HB5374 AN ACT CONCERNING HEALTH COVERAGE MANDATES FOR CERTAIN HEALTH CONDITIONS

SEC. 2 INSURANCE COVERAGE FOR PANS AND PANDAS

Providing Equal & Comparable Coverage to Medically Necessary Care

Legislative Rationale

Mandated insurance coverage for PANS/PANDAS ensures access to medically necessary care at minimal cost, while reducing avoidable disability, educational disruption, workforce loss, and long-term public expense. Without clear coverage standards, costs shift from insurers to families, schools, and public systems. Mandated coverage promotes equitable, criteria-based access to care and improves outcomes by supporting timely treatment. **The cost of care is small. The cost of inaction is not.**

Why Insurance Coverage Is Necessary

The Cost of Inaction Exceeds the Cost of Care

PANS/PANDAS are immune-mediated conditions characterized by sudden or newly worsening neuropsychiatric symptoms, such as obsessive-compulsive behaviors, restricted eating, anxiety, aggression, cognitive impairment, and functional decline. **Delaying or denying physician-recommended treatment often leads to greater severity, disability, and higher costs.**

Without mandated coverage, patients face insurance denials for medically necessary care. Families are forced to delay treatment, rely on psychiatric-only care that does not address the underlying disease process, or pay out of pocket, often at catastrophic financial cost.

Delayed or denied treatment leads to:
- Increased emergency visits and psychiatric hospitalizations
- Prolonged educational disruption, including homebound or out-of-district placement
- Higher risk of long-term disability and reliance on public systems
- Workforce loss occurs when parents or adult patients cannot maintain employment
- Immeasurable human suffering: Delayed or denied treatment causes severe neuropsychiatric symptoms not reflected in cost data and impacts the entire family

Failure to mandate coverage does not eliminate costs; it shifts them to families, schools, emergency services, and public programs, increasing the risk of lasting harm.

Precedent: Coverage Is Established and Workable

Twenty states have enacted legislation or policies providing insurance coverage for PANS/PANDAS, reflecting recognition that timely treatment reduces long-term disability and public costs.

Twenty states with insurance coverage include: Arizona, Arkansas, California, Colorado, Delaware, Georgia, Idaho, Illinois, Indiana, Kansas, Louisiana, Maryland, Massachusetts, Minnesota, New Hampshire, Oregon, Rhode Island, Tennessee, Virginia, and Washington. (Coverage type and scope vary.)

A major national insurer has updated its medical policy to recognize PANS and PANDAS, allowing coverage when diagnostic and medical necessity criteria are met. This demonstrates that coverage can be implemented responsibly with clear standards and clinical review.

Relying on individual insurer policies creates inequity. Patients with the same diagnosis may receive different care based on their insurance plan or location. Mandated coverage ensures consistent, criteria-based access for both pediatric and adult patients.

Financial Impact: Minimal Cost, Meaningful Protection

Actuarial analyses consistently show that mandated PANS/PANDAS coverage has a negligible impact on insurance premiums.

- Virginia estimated the cost at **$0.0046 per member** per month—less than half a cent.
- Other state analyses report similarly minimal impacts, often measured in fractions of a cent.

Not all patients require high-cost treatment. Many improve with early diagnosis, treatment of underlying triggers, immune stabilization, and appropriate psychiatric care. Coverage supports timely, clinically appropriate care rather than crisis-driven interventions.

A review by the Rhode Island Office of the Health Insurance Commissioner **found that mandated coverage does not meaningfully increase premiums**. The analysis did not assess the costs of delayed care, hospitalization, educational disruption, or long-term disability, where the greatest burdens occur.

Bottom line: Mandated coverage has minimal cost. Delayed or denied care drives far higher long-term expenses.

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Connecticut PANS/PANDAS Partnership

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TESTIMONY EXCERPTS

134 Testimonial Submissions
128 Support
6 Neutral
0 Oppose

Gabriella True

CT Resident, President - Alliance to Solve PANS & Immune-Related Encephalopathies (ASPIRE)

No one should have to choose between one child over another… His doctors recommended IVIG again, but without coverage, it was financially impossible. So he was denied disease-modifying, life-altering treatment, leading to prolonged suffering and permanent losses.

