

On October 19, 2009, my then 5 year old son woke up a completely different child. He was suddenly suffering from severe separation anxiety, irritability and difficulty falling asleep. He was also running a high temperature and had received a flu vaccine less than 24 hours earlier. Our pediatrician assumed our son had gotten the flu from the vaccine.

Our son did not get better. He got worse. We had no idea what lay ahead for us. Our bubbly, bright, curious, gentle, kind little boy, who had started kindergarten only two months prior, turned into a boy we did not recognize. He came to develop OCD, tics, chorea like movements, sensory disorder, sleep disturbance, raging anger, loss of social skills, unreasonable fears, night terrors, in addition to the irritability and separation anxiety so severe I could not leave his sight, except to go to kindergarten half days. He had to be told I would stay at school and not leave him. I could not even leave him with my husband. He would go into a panic attack.

We went to many doctors who did not know what was wrong with him or diagnosed him with a mental health disorder. We did not feel a mental health disorder suddenly came on overnight in a 5 year old, so we continued to consult with doctors. Eventually, in 2010, I took him to New Jersey to a doctor who treated children with PANDAS/PANS after I saw a program on Mystery

Diagnosis. He was enrolled in a research study at the University of Oklahoma testing the validity of markers of brain autoantibodies that are involved in PANS. He tested positive. That test is now on the market and CLIA certified is now called the Cunningham Panel. It is also not covered by many insurance plans.



Our son was diagnosed with PANS in 2010 and began treatment. We had an HMO at the time and had to leave it at the end of the year because doctors who treated PANS were out of state. During open enrollment at my husband's employer, we chose BCBS PPO. There were no providers treating PANDAS/PANS in Michigan in 2010, necessitating our going out of state.

In 2011, after taking antibiotics for 7 months and seeing some gains but not regaining full health, we took our son to Chicago for intravenous immunoglobulin therapy (IVIG). Our insurance was charged \$20,000 for the two day treatment, which they paid, less our 20% deductible. Our son weighed 50 pounds at that time. The immunoglobulin price is based on how much product is needed for the weight of the child. Our son began to come back to us and in three months was functional and happy again.



Eighteen months later, our son came down with pneumonia and he was back to square one at nearly 8 years old. We went back to Chicago for another round of IVIG, which then cost approximately \$22,000 since our son now weighed 55 pounds. BCBS approved the second round of IVIG and our son returned to health over the period of about a year. He remains on a prophylactic dose of antibiotics, as is protocol per the National Institute of Mental Health's treatment recommendations.



Today, in 2018, our son is fourteen and has entered a college prep high school. He is an honors student. He plays tennis and the clarinet in band. He hopes to make the diving team at Catholic Central High School.

Since the last time our son had IVIG in 2011, BCBS MI PPO no longer covers IVIG for PANDAS/PANS. Our son now weighs 147 pounds. We could not afford this treatment again, at the exorbitant cost for his weight, out of our pockets without a serious financial hit to us.

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.

We implore you to support us by voting in favor of in establishing a **PANDAS/PANS Advisory Council, House Bill 5036**, 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.

We also urge you to consider and move forward House Bill 5035, which would mandate insurance coverage for PANDAS/PANS treatments.

Regards,

Steve and Cindy Groene, South Lyon

Melissa Weipert

From: brenda.zook@spectrumhealth.org
Sent: Thursday, September 20, 2018 6:52 PM
To: Melissa Weipert
Subject: Bill HB 5036

I am writing in support of bill HR 5036 and asking that legislatures do this as well.

My name is Brenda Zook Dornan residing at 6089 Egypt Forest RD NE Rockford but I have practiced Family Medicine as Brenda Zook, MD for 30 years in Sparta Michigan. During these thirty years, there have been tremendous changes in medicine with many advancements not only diagnosis and treatment but also even disease types. Fibromyalgia was not a diagnosis that was even known or taught in school but readily accepted at this time. What I was taught in medical school to be the cause of migraine headaches is now known to be an effect of the chemical changes which are causing the headache. There are innumerable examples that I could present. The debate that this bill brings up is not does PANDAS/PANS exist or not. There is an ever increasing amount of research that is pointing towards autoimmune/infectious causes of neuropsychiatric symptoms that are affecting more and more people particularly our children. The reason this bill is so necessary is to insure that we are able to provide care for these children who so desperately need help. As this is a newer diagnosis with many treatments still being determined, insurances are able to simply deny treatment. This leaves families even more fragmented as savings are drained trying to seek answers. Often times one of the parents is giving up a job to stay home due to severity of the child's symptoms thus furthering the financial impact. The negative financial and emotional stress have a very strong negative impact on many of the marital relationships as well if not heavily guarded. Would insurance coverage for this diagnosis correct all of this, the answer is obviously not completely but it would make a significant difference.

