

Emily Durfee

From: [REDACTED]
Sent: Wednesday, March 4, 2026 2:35 PM
To: Rep. Julie Coulombe
Subject: HB 292

Follow Up Flag: Follow up
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[REDACTED]
[REDACTED]
Re: Support for HB 292

Representative Coulombe,

I am writing with wholehearted thanks for you sponsoring HB 292.

As a parent who has been fighting for treatment for PANS on behalf of my son for the last four years, to see this coming before the legislature is so heartening. Not only for my family - this would make such a difference for so many others; if it saves a child from waiting years for effective treatment, plus the mental, psychological financial and emotional toll it leaves, the impact cannot be overstated.

As I am sure you are aware, it is estimated that 1/200 kids in the U.S. have this diagnosis. In Alaska in particular, there is really no one treating this effectively, resulting in a huge cost to Alaskan families, as we seek out of state treatment options. There is a huge out of pocket cost for testing that only naturopaths or functional med doctors tend to do, that help with diagnosis. This is extremely prohibitive to getting timely diagnosis and treatment.

IVIG costs run from \$10-30,000 per treatment (depending on medication, dose needed, location, etc) and the average person needs at least 3-5 rounds to show efficacy (this varies hugely case by case, and depends on severity). Passing this bill would make a huge difference for many Alaskan families. We are going broke trying to get treatment for our kids.

As an Alaskan parent whose child has been staggeringly impacted by PANS, thank you for sponsoring HB 292.

Please, reach out if I can answer any further questions about how deeply this has impacted our family, PANS/PANDAS in general, or anything that may be helpful.

[REDACTED]
[REDACTED]

Emily Durfee

From: [REDACTED]
Sent: Thursday, March 5, 2026 9:51 AM
To: House Health and Social Services
Cc: Rep. Julie Coulombe
Subject: HB 292

My name is [REDACTED] and I am an Alaska constituent, located in Craig. I am writing to you to request that you vote pro on HB 292, IVIG for PANDAS/PANS kids. We became informed of PANDAS/PANS when our neighbor's 9 year old daughter developed it overnight after a typical illness for a school aged kid. You will immediately become a memorable hero to these and the future Alaskan families that are currently and will be diagnosed with PANDAS/PANS in the future.

My friend's daughter is a classic case of PANS. She literally became ill and a different person overnight when her immune system attacked her basal ganglia of the brain. It took a couple months to find a functional medicine doctor that would treat her with a five week course of an antibiotic and a six week course of naproxen. It took eight months for her mental cognition to completely heal and return. Thankfully, she is healthy right now and back to baseline. But they live their life on edge everyday, knowing that an infection, virus, cold, puberty, dental infections, loss of baby teeth, and even mold can trigger another flare, sending the family into crisis mode once again. If antibiotics and steroids don't heal her, there will be a likely chance that she will be a good candidate for IVIG. If the family cannot access IVIG, **WITHIN A TIMELY MANNER**, and **avoid declines**, they will be forced to watch their young daughter lose mental and physical abilities very quickly, risking permanent brain damage. Risking the possibility that they will **NEVER** get their bright, joyful, intelligent, and confident daughter back! They live in great fear knowing that IVIG is not mandated in Alaska, even though it is in 15 other states, which they are not able to live in due to their fishing and boat businesses.

Paying for ongoing IVIG treatments, **\$15,000 to \$30,000 per month typically**, will be a very temporary option for them as savings will dry up. My heart breaks daily for the families that are less fortunate than them, with zero savings or valuables to sell. **Many medical expenses and appointments are already out of pocket**, even prior to IVIG. Without treatment, parents are forced to watch their child decline on the couch each day, not knowing if they will ever get their child back. PANDAS/PANS is such a thief! No child deserves this suffering and to be ignored by leaders that have the authority and power to heal them. Please vote on HB 292 as soon as possible.

Please note that the fiscal note for HB 292 is minimal. Please prioritize this bill, especially since the state expense is significantly lower than most bills.