Families with means drain savings. Families without means watch their child deteriorate and risk losing their lives. Often a parent leaves the workforce, reducing taxable income… This inequity moves cost to the most expensive and least effective parts of the system, the emergency care, schools, long term systems, instead of timely medical treatment.

Similar private insurance mandates in 15 other states, including Massachusetts, Rhode Island, and New Hampshire show that coverage didn't significantly raise premiums. The impact is only pennies or even fractions of a penny per member per month.

Lack of coverage increases human suffering and shifts increase to long term cost to families, patients, and other state systems. The states and family lose more by not having insurance coverage.

This bill is a practical measure to improve equity and access, align Connecticut with neighboring states, and ensure that medical decisions remain with qualified clinicians rather than being dictated by inconsistent insurer policies.

Liz Salsedo-Surovov

CT Resident - Parent

Because insurance did not cover PANS/PANDAS, his diagnosis and appropriate care were delayed for over a year. This delay changed everything. What was treatable became chronic… We faced repeated medical visits, and our home became a place of special education, homebound instruction, paid for by our district.

Therapies, such as ABA, and many work absences for my husband and I… Nine years into this journey, my son has still not received IVIG, because it is not covered by insurance… Families cash out savings. They take from their retirement. They take from their future, future security, to pay for their present…

Families like mine seek special education. We have homebound services. Since second grade, my son's now in 8th grade, that's six years that he has had an IEP and had homebound instruction… We have two children. Times that by two…

Passing HB5374 will ensure equity and access to medically necessary treatment. It will prevent avoidable disability. And it will stop families from being financially devastated just to save their children.

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TESTIMONY EXCERPTS

Lauren Brush

Clinical Psychologist
Institute of Living

“The system is not built for these children… PANS sits at the intersection of medicine and psychiatry, and when care is fragmented, children fall through the cracks…

I was able to advocate aggressively. I knew who to call. I had relationships with hospitalists and leadership. I understood the language of documentation and medical necessity… Because of that, my son received IVIG and specialized care… But access should not depend on who your parent knows.

I am a single parent. I took FMLA. My sister left a lucrative career as a costume designer in New York City to help care for my younger child. We depleted savings and incurred debt. We lost wages, the state lost taxable income, and I am one of the lucky ones…

Today, he is in seventh grade, in honors classes, with an IEP and a 504 plan. He still requires monthly IVIG. He has not fully recovered, but he is functioning because he had access to treatment…

As a clinician, I see what happens when children with complex psychiatric presentations do not receive timely, appropriate medical care. They become long-term burdens on every system: schools, hospitals, disability services, families, and government support programs… HB5374 is not just about coverage, it is about equity.

Paula Penna

CT Resident - Parent

When insurance does not cover PANDAS and PANS, the cost does not disappear. It gets dumped somewhere else. It gets dumped on families, on schools, on hospitals, and eventually the state…

I have owned a Music Academy for 28 years… I ended up having to lose most of that business… And that led to the the state losing for my taxable income… and also employment for many of the people, the teachers that worked for me.

The judge handling custody issues said that PANDAS and PANS was not a real disease, because insurance did not cover it… I ended up having to make the choice between paying my mortgage, or helping my child… So I did not pay my mortgage… I had to foreclose on my home and file for bankruptcy… If it's not covered under insurance, it can't possibly be real and therefore, I lost.

An anonymous donor ultimately paid for one IVIG treatment for my older daughter after hearing my testimony in a previous legislative hearing. Two weeks after receiving IVIG, she returned to school. She raised her GPA from 2.5 to 3.74, later graduating summa cum laude from the University of Hartford.

Barbara Rutkowski

CT Resident - Parent

We drove two hours, and within 15 minutes, she looked at me and said, ‘Your daughter needs IVIG’… Three months later, she had her first infusion.

would love to tell you it's a huge success story after that… but it had been three years prior that she needed it… And although it did help… the damage of prolonging her treatment caused damage that IVIG alone could not completely reverse.