I watch these children in my practice that I am most certain have this diagnosis but because of lack of coverage find my hands tied to give the kind of care that would bring this child and family back to normalcy. This is a disease process that robs an individual of their childhood, a family of their unity. I have a 10 year old patient who has repeatedly been pushed into psychiatric diagnoses/hospitalizations despite signs of significant medical causation. None of her psychiatric medications or treatments have provided benefit and have actually worsened the situation. She is currently living at a boarding ranch in Tennessee due to the emotional trauma that was being inflicted on the other children in the home. The emotional strain on the parents to make that decision was immense.

I have experienced the complete turn around of these children when you can diagnose them early and get them on treatment despite everyone else wanting to simply put a psychiatric label on them. I find parents hesitant to even explore this road as soon as I mention that insurance is not likely to cover the majority of this care. This needs to change for the sake of our children!

Brenda Zook,MD

2111 12 Mile Rd Sparta MI 49345

Melissa Weipert

From: Marge Lisius <mlisius@gmail.com>
Sent: Thursday, September 20, 2018 7:08 PM
To: Melissa Weipert
Subject: HB 5036

To the State of Michigan House Health Policy Committee,

I am voicing my support for HB 5036 to allow the formation of a PANDA/PANS advisory council. Increasing awareness of this horrific illness and its effects on children and their families is the key that will unlock timely, accurate diagnosis leading to better access to specialists, treatment and support.

Thank-you,
Margaret Lisius

Melissa Weipert

From: Rebecca Paul <rpaul1018@hotmail.com>
Sent: Friday, September 21, 2018 6:01 AM
To: Melissa Weipert
Subject: bill HB 5036

Dear Health Policy Committee,

I am writing to express my support for bill HB 5036 with the hope it will allow for the formation of a PANS/PANDAS advisory council. This is very much needed and kids with this disorder need the support from our State and medical community. My daughter has been suffering with PANDAS for 7 years. It took a year and a half for proper diagnosis and treatment. If there were more awareness and support she would have been treated sooner.

Sincerely,

Rebecca Paul

Melissa Weipert

From: Rosalie Garrick <rgarrick70@yahoo.com>
Sent: Friday, September 21, 2018 7:23 AM
To: Melissa Weipert
Subject: HB 5035 & HB 5036 request

Dear Ms. Weipert & members of the House Health Policy Committee,

I am the best friend of Meaghan McCann who has an awesome daughter named Claire. Claire is 9 years old and has been diagnosed with PANDAS a few years ago. I have seen both her and her family deal with this disease, and I am asking for support from you.

This email is for support of HB 5036 to establish an advisory council of PANDAS in the state of Michigan. This disease needs more awareness and benefits not only from our residents, but also from our government. I have never heard of this disease until Claire was born. She is so young and it breaks my heart to see her suffer and not have a cure for this. Her mom has been so resilient and has been doing so much to bring awareness to everyone that will listen. The family needs your support in this time of need.

In addition, I also support HB 5035. This will provide insurance coverage and treatment for this disease and any other debilitating disease of a family member. This is so important for families seeking help that do not have the necessary means to do so.

Thank you so much for your kind consideration.

Sincerely,
Rosalie Garrick

Melissa Weipert

From: Dawn Huggard <dawn.huggard@gmail.com>
Sent: Friday, September 21, 2018 9:10 AM
To: Melissa Weipert
Subject: Support for HB5036/HB5035

Dear members of the House Health Policy Committee,

Please, please consider supporting HB5036 that will establish an Advisory Council on PANDAS/PANS in the state of Michigan. 10,000 children in Michigan are affected by this condition and we need to not only have better awareness, but access to diagnosis and treatment for those affected. In addition, I urge you to support HB5035 to provide insurance coverage for diagnosis and treatment deemed to be a medical necessity for an individual suffering from this debilitating illness. Middle class families should not suffer under the burden of exorbitant medical expenses while lower income families can not even be diagnosed - neither condition is acceptable in a nation as advanced as ours. So please, please consider supporting HB5036 and HB5035.

Thank you for your consideration,

Dawn Huggard
10306 N. Canton Center Rd.
Plymouth, MI 48170

Melissa Weipert

From: Steve -L 2 <sclicber@aol.com>
Sent: Friday, September 21, 2018 9:24 AM
To: Melissa Weipert
Subject: HB 5036

This email is to express my support for HB5036 which allows for the formation of a Pandal/Pans advisory council

My granddaughter suffers from Pandal. It is a extremely difficult mediical condition to properly diagnose and control.

Through relentless efforts from her parents she has, after years of suffering finally been able to begin to recieve medical treatments. However as Pandal is not well understood in the medical community they have had to seach far and wide for proper medical care, at great time and expense.

Hopefully this bill will allow their and other families to receive the proper care they require, without having to take the complete burden to find it on to themselves.