IVIG has a 70% efficacy rate and it is the **final hope** for many. Please create hope soon, since **the longer treatment is denied and delayed, the less effective treatment is. This is a race to health.**

Unfortunately, **lives have been lost** that could have been saved, as some ill kids and young adults gave up the fight and took their own lives while waiting for IVIG insurance approval.

My friends experienced similar darkness of this illness within the first 2 months of onset, prior to receiving an antibiotic. It came on quick and the previously joyful and confident daughter verbalized, **"I want to kill myself!" after she fell ill.** I'll never forget the day when they delivered all the household knives and

sharp objects to another neighbor's home to protect their daughter. Please do not let these kids and families continue to wait any longer! This treatment works and changes lives forever! Thankfully, our friend's daughter's symptoms improved immediately, as soon as she was treated with an oral antibiotic, and naproxen.

Majority of Alaska PANDAS/PANS families **can't** afford IVIG out of pocket. Please recognize the financial strain on these families since many PANDAS/PANS patients require 24/7 care due to night rages, monitoring for safety, and providing consistent care throughout the day due to mood and food security, OCD, as well as multiple weekly doctor appointments. It typically requires one parent to be the full-time caregiver in all cases, regardless of severity. I have no idea how a single parent emotionally, physically, and financially survives this illness. Thankfully, in Washington, even **Medicaid patients already have access to IVIG**, as they are developing a similar mandate.

It is estimated that 1 in 200 kids get PANDAS/PANS. PANDAS/PANS is not declining, it is just beginning to get recognized and diagnosed in every state. **Most kids will not require IVIG, but the ones that do, will have likely already exhausted all other options.**

Lastly, I encourage you to please access **PANDAS PARENTS** on Facebook. It is an authentic peek into the lives of these families as they try to support each other with treatment ideas while waiting for IVIG approvals, knowledgeable providers, several insurance claims, and desperate requests for help when IVIG is denied. I encourage you to be **brave** as it isn't easy to read their stories, but it is important that you have a clear understanding of the symptoms and urgencies.

Thank you for your time and consideration. Please be our voice for HB 292.

Emily Durfee

From: [REDACTED]
Sent: Tuesday, March 3, 2026 5:36 PM
To: House Health and Social Services
Cc: Rep. Justin Ruffridge; Rep. Rebecca Schwanke; Rep. Andrew Gray; Rep. Zack Fields; Rep. Julie Coulombe; Rep. Mike Prax; Rep. Donna Mears; Rep. Genevieve Mina
Subject: HB 292: Insurance Coverage for Pediatric Autoimmune Neuropsychiatric Disorders

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I strongly support HB 292 which provides Insurance coverage for youth suffering with PANS/PANDAS. These are post infectious neuro-inflammatory disorders with severe and sudden onset of Obsessive-compulsive Disorder (OCD),

tics (both motor and vocal), eating restrictions, and mood/anxiety disorders.

Families dealing with children with one or the other of these syndromes should be well supported medically.

Early intervention leads to better outcomes and treatment options should not be disputed for insurance coverage. Fifteen states have passed this legislation and four are pending. Children in Alaska also deserve to be supported.

A simple case of strep throat can lead to a child developing PANS/PANDAS. Causation of these syndromes is

not completely understood but generally it is a common infection by a virus/bacteria/fungus that sets the stage.

There are families in Fairbanks and throughout the state that are dealing with this right now. Please support this legislation.

Thank You.

[REDACTED]

[REDACTED]

Laughter: The tangible evidence of hope.

Emily Durfee

From: [REDACTED]
Sent: Wednesday, March 4, 2026 2:27 PM
To: Rep. Julie Coulombe
Subject: HB 292

Follow Up Flag: Follow up
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Representative Coulombe,

Please vote to pass HB 292.