But here's what's important for the committee to understand. As much as the humanity of it all is important, the medical cost did not go away. It might have been delayed, but it has ballooned… In addition to the more intensive, more expensive care she will now need.

I left the workforce and stopped paying taxes on my six-figure salary and 30% bonus … Our family didn't spend money and put it back into the economy here in Connecticut that we would have… And the school system has provided services and accommodations for years… It's costly.

So mandating coverage for medically necessary treatments like IVIG changes lives.

TESTIMONY EXCERPTS

Jennifer Frankovich, MD, MS

Clinical Professor of Pediatrics –Rheumatology Stanford School of Medicine, Stanford Children's Health

The consequences of these conditions can severely disrupt a child's life, leading to abrupt changes in behavior, mood disturbances, and significant functional impairments.

Research demonstrates that early intervention and effective treatments are crucial in improving outcomes for these patients. When care is delayed or restricted by insurance barriers, the risks of long-lasting effects increase significantly. Timely access to therapies, including intravenous immunoglobulin (IVIG), can make the difference between a child's rapid recovery and a trajectory toward chronic health challenges.

HB5374 is essential for addressing these needs, as it mandates coverage for necessary treatments for these specific health conditions, which aligns with evidence-based practices that can lower the incidence of long-term debilitating illnesses. The legislation recognizes that, for some patients, certain therapies may quickly become the only effective option after less intensive treatments fail.

Moreover, this bill represents a profound acknowledgment of the broader impact that inadequate healthcare coverage can have on families. Children requiring treatment may miss school, and parents may miss work, leading to substantial social and financial burdens — especially when critical healthcare costs are not covered. Ensuring comprehensive coverage alleviates these pressures and fosters a supportive environment for families navigating these challenges.

Additionally, HB5374 protects patients from discriminatory practices that limit access based on treatment history or diagnosis. By promoting a collaborative approach to healthcare that empowers physicians to recommend necessary therapies without bureaucratic hurdles, this legislation is aligned with the ethical obligation to provide tailored and effective care.

J Patric Whelan, MD, Phd

Dept of Pediatrics, Division of Allergy, Immunology & Rheumatology UCLA - Mattel Children's Hospital

I completed my doctorate in Microbiology & Immunology under the guidance of an immunologist who was the doctor for David Vetter, the boy in the plastic bubble, and I've spent my career studying similar immunodeficiency disorders. I hold faculty appointments at UCLA in Los Angeles, and for 30-years at Harvard Medical School. For the past 17-years I have been caring for children with PANS and PANDAS, dating to my years on the staff at Massachusetts General Hospital in Boston. With no established PANDAS centers in most states, we have been seeing growing numbers of families who travel all the way to Los Angeles to undergo evaluation and initiate care. Among the nearly 900 families we are currently following, about 2/3 turn out to have evidence for immune deficiency – which is a major predisposing factor to PANS and PANDAS.

I am currently caring for about 150 children who have received IVIg for treatment of severe PANS/PANDAS, and I can attest that more than 80% of them experience significant improvement – including resolution of suicidality and a return to productive lives with resolution of severe behavioral problems, bedwetting, and inability to succeed in school.

The money spent by insurance companies on the bureaucracy geared toward denying coverage, including new impersonal AI-based technologies, could be so much better-spent providing care to these desperate Connecticut families. I look forward to continuing my support for the many local pediatricians around the country who are trying their best to save these children and their families from years of lost productivity and emotional anguish.

TESTIMONY EXCERPTS

Angela Tang, MD, FAACP

Stanford University

These devastating inflammatory disorders of the brain abruptly destroy everyday functions such as learning, playing, sleeping, walking, and even eating/drinking and are often misdiagnosed as psychiatric illness. When PANS strikes, entire families are removed from functioning society as they struggle to support their sick child. Children require special education supports, including very costly home hospital school, and parents sell homes and collect unemployment to pay for care. Yet effective treatment exists, and expert consensus groups have established standard-of-care practice guidelines which include treatment with intravenous immunoglobulin (IVIg) since 2017.