Thanks and regards

Steve Lieberman

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

Sincerely,

A handwritten signature in black ink, appearing to read 'Lindsay Lieberman', with a long horizontal flourish extending to the right.

Lindsay Lieberman, Hudsonville

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

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

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

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

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

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

Eventually, I found a doctor in pediatric neuro-immunology 3 hours away. We waited 3 months to get in; he prescribed a 5-day steroid burst to determine if her symptoms were in fact organic in nature rather than

psychological. To my amazement she responded. She matured so much I felt like I had missed years of her life. I had my daughter back, and not just the daughter that I had lost in January but the daughter I lost years before! She was happy, goofy, she had energy and wanted to play and be active. She played age appropriately with friends. Her OCD diminished, and she could tolerate life and live. She wore some shorts instead of skirts. She went to school without anxiety and didn't need to use her "sensory spot". Most importantly she was happy again!

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

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

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

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

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

Children with this illness who go untreated will be accessing many mental health and social services throughout their lives including: psychiatric care, school services, and other social services. It is no secret that Michigan's mental health system is overwhelmed. Imagine if these children were identified early and promptly treated. It would largely eliminate their need for many social services in the future. Please consider passing HB 5036 to form an Advisory Council for PANDAS/PANS. No child should be forced to go through what my daughter experienced simply because of a lack of awareness and education.

Sincerely,



Lindsay Lieberman, Hudsonville

Denise Lanfear
734 N. Main Street
Clawson, MI 48017

Re: Health Bills HB5036 and HB5035

To the Health Committee:

It was a normal evening in our household of 3 boys. At that time, they were 12, 8 and 5. My husband and I were getting them in their bedtime routine when all of a sudden our middle son Raymond started to panic. He was in the bathroom and was telling us he couldn't stop feeling like he had to go to the bathroom. We rushed in there and he kept saying it over and over and we didn't understand what was going on. We finally got him to head to bed when more panic set in. Raymond said he "couldn't get out of the bathroom." There was absolutely nothing blocking his way but he saw the line on the hardwood floor between the bathroom and the hallway and that is what he felt was blocking him. He "was trapped" and couldn't cross the line. My husband and I were absolutely baffled and frustrated as to why he was acting this way. My husband picked Raymond up and carried him into the bedroom while Raymond screamed. You have to imagine the panic, frustration and confusion that set in immediately with us and our other children. You immediately wonder why is he acting this way! Once in the bedroom Raymond would normally give me a kiss goodnight. That kiss goodnight on my cheek took him three hours. He kept saying he had to "Re-do" it because it wasn't right, or it wasn't in the right spot on my cheek or the right pattern. We were all crying at that point scared out of our minds. Raymond kept telling us "my brain is telling me to do this and I can't stop it."

The change in Raymond happened as quickly as turning a light switch on/off. I will never forget that night. Up until that point Raymond was a perfect child. Easy going, perfectly behaved, did amazing in school, and was always the child teachers loved to have in class. Raymond rode horses as his sport – he did English riding and loved it more than anything and he would work in the barn on Monday evenings cleaning the horse stalls. One thing had happened the week before and that was Ray had a fever and double ear infection.

The next morning, I immediately called the Pediatrician who told me that is OCD and I need to get him to a Psychologist immediately. I could bring him that day because that next morning I couldn't get Raymond to school. My child who loved school and followed directions perfectly would not get off the couch, would not get dressed and would not stop screaming and crying. Raymond wouldn't eat either because he felt if he touched food it would then be dirty and he could get sick. We got him in the shower but he couldn't get clean enough and then he couldn't get out. Imagine as a parent having your child change right in front of your eyes – drastically change. Raymond again kept saying "my brain won't let me." Ray's color in his face was gone and he had dark circles under his eyes. This all happened in a matter of 12 hours. His happy fun-loving spirit and laugh was gone – it was as if it was stolen.

We headed to the Psychologist, Raymond in his pajamas. It took us about an hour to get from the front door to the car because of the lines in the cement that were now huge obstacles to get past. When we got there I explained what had happened. The Psychologist asked Raymond questions and observed him. The Psychologist told me that he has no idea what this is, but this is not adolescent OCD and he has never seen a case this extreme that came on overnight. He recommended we go to a neurologist.

Still baffled by this entire change in our son we started to do some research. My sister is a Doctor so she had access to the medical library. She sent me information on something called PANDAS – Pediatric Autoimmune Neuropsychiatric disorders associated with Strep. I read the information and it said that symptoms of it are a sudden onset of extreme OCD, severe separation anxiety and rage/anger. This sounded like Raymond exactly – and it is all caused by strep. Seems easy enough to diagnose and treat right? Wrong!