With sincere appreciation,

[REDACTED]

Emily Durfee

From: [REDACTED]
Sent: Wednesday, March 4, 2026 7:40 PM
To: Rep. Julie Coulombe
Subject: HB292

Dear House Representatives,

Hello! I am [REDACTED], an Alaska constituent from Craig on Prince of Wales Island. I urge and request that you vote pro on HB 292, IVIG for PANDAS/PANS kids. I witnessed the emotional, and physical burden that a family friend of mine experienced before, during, and after their daughter was diagnosed with PANS. They had to jump through many hoops to provide the proper treatment for their girl, of which resulted in out of pocket expenses. Thankfully they had savings. I can't imagine what a family without savings would do.

While many health issues are stressful, PANDAS/PANS is immediate trauma for the child and trauma as it has a quick onset, and often occurs overnight. PTSD is the result for many caregivers since emergency rooms and residential hospitals do not treat P/P properly or timely. In fact kids typically get worse very quickly when they become inpatients. Families take day and night shifts to ensure their child's safety which can lead to limited income for many families.

IVIG ranges from \$15,000 to \$30,000, out of pocket, about every 3 to 4 weeks. Most kids do not require IVIG, but it is one of the last hopes for many. Of those cases, they might need 3 to 30 sessions of IVIG.

Families would experience much less stress if the treatment was covered by insurance. Their daughter's case is considered mild. Based on my memories and our conversations, I cannot imagine how the families of children with moderate to severe cases of PANDAS/PANS physically and emotionally heal after experiencing the quick and long term onset of PANDAS/PANS symptoms. Please help and become these kids' heroes. We must intervene and support this fragile population since insurance companies frequently allow themselves to deny coverage leading to exponential declines and even loss of lives since the torment of this illness has led some to suicide. Thankfully, IVIG has about a 70% efficacy rate for moderate to severe cases. Please be part of their healing process!

Sincerely,
[REDACTED]

Emily Durfee

From: [REDACTED]
Sent: Tuesday, March 3, 2026 11:21 AM
To: House Health and Social Services
Cc: Rep. Julie Coulombe
Subject: Please Prioritize HB 292

Follow Up Flag: Follow up
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My name is [REDACTED] and I live at 1620 Washington Drive, Apt 11, Fairbanks AK 99709.

I'm emailing to seek your support on HB 292 so children with PANDA/PANS can have access to life-saving treatment known as IVIG. PANDA/PANS are post-infectious neuroinflammatory disorders that have profound and life-altering symptoms such as OCD, tics, eating restrictions and more. These disorders require medical treatment and too often, insurers deny coverage. Earlier intervention leads to better outcomes.

15 other states have passed legislation, with four more pending. Don't leave these Alaska children behind.

Can we count on your support?

Regards,
[REDACTED]

Emily Durfee

From: [REDACTED]
Sent: Thursday, March 5, 2026 1:07 PM
To: House Health and Social Services
Cc: Rep. Julie Coulombe
Subject: Please Support HB292

Dear Representative Mina, Representative Gray, Representative Fields, Representative Mears, Representative Prax, Representative Ruffridge, and Representative Schwanke,

I am writing to urge your speedy approval of HB292, an act which would require insurance companies to provide coverage for little-understood and devastating pediatric autoimmune neuropsychiatric disorders, which can be prohibitively expensive for Alaskan families.

My family is affected by a pediatric autoimmune neuropsychiatric disorder. While our diagnosis is recent and we are not suffering to the degree other families have, we know without prompt treatment our child's condition may continue to deteriorate. With many other serious and complex health conditions in our family, we are already personally acquainted with the unnecessary challenges and additional burdens imposed by insurance companies being reluctant to cover treatments, even life-saving ones, and with hardship in finding practitioners open-minded enough to consider diagnoses that were not understood in the mainstream when they attended medical school. The medical field is advancing by leaps and bounds, and this act will require insurance companies to provide the services they are paid for, and provide the recognition needed for doctors to provide the support families desperately need in a medical landscape already challenged by scarcity of expertise in our state.