The problem is that insurers have all published their own guidelines for IVIg that clearly declare it to be “not medically necessary” or “experimental” or simply “may not be approved” (2,3,4).
As a Medical Director working in Utilization Management, I can vouch that these insurance documents are NOT written by physician experts but rather by pharmacist employees who have never seen a case of PANS. This conflict of interest means that they ignore the science. I am providing references for the peer-reviewed, expert consensus treatment guidelines below (1,5,6) as well as 12 separate studies showing effectiveness of IVIg.

In this setting, only children from wealthy or extremely well-connected families (like mine) can navigate to wellness. The rest flounder, brain inflammation robbing them of childhoods, lifelong neurologic function, and sometimes, life. In 12 months in 2024, the Georgetown Pond Brain Bank more than doubled the number of PANS brains in their collection from three to SEVEN.

It is obvious that children with PANS need protection. We are not talking about the insurer denying the cholesterol medicine your doctor prefers. This is truly life threatening, brain threatening, and urgent. Over a dozen states have recognized this need and passed legislation similar to HB2196.

Connecticut stands to save untold millions in special education, unemployment, and long term disability costs, expenses that insurers currently shift to the state by denying urgent care. Since California’s law took effect 12 months ago, our Department of Managed Healthcare stopped needing to perform independent medical reviews (IMR) for IVIg in PANS, saving the state even more money.

Xander Nweeia

CT Resident - Patient

Please imagine what it is like for a 15-18-year-old's life to vanish and become crippled with OCD, anxiety, rage, brain fog, fatigue, and depression. I was hopeless. My doctor, who is private pay, and my parents never gave up on me. Sometimes my parents didn't leave my side for weeks at a time.

Eventually, antibiotics and steroids helped, but IVIG would have stabilized me faster and more completely; I would not have lost most of my high school experience. This may seem inconsequential to you, but please know it is not. Imagine if your part of your 8th, 10th, 11th, and 12th grades were spent living in isolation, pain and with traumatic symptoms.

For my senior year, I had to go to a special school in my district. I only had two real friends left. I never finished Eagle Scout or played lacrosse again, but I did graduate. I attended Lincoln Tech and now proudly work as an electrical apprentice. I am building a future for myself. But I worry about having another flare, because symptoms can come back, and there is still no reliable access to treatment in Connecticut if that happens.

I want to work. I want to keep contributing. I want to pay taxes, build a career, and live on my own. But that depends on whether I can get medical care if I relapse. Relapses are a reality. Insurance coverage is not just about treatment in the moment.

Do you not think it is unacceptable to keep kicking the can down the road over 14 years? I do. If you had passed legislation back then, I would have gotten IVIG. I would not have lost so much of my childhood and my future. I don’t know why you think it is cheaper to not help us. It is not

TESTIMONY EXCERPTS

Craig Shimasaki, PhD, MBA

President & CEO
Moleculera Biosciences, Inc.

I submit this testimony as a medical research scientist with over 35 years of experience in neuroimmunology and as President and CEO of a clinical laboratory that specializes in testing for antineuronal antibodies in children with PANS and PANDAS. Over the past two decades, our laboratory has evaluated more than 16,000 patients in the United States and internationally, generating one of the largest clinical datasets related to these conditions.

From both clinical and research perspectives, the consequences of inadequate insurance coverage for these patients are profound. Families routinely report being denied coverage for medically necessary diagnostic testing, immunologic evaluations, antimicrobial therapies, and immune-modulating treatments—despite growing scientific evidence supporting their role in recovery when appropriately applied. As a result, parents are often forced to pay out of pocket, deplete savings, or forgo care entirely.

Preliminary findings indicate that families commonly consult between five and fifteen physicians over periods ranging from three to more than ten years before receiving an accurate diagnosis. During this time, they incur tens of thousands of dollars in uncovered medical expenses, miss work, and endure significant emotional distress while their children's conditions worsen.

The lack of mandated insurance coverage creates clear inequities in access to care. Children from families with fewer financial resources are disproportionately harmed, as they are least able to self-fund medically necessary treatment. This results in preventable disease progression, increased utilization of emergency and inpatient psychiatric services, and, in some tragic cases, irreversible outcomes before proper medical intervention is provided. Early recognition and appropriate treatment of PANS and PANDAS are not only clinically effective but also economically responsible.