I called the Pediatrician and she told me that she has only heard of it one time and it was a question on one of her board tests before but she has no idea what to do to treat it so to go to a neurologist. I did a search of PANDAS and neurologists and there was one in Michigan – just one but he happened to be close at Children's Hospital in Detroit. Perfect – I called – 10 weeks. We could get in to see him in 10 weeks. How was I going to possibly go 10 weeks? Raymond was still not getting dressed, eating, moving off the couch, able to cross lines....his hands were red and raw from over washing them. I could get him to school sometimes if I didn't leave the building.

I called Raymond's ENT in the meantime. He brought us in and was intrigued by this concept as he had never heard of PANDAS before. He put his residents on it to research. The ENT ordered blood work for strep titers because the strep test/swab was negative for strep. He also wanted to put new tubes in his ears because of the ear infections and wanted to make sure there was no strep anywhere. Blood test results came back with high positive strep titers. So now what? He didn't know. He sent me on our way with our bloodwork and told me to keep him updated so he can learn from this as well.

So now I have encountered a pediatrician, psychologist and an ENT who are intrigued by have never heard of PANDAS enough to diagnose it nor do they know how to treat it. In the meantime, Raymond is the same or worse depending on the day and has developed facial tics as well to go along with everything else. He refuses to sleep in his bed but we need him to get sleep so we sleep with him every night. We are all scared.

About three weeks after the onset, Raymond wakes up one morning and asks us if we can please bring him to the hospital because his brain isn't working. He is 8 years old, imagine your 8 year old asking you that question. It was a blizzard that morning, schools were cancelled but we brought him to the ER at Children's hospital – it took us 2 hours to get there but we went. We arrived to the ER and went to triage. After explaining to the nurse, she had no idea what we were talking about, Raymond was put in a room where we were visited by Child Protective Services – not once but twice. We were questioned as if we did something wrong or did something to Raymond. Did he get a hold of prescription drugs, alcohol, etc. The questioning was horrible. We finally were visited by a neurologist and a neurology resident. Raymond was lying in bed and so observing him at that moment was not giving the neurologist a glimpse of what we had been dealing with so we were being somewhat dismissed. Luckily, my husband brought videos. My husband brought the Doctors in the hallway and showed them videos, Raymond was then admitted for testing. The Doctors still didn't know what "this" was. So for those of you reading this keeping score we have 2 neurologists, an ENT, a Psychologist and a Pediatrician who have no idea what PANDAS is or how to treat it.

I am going to speed up a bit on the next 5 months.....at the hospital Raymond was given a spinal tap and a MRI. They were inconclusive so they sent us to a Behavioral Cognitive Therapist and a Psychiatrist. The Psychiatrist put Raymond on Zoloft – 25 mg. When that didn't work raised it to 50mg and then to a 100mg. It wasn't working – he still had his symptoms plus now there were moments where he was

almost catatonic. Finally had our 10 week appointment with the neurologist who believed in PANDAS. He diagnosed Raymond with PANDAS as long as every other test for every possible auto-immune disease turned out negative. Raymond went to multiple blood draws, saw Pediatric Immunologists and needed a PET Scan and another MRI. By this time Raymond has missed 40+ days of school and was late 72 times. Thank goodness for our amazing school system that accommodated Raymond in so many ways. There were many days when Raymond spent the morning at school straightening all the boots in the hallway so he could go into the classroom.

Everything comes back negative so Raymond is then diagnosed with PANDAS and that in order to treat Raymond he needs IVIG or Plasmapheresis. We are sent to a Pediatric Neuro-Immunologist. Raymond now needs more bloodwork. We accomplish that and go to what we hope is our last appointment before we can actually treat Raymond. Raymond keeps asking every appointment we go to when they are "going to fix me?" This whole time Raymond knows his brain isn't working and he can't control what he is doing. We speak to the Doctor and he agrees he needs IVIG which is Intravenous Immunoglobulin and basically can reset his immune system. We now have two Doctors – a Neurologist and Pediatric Neuro-Immunologist agree that this is what we need for Raymond. He informs us at the appointment that insurance may not cover it and he will call us when they find out and we can schedule it, etc.

It took a couple of weeks but I will never forget that phone call. The nurse told me that Raymond needs IVIG but our insurance doesn't cover it. I said, no problem I will pay for it. She said that it would be over a \$30,000 bill. I told her that I didn't care, I would sell my house, whatever I needed to get my son back. She told me that the Doctor will not do IVIG for cash and that he only does it when approved by insurance. I asked her what do I do now. Her reply was "I don't know, I am really sorry." I asked for her to have the Doctor call me. They never called me back.