I am tired of seeing my child spiral into panic and horrific fear in the face of autoimmune triggers. The last thing she needs is to be subjected to gaslighting from the insurance industry, and a slow-walk on treatments to help her get back to her true self. She has a childhood to enjoy. Please help me as I seek to help my child grow beyond this disorder to her full, brilliant potential.

Thank you for taking my comment.

Thank you also to Representative Coulombe for sponsoring this bill.

Sincerely,

[REDACTED]

Emily Durfee

From: [REDACTED]
Sent: Tuesday, March 3, 2026 5:10 PM
To: House Health and Social Services
Cc: Rep. Julie Coulombe
Subject: HB 292

Follow Up Flag: Follow up
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Hello,

My name is Amanda Campbell and I live in Homer, Alaska. I am emailing to seek your support on HB 292 so that children in Alaska that have PANS and/or PANDAS can have access to life saving treatment known as IVIG. PANS/PANDA is a pediatric neuropsychiatric disorder causing inflammation in the brain when the immune system overreacts and attacks the brain. This can cause terrible symptoms such as OCD, restrictive eating, debilitating anxiety and loss of motor control amongst an array of other symptoms.

My son is still dealing with the repercussions of having this disorder and not getting the treatment he needed in Alaska when he needed it. We had to go to New Hampshire to get the medical support that we needed for him to heal. Earlier interventions lead to better outcomes as with any disease or illness. Too often doctors and insurance carriers deny that this disorder is real. 15 states have passed this legislation, please consider doing this for our Alaskan children so that my child can be treated here in our home state along with all the other Alaskan kids who need this.

Thank you,

[REDACTED]

Emily Durfee

From: [REDACTED]
[REDACTED]
To: Wednesday, March 4, 2026 10:48 AM
House Health and Social Services
Cc: Rep. Julie Coulombe
Subject: Vote pro on HB 292

Follow Up Flag: Follow up
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Dear House Representatives,

My name is [REDACTED] and I am an Alaska constituent on Prince of Wales Island. I want to encourage and request you to vote pro on HB 292 regarding IVIG treatment for PANDAS/PANS kids.

P/P is a type of autoimmune encephalitis where various infections and brain inflammation trigger the immune system, causing the autoimmune system to attack the basal ganglia which results in physical, emotional, behavioral, psychological, and neurological symptoms that can literally steal your child overnight.

Thankfully, my close family friend, Emma Endsley, responded immediately to the first line of defense which is typically an antibiotic for the infection and naproxen for the brain inflammation. A small percentage of kids are considered severe and require IVIG infusions approximately once a month for 3 to 20 months. Each infusion ranges from \$15,000 to \$30,000, out of pocket, depending on the weight of the child. It is very typical that families are denied IVIG. The sooner that P/P is properly treated, the more effective treatment is so you can see it is especially a race to get IVIG treatment in some cases.

15 other states have approved similar bills, including California and Oregon unanimously, and we are hoping Alaska becomes the 16th. Thankfully, Alaska Medicaid already covers IVIG. Please note that a 3rd party fiscal study was completed for other states and Alaska premiums would see, literally, their monthly premiums increase just pennies each month since the majority of patients do not require IVIG. But for the ones that do, IVIG is one of their last hopes. IVIG has high efficacy rates and improves the lives and heals 70% of the cases that receive it. Thankfully AAP, the American Academy of Pediatrics is recognizing the need for urgent, timely, and aggressive treatment based on studies in their publications.

In closing, I ask you to please vote pro on HB 292. There have already been too many lives lost, families destroyed emotionally and financially, and children whose entire childhood and young adult lives were stolen from them due to this illness, as well as improper treatments. Please restore their hope and the hope for the future cases. There will be more cases but Alaska can prepare and help heal this vulnerable and desperate population. It is financially impossible for the high majority of cases to access proper care without this bill.

Thank you for your time and consideration.

Sincerely,
[REDACTED]

Sent from my Galaxy