When underlying infections, neuroinflammation, and immune dysfunction are properly addressed, antineuronal antibody levels frequently normalize, and many patients experience marked improvement or full functional recovery. In contrast, delayed or denied care leads to higher long-term costs for families, insurers, schools, and state systems.

Barb Shepard

Licensed Mental Health Counselor

In my clinical practice, I witness firsthand the devastating consequences of delayed or denied care for children with PANS/PANDAS. I regularly work with adolescents who were misdiagnosed or dismissed for years—often told their symptoms were purely "behavioral" or "psychiatric"—when they were, in fact, experiencing an autoimmune-driven neuropsychiatric illness. By the time these children reach appropriate care, the illness is often far more severe, entrenched, and resistant to treatment.

Early intervention dramatically improves outcomes and reduces long-term disability. Some children with PANS/PANDAS lose the ability to speak, eat, attend school, or leave their homes. The financial burden on families is immense. Medically necessary treatments such as IVIG can cost between $10,000 and $20,000 per infusion and are frequently denied by insurers. Many families are forced to seek out-of-network care or travel long distances to find knowledgeable specialists, compounding costs with travel, lodging, and missed work. These financial stressors come on top of caring for a child who may be unable to eat safely, sleep independently, regulate emotions, or attend school due to an autoimmune condition affecting the brain.

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TESTIMONY EXCERPTS

Noemi Adame, MD

Culver Pediatrics

Children with PANDAS/PANS do not respond to conventional anti-depressants. The root cause of their condition is brain inflammation from a misbehaving immune system. IVIG helps reset that immune system.

Before treatment, my patients took more medications, had more ER visits, and more doctor visits. NOT treating is more costly than treating. Beyond the dollar amounts, the cost in lost school days for the child and lost work days for the parents causes financial damage to the family, workforce, and economy.

Amy E. Clarke, DNP, RN, IgCN®

Chief Clinical Officer
Immunoglobulin National Society (IgNS)

Policy Considerations and Healthcare Stewardship

Establishing clear insurance coverage parameters for medically necessary care supports patient-centered decision-making while promoting responsible healthcare stewardship. Coverage mandates help ensure that clinical decisions remain grounded in medical necessity rather than administrative barriers.

In our collective clinical experience, clearer coverage pathways lead to earlier intervention, reduced care fragmentation, and more efficient use of healthcare resources. These outcomes benefit patients, families, providers, and the healthcare system.

Thank you for your consideration of this testimony and for your commitment to addressing healthcare inequities through thoughtful policy. Ensuring timely access to medically necessary treatment supports patients, strengthens families, and promotes more consistent and responsible healthcare delivery.

Anna Conkey

Director, Neuroimmune Foundation

For a subset of patients, expert-informed clinical care includes immune-targeted and infusion medications when medically necessary. Unfortunately, families routinely encounter coverage denials and lengthy appeals, even with insurance, delaying access to appropriate treatment and compounding financial and emotional strain. Access to medically necessary care should not depend on a family's resources or ability to fight their insurer.

Amanda Peel

Director, National Alliance for PANS PANDAS Action (NAPPA)

Without appropriate treatment, children risk chronic disability that extends into adulthood — increasing long-term reliance on public assistance, disability systems, and mental health services.
The financial burden of delayed treatment is not theoretical. It is already being borne by Connecticut families and public systems.

Access to medically necessary care for PANS/PANDAS currently depends on a family's financial means, the generosity of an employer-sponsored plan, or the discretion of an insurer. That is inequitable and medically unsound.

Delays in care that allowed inflammation to persist and symptoms to worsen No one's access to appropriate medical treatment should depend on whether their family can self-fund five-figure medical expenses or navigate complex insurance appeals. Access must be consistent, equitable, and medically guided.

Mandating insurance coverage for medically necessary PANS/PANDAS treatment is both a moral and financial imperative. It prevents avoidable suffering, reduces long-term system costs and protects families from financial devastation. Importantly, it ensures early intervention when recovery is most likely.
Legislators must understand that inaction carries measurable human and economic consequences. The absence of a mandate does not save money — it shifts costs to families, schools, emergency systems, and long-term disability programs.