At this point in our life we are almost strangely used to Raymond and his new behaviors – he hoards everything so our house is a mess, he thinks his younger brother is a giant germ so we have to keep him away from Raymond, our oldest son carries Raymond around to avoid Raymond having to "cross lines." My parents have put rugs on their tile floor to hide all the lines so that Raymond can be comfortable at their house. Raymond has taken over our bed and my husband and I sleep in his bunk bed. Raymond has lost 15 pounds and everyone is used to him wearing his pajamas all the time. I pretty much had to quit work because Raymond couldn't be apart from me. Raymond carries a stuffed animal to school every day as if he is 3 years old. It is no longer our child – he looks different, he doesn't laugh, and he knows there is something wrong with his brain – he can't shut it off.

So now I have a diagnosis and what treatment Raymond needs but they won't administer it and insurance won't pay for it. So I did more research. I found two out of state Doctors that treat PANDAS. I emailed the closest one in Illinois – Dr. Kovacevic. He emailed me back right away – it was 4th of July weekend. He said if you can get here Monday I will see Raymond. We packed the car and drove to Illinois.

Dr. Kovacevic asked Raymond questions and observed his behaviors. He asked us questions and then sent us for more bloodwork. Raymond still had strep in his system. Dr. K. said that Raymond definitely needs IVIG (Raymond already had his tonsils and adenoids out when he was little) and we could do it in August. Again, insurance won't cover it but Dr. K will administer it. There was no question about it, yes.

Raymond was so excited – he was going to get treated. We hopped on the train to Illinois in August and headed to get IVIG. It was going to cost a lot of money so I called the credit card company and told them we had a medical situation, they allowed us to raise our maximum and charge this procedure.

Two days of infusions, steroids and antibiotics along with many supplements to keep Raymond healthy after IVIG. After three weeks, Raymond's color came back to his face. Raymond laughed – what a wonderful sound it was to hear his real laugh again. He ate food, he got dressed, the OCD faded away – he could walk through the house, he could cross lines, he could function. Four weeks after IVIG he successfully went to school – 3rd grade! It took about a full 3 months for Ray's immune system to be rebuilt and for us to completely see Raymond come back but imagine as a parent watching your son come back to you.

Raymond had months of his childhood taken away from him and he is one of the lucky kids as some go years or never get treated. It is Raymond and our family's goal to help all these kids and step one is to form an advisory council so that this disorder can get the proper research and Doctors and the health community can be properly educated.

Three years later Raymond is still symptom free. He has some PTSD from the disorder but he has worked through a lot of it. Here is a narrative Raymond wrote about his journey....

Sincerely,

Denise Lanfear

The Hurricane

Myself - Raymond Lanfear, a survivor of O.C.D, and a brave kid.(O.C.D.: a sickness that takes over your brain or a sickness that controls most of your brain.) I was starving, because of the sickness in my brain, everything I did felt like a hurricane. First as I looked at myself in the mirror, I was sweating, I couldn't eat perfectly so I didn't eat at all. Every night I stop before I go to bed to use the bathroom, but when I tried to get out of the bathroom, I couldn't. It was like there was a wall I couldn't pass without something bad happening.

A couple minutes later my dad slowly walks to the bathroom and picks me up while I scream, " No, take me back!!!!" , and to this day I still thank him for not.

I couldn't do anything, I felt like a robot being controlled by an evil thing, myself (O.C.D.) I went to bed in horror of myself, feeling like I was the puppet in a magic show. I got into my bed, crying. I couldn't tell what it was. As I got into my bed I asked my mom, " What is this?" To this day I ask my mom a similar question, " How did it start?"

Myself - Raymond Lanfear, a brave kid, but in a crisis still weeks later. I wait, I listen, and try to see. As I wait with my dog in my bed, my mom sits in the chair in my room and waits. Just after that I laid for a while in my bed looking confused and thinking one question, " What is this?" I keep asking myself for a long time then I start to wonder, " What should I do?", " Should I ask to go to the hospital?"

Finally I realize what I must do, so I do it, " Mom, help me," I say so very quietly to my mom, my mom can barely hear me.

"What was that honey," my mom says cautiously

"Can we go to the hospital tomorrow, please?" I ask. My mom's face was almost crying and worried, because my mom must know how much pain I'm in to want to go to the hospital.

But finally my mom said, " O.K. honey." That was when I realized and then said it out loud, " I'm scared.....mom." Myself - Raymond Lanfear, needs help in a crisis worse than a hurricane.

I was once a happy kid changed, because of a hurricane..... A hurricane that came very imperiously and unexpectedly. (When I say hurricane it's my way of saying almost O.C.D.,because that what it felt like, it felt like a hurricane.) Before O.C.D/Pandas/or Pans. I did things more freely and I remembered it. (The medicine that I got to free me from O.C.D. also made it so I don't remember any of that even happened.) Before O.C.D/Pandas/ or Pans. I wore all colors now it's just black and little bit of blue and white. I used to say 2nd grade was one of the best years of my life, but now I don't even remember it.

Today and almost every day I ask my mom, " When will I remember?"

Then my mom always says, "Not for a very long time."

Writing, Remembering, and a Very Long Time, are words I think about a lot. I always wanted to write a book on O.C.D., but how can I do that if there is no possible way for me to remember it right now? Now I say, " One second I was there, another second later I'm gone." I remember really important parts, but not for long. I might not even remember this part of my life next year, " Who's to know?" Sadness, happiness, and gladness, and those are words everybody should think about. You are probably thinking how can a hurricane make somebody happy? Why, because I am on the other side of it. Now I can help other kids get on the other side too.

My memory of what I overheard of Doctor Kovacevic said, "He might remember it around the age of 23. To this day sometimes people still remember me being on Fox 2 News. Now today my challenge is just fighting off the habits left from O.C.D, because I fought off O.C.D. like a wild mustang. But till this day I know I'm different, I know I wear black, I know everybody else will never be like me, and I'm glad.

By Raymond Lanfear



September 18, 2018

To Whom It May Concern,

This past week I was invited to comment on House Bill 5036 by a parent of a former patient that I have known since he was 6 yrs old. Carter was initially referred to me by another child psychiatrist from the Detroit area. The presenting complaint at the time was that Carter "was displaying a lot of anxiety". He would "get stuck and perseverate on an anxious thought and escalate to wild and rageful tantrums." Parents were overwhelmed. He had been an "easy child" until about 18 months old when his behavior changed drastically. He started exhibiting significant sensory issues & marked spikes in anxiety triggered by intrusive thoughts. He was overwhelmed by compulsive rituals and fears of contamination.

That was seventeen years ago. Carter is about to turn 23. What I thought at the time was a child experiencing symptoms of generalized anxiety with a provisional diagnosis of obsessive-compulsive disorder turned out to be much more complicated. It is an understatement to say that Carter's journey has been painful.

In February of 2015 the Journal of Child & Adolescent Psychopharmacology devoted an entire issue on a relatively new set of disorders entitled Pediatric Acute Onset Neuropsychiatric Syndrome. This special issue included expert discussion on the clinical presentation, differential diagnosis, treatment challenges, and the importance of a multidisciplinary treatment team to provide effective treatment for these children and their families. I want to underscore the importance of the multidisciplinary treatment team. In Carter's case, achieving that goal was a painstakingly slow process. It took several years to make an accurate diagnosis and although this writer was involved in that process, it was the expertise of the other clinicians, the PANDAS expert, the pediatric neurologist, the infectious diseases expert, etc. that complemented, and in some cases, drove the treatment. Most importantly, throughout this entire process, Carter's parents, particularly his mother Rachel, was the driving force in procuring appropriate therapy for her son.

Carter's journey started 17 years ago, but a lot has changed since Dr Sweedo at NIMH first described PANDAS in the late 90's. We now have newer therapies, more research and better outcomes for our patients and their families.

Thank you for your time

A handwritten signature in black ink, appearing to read "M. Barnes".

Michael Barnes, DO

Board Certified Child & Adolescent Psychiatrist

3960 Patient Care Drive, Suite 104 | Lansing, MI | 48911

517.887.9801 Office | 517.887.9826 FAX

www.parrehab.org

September 19, 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 Carter Helinski, and I am writing to show support for HB 5036. I would like to share with you what it feels like to have P.A.N.D.A.S./ P.A.N.S. a life altering autoimmune disorder, that no one, especially a child, should ever have to experience. I was diagnosed with PANDAS at age 7, and later PANS at age 14. By overcoming the worst of this debilitating illness that causes literal brain inflammation, and fighting my way out of the trenches, I feel as though it's my duty to advocate for the rest of the PANDAS community. No child should feel trapped within their own mind, unable to escape from the daily pain, torment and suffering this disorder causes. There is no worse feeling than realizing that your brain has been hijacked. I remember as a child begging for help from literally anyone - doctors, my parents - anyone that could make it stop. For the longest time I felt hopeless, irate that this illness was robbing me of my childhood. That I was different from the rest of my peers, watching my dreams of living a normal life disappear right before my eyes. I felt helpless, and hopeless, and at times I just wanted to die. My childhood, and even my adult life to some extent, have been filled with visits to countless doctors and specialists, many of which were of little to no help. During the worst of this illness, I felt as though I was a burden to my family, especially due to the substantial amount of money my parents had to put forward for my treatment. It wasn't until I received my IVIG treatment that portions of my real self-began to shine through.

I am now thriving as a senior at Michigan State University, both academically and socially. Both realities that I never could have imagined for myself years ago. No child deserves to suffer and have their life limited by an illness that actually has a cure. My responsibility as a survivor, and

more importantly a role model for all of those still suffering, is to be a voice of advocacy. Please consider passing HB 5306 to establish an Advisory Council for PANDAS/PANS. Treatment should be available to everyone, no matter their financial situation. These tormented kids depend on it to have any fighting chance at living a normal, bearable life.