TESTIMONY EXCERPTS

Susan Fandacone

CT Resident

Alongside the emotional devastation came something we never expected, financial trauma. We did everything parents are told to do. We sought specialists. We followed medical advice. We pursued treatments recommended by doctors. Again and again, we were met with insurance denials.

IVIG has been recommended as a medically necessary treatment for our daughter. Our insurance will not cover it. We are not refusing treatment. We are being priced out of saving our child.

IVIG costs more than our family can afford out of pocket. After years of medical expenses, we simply do not have the financial ability to pay for it ourselves, even though it could dramatically change her life and potentially save it. No parent should have to look at a treatment that could help their child and know the only barrier is cost.

Over the past several years, we have drained our savings trying to keep our daughter stable. We have opened multiple credit cards just to pay medical bills. We refinanced our home to continue funding care.

Every decision has been made out of desperation to help our child get better. Families like ours are put in an impossible position, choosing between financial survival and medically necessary care.

Sherri Duval

Founder - Where There's a Will Foundation

This is a terrible sickness that affects the whole family . Worst of all, it can have a fatal outcome if left untreated.

Had my son received the proper treatment, I know he would still be here today. I strongly urge you to help these families and children so they do not have to endure the loss we have had to. It's unbearable to know there were treatments out there to save my child and he didn't get them. Please don't let finances be the reason we lose another child.

Jennifer Vitelli

LOOK. Foundation, Inc

PANS and PANDAS are medical conditions often triggered by infections such as strep, Lyme disease, COVID-19, or other pathogens that cause inflammation in the brain. The symptoms can look exactly like mental illness: sudden-onset OCD, eating restriction, rage, tics, severe anxiety, depression, and even suicidal thoughts. But these are symptoms of immune-mediated brain inflammation. With proper diagnosis and appropriate medical treatment, children and young adults can heal.

The stakes are enormous. Roughly 1 in 5 children experiences a mental health disorder each year, and suicide is the second leading cause of death among young people ages 10 to 24. When a treatable medical condition is left unrecognized or untreated, the consequences can be devastating.

Prolonged denials delay initiation of critical immune therapies. During that time, inflammation may persist, symptoms may worsen, and children may experience further functional decline. When treatment is delayed, the burden does not disappear. It shifts to families and to the state through increased emergency department visits, psychiatric hospitalizations, educational disruption, and long-term support needs.

Intravenous immunoglobulin, or IVIG, is considered only in a small subset of the most severely affected children, approximately 10 percent, often those with extreme impairment or life-threatening symptoms. When medically indicated, access to this therapy can be pivotal in stabilizing and restoring a child's functioning.

Gaps in coverage for immune therapy leave severely ill children waiting for necessary intervention. Prolonged barriers to care can contribute to worsening symptoms, increased reliance on emergency and inpatient psychiatric services, and, in some cases, tragic loss of life.

TESTIMONY EXCERPTS

Susan Newman Manfull, PhD

Co-Founder - The Alex Manfull Fund

My husband and I, devastated by the loss of our only child, established this organization to increase awareness, education, and research on PANDAS and PANS. We do not want another life to be cut short -- or derailed-- by these disorders.

TAMF is painfully aware of the financial hardships suffered by families with children with these disorders. These families are already navigating a complex medical disorder that drastically alters the lives of their children and every other member of their household.

Families sometimes “split up” so that one parent will be the caretaker of the child with PANDAS or PANS and the other parent or family member will take care of the other child or children. And, in the worst-case scenario, as was the case with my daughter Alex Manfull, those with PANDAS and PANS succumb to the condition. Evidence presented in Clinicopathologic Characteristics of PANDAS in a Young Adult: A Case Report suggests our daughter’s brain was significantly impacted by PANDAS/PANS.

All too often, the families are met with insurance denials for treatments prescribed by providers. Without successful treatment, these other costs will continue to mount, and the lives of the children, adolescents and young adults suffering from PANDAS or PANS remain on hold while their conditions worsen. Plainly, the costs to the state will only increase if treatment is denied.

Despite solid research from multiple institutions such as Stanford, Harvard, Yale, Dartmouth, Georgetown, Columbia, Albert Einstein College of Medicine, and the Universities of Arizona and San Francisco, insurance companies continue to attempt to substitute their judgment for that of providers who have familiarized themselves with the research while treating their patients.

Angela Gentile

Co-Founder - Virginia For PANS Association

Insurers typically deny coverage for doctor-prescribed treatment, despite the severity and seriousness of the disorders.

Without treatment, patients face unnecessary and costly hospitalizations, and parents and caregivers are often forced to give up their work or seek treatment out of state in order to care for their sick kids. Desperate families often go into debt and even sell or refinance their homes to pay for treatment out-of- pocket.

Lack of early intervention can result in life-long disability and even death, while placing an additional burden on schools, police, health care systems, and even insurers. And yet the condition is treatable, and physician-prescribed treatments consistent with existing treatment guidelines for PANS and PANDAS are unequivocally medically necessary.

According to the Virginia Board of Insurance, the cost of treatment is less than half a cent per insurance plan member per month–a negligible cost far outweighed by the risks of denying and delaying treatment.

Katharine Emmet

Rhode Island Resident - Grandparent

At one point, our family had to seriously consider moving to Rhode Island, where I live, just to get insurance coverage that Connecticut would not provide.

We talked about what that would mean: uprooting the kids, changing schools, leaving jobs and our community—not for new opportunities, but just to get basic medical care. No family should have to think about moving to another state just to get the care their child needs.

I wrote to my own legislators in Rhode Island to support our mandate, and I have kept up with the state’s report on how it has worked. I have met with PANS doctors and researchers and tried to understand the science as much as I can. These are thoughtful, careful, and highly respected people in the medical field. We need to listen to them.

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TESTIMONY EXCERPTS

Beth Lambert

Executive Director - Documenting Hope Connecticut Nonprofit Organization

As an organization that serves families across our state, we have seen firsthand the financial, emotional, and psychological toll of delayed or denied care. When insurance coverage is denied or severely limited, families are often forced to:

- Pay tens of thousands of dollars out-of-pocket for medical evaluations, laboratory testing,
- and treatments.
- Reduce work hours or leave employment entirely to care for a critically ill child.
- Deplete savings accounts, retirement funds, and college savings.
- Face housing instability due to mounting medical debt.

This is the daily reality for families in Connecticut dealing with these devastating conditions. When medically necessary care is delayed or denied, the costs do not disappear, they simply shift. They shift to:

- Schools, which must implement complex Individualized Education Programs (IEPs),
- provide special education services, and in severe cases, arrange for homebound
- instruction.
- Emergency departments and hospitals, when children deteriorate to psychiatric crisis.
- Crisis intervention systems, when families have nowhere else to turn.
- Public disability systems

Kelley & Brian Biskupiak

CT Residents - Parents

Today, Ben is 17 years old. A junior at Loomis Chaffee School. He is looking at colleges, navigating the baseball recruiting process, and living a full, joyful, deeply social life. He has also become an advocate for PANDAS and PANS awareness, courageously sharing his story to educate others and to ensure that families in the middle of the struggle do not feel so alone. What once nearly stole his childhood has now become part of the way he serves and strengthens others. That outcome should not depend on a family's financial capacity.

Sherri Duval

Founder - Where There's a Will Foundation

This is a terrible sickness that affects the whole family . Worst of all, it can have a fatal outcome if left untreated.

Had my son received the proper treatment, I know he would still be here today. I strongly urge you to help these families and children so they do not have to endure the loss we have had to. It's unbearable to know there were treatments out there to save my child and he didn't get them. Please don't let finances be the reason we lose another child.

Diana Pohlman

Executive Director - PANDAS Network

Early diagnosis and treatment prevent permanent lifelong injury.

New 2020-2025 research by Stanford, Yale, Oklahoma & Columbia Universities prove that brain inflammation is occurring with strep and other infections in a subset of children. We also believe there is a genetic component