Thank you for your time and consideration,

Carter Helinski

Melissa Weipert

From: Elizabeth Manchen <ebm48021@yahoo.com>
Sent: Friday, September 21, 2018 11:37 AM
To: Melissa Weipert
Subject: Support for 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 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. Our son was diagnosed with PANS last year so this is near and dear to our family. Thank you.

With much appreciation for your consideration,

Elizabeth B Freitas
51118 Courtyard Drive
Chesterfield MI 48047
586-248-1107

Melissa Weipert

From: Rhelinski <rhelinski@aol.com>
Sent: Friday, September 21, 2018 12:10 PM
To: Melissa Weipert
Subject: Letter of Consideration - HB 5036
Attachments: MIAPPSignaturesHB5036(1).pdf; MIAPPSignaturesHB5036(2).pdf;
MIAPPSignaturesHB5036(3).pdf

Ms. Wiepert:

Last week, I had the honor and privilege to attend the annual conference of the Michigan Chapter of the American Academy of Pediatrics, as a representative of the Great Lakes PANDAS/PANS Advocacy and Awareness group. While there, I spoke with many of the attendees about the proposed HB 5036, presented a copy of the bill, and received much support for the idea of an Advisory Council. Attached, please find signature pages of the medical professionals in attendance that signified their support for the passage of HB 5036.

Thank you for your consideration of these signatures into public record of support for HB 5036.

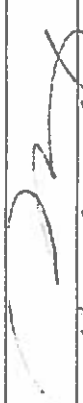


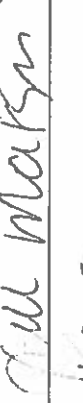

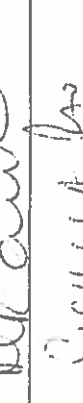


Sincerely,

Rachel Helinski
Great Lakes PANDAS/PANS Advocacy and Awareness

House Bill 5036 will amend the Michigan Public Health Code 1978 PA entitled "Public Health Code" (MCL 333.1101 to 333.25211) by adding section 5145 to create a PANDAS/PANS Advisory Council.

THE PEOPLE OF THE STATE OF MICHIGAN ENACT SEC.5145. (1) THE ADVISORY COUNCIL ON PEDIATRIC AUTOIMMUNE NEUROPSYCHIATRIC DISORDER ASSOCIATED WITH STREPTOCOCCAL INFECTIONS IS CREATED WITHIN THE DEPARTMENT.









We the undersigned, do express support of, and agreement with, HB 5036 and the need for an Advisory Council to be created to meet the medical needs of individuals in the State of Michigan who have been diagnosed with PANDAS/PANS.

Signature	Printed Name & Title	Address	Phone Number	Date
	ERICA BOILE - MSUCOM med. student	51291 Plymouth Lk Cir. Plymouth, MI	734-233-1207	9-14-18
	Mackenzie Fontaine - MSUCOM med student	4638 Tarter Ln Holt, MI	989-990-8202	9-14-18
	Pamela Berry MD	29255 Northwestern #100	248-358-2410	9-14-18
	Jill Matson, CRNP	7466 Edgewood + Trevelton	MI 7487753450	9-14-18
	Karli Leiker MD	1378 N. Leeward Ludington 49431	231-530-3324	9/14/18
	Melissa Gower MD	2215 N Cedar	Sign in	9/14/18
	Susanna	604 Linden Bay	231-776 4410	9-14-18
	Steven Wassenaar MD	725 Washington Street OK Post MI 48371	(248) 60282337	9-14-18

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We the undersigned, do express support of , and agreement with, HB 5036 and the need for an Advisory Council to be created to meet the medical needs of individuals in the State of Michigan who have been diagnosed with PANDAS/PANS.

Signature	Printed Name & Title	Address	Phone Number	Date
	Sujal Panchal	19020 E 24 St Livonia, MI	734 362 5760	9/14/18
	Anil Alachari			9/14/18
	Paula Chotkazy MD	15381 Bay Hill Dr Northville, MI	248.562.9662	9/14/18
	JEAN CUSSON, MD	LANSING, MI	317-877-3000	9/14/18
	Theresa Guinther, DO	1332 N. Tower Essexville, MI	989-385-2237	9/14/18
	Guendolen Reyes, MD	300 E 14th St Flint, MI 48906	510-240-6915	9/14/18
	Anna Hukun MD		586-444-1859	9/14/18
	Lois Booms NP	168 N Casser. Rd Lapeer, MI	—	9/14/18

House Bill 5036 will amend the Michigan Public Health Code 1978 PA entitled "Public Health Code" (MCL 333.1101 to 333.25211) by adding section 5145 to create a PANDAS/PANS Advisory Council.

THE PEOPLE OF THE STATE OF MICHIGAN ENACT SEC.5145. (1) THE ADVISORY COUNCIL ON PEDIATRIC AUTOIMMUNE NEUROPSYCHIATRIC DISORDER ASSOCIATED WITH STREPTOCOCCAL INFECTIONS IS CREATED WITHIN THE DEPARTMENT.

We the undersigned, do express support of, and agreement with, HB 5036 and the need for an Advisory Council to be created to meet the medical needs of individuals in the State of Michigan who have been diagnosed with PANDAS/PANS.

Signature	Printed Name & Title	Address	Phone Number	Date
	Christina Miller	24531 Kneelwood St Novi MI 48375	248-709- 0941	9/14/18
	Colleen Dodich, MD	7218 Rishling St Mattawan MI 49071	(734) 730- 3782	9/14/18
	June Elias, MD	404 Parnice Ct Plymouth MI 48132	248-743-7382	9/17/18
	VICKI MOELLER, RN	3108 Shindpoint Dr Brighton MI 48114	248-525- 2325	9/17/18

Melissa Weipert

From: Paula Mondoux <pmondoux53@hotmail.com>
Sent: Friday, September 21, 2018 12:16 PM
To: Melissa Weipert
Cc: denisechampine@yahoo.com
Subject: HB5035 and HB5036

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 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.

Thank you,
Paula Mondoux
41823 Prunum
Sterling Heights, MI. 48314



Restorative

Teresa Birkmeier-Fredal MD

245 Barclay Circle Suite 600

Rochester Hills, MI 48307

Phone: (248)289-6349

Fax: (248)289-6923

September 21, 2018

Chair Hank Vaupel

Vice-Chair Jim Tedder

Representative Joseph Graves

Representative Daniela Garcia

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Representative Bronna Kahle

Representative Jeff Noble

Representative Winnie Brinks

Representative LaTanya Garrett

Representative Sheldon Neeley

Representative Jim Ellison

Representative Abdullah Hammoud

Representative Kevin Hertel

I am writing in support of **House Bill 5036** to establish a **PANDAS/PANS Advisory Council**. I am a physician in Michigan who has been treating children with the disorder PANS (Pediatric Acute Onset Neuropsychiatric Syndrome) and its subset PANDAS (Pediatric Autoimmune Neuropsychiatric Disorder Associated with Strep) for many years. This is a devastating disorder to the children who suffer from it and their families.

I have patients who would benefit from treatments, such as IVIG (intravenous immunoglobulin) therapy and plasmapheresis, among other treatments available. Unfortunately, it is very difficult to impossible to get these treatments covered under insurance. These treatments are normally reserved for children with the most serious, advanced cases of PANS. These children are suffering tremendously and the need for IVIG and plasmapheresis is great. Children should not have to suffer from this medical disorder because insurance companies do not want to cover all of the available and recommended treatments.

I call on you to establish the **PANDAS/PANS Advisory Council** with the passage of **House Bill 5036** and consider and move forward House Bill 5035 and establish an insurance coverage mandate for children with PANDAS/PANS.

Regards,

Teresa Birkmeier-Fredal, MD

Cathy Liller
23850 Wilson
Dearborn, MI 48128

Sept 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:

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).

The condition affects my granddaughter, Grace Gauthier. The symptoms that manifest are tics, most often associated with Tourette Syndrome. Raising awareness of the condition would assist 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 granddaughter and countless other children in the state of Michigan. Thank you for your consideration.

Sincerely,

Cathy Liller RN, BSN
Adjunct Faculty
University of Detroit Mercy
Henry Ford College

Melissa Weipert

From: Dee Payment <dpayment7@gmail.com>
Sent: Friday, September 21, 2018 1:58 PM
To: Melissa Weipert; Meaghan McCann
Subject: HB5035 and 5036

Dear Members of the House Health Policy Committee,
As a Grandparent of Claire Leginza, who has been diagnosed with Pediatric Auto Immune Neuropsychiatric Syndrome, I have seen an extreme need for not only awareness of this disease, and better diagnosis and treatment, but insurance coverage as well. This little girl and her family are suffering terribly, and I have witnessed it first hand. Claire cannot attend school due to her vulnerability and sensitivity to the germs that are in schools. She also has extreme separation anxiety which requires her mother to be with her literally 24/7. She as an extremely limited diet, and takes numerous medications such as steroids, antibiotics, anti depressants, etc. There are limited resources to help this child and her family. She is 10 years old.
Please, please, support and enact HB 5035, and HB 5036 to help Claire and thousands of other children diagnosed with PANS/PANDAS.

Sincerely,
Dee Payment, 231 843 8750
dpayment7@gmail.com
Ludington, MI. 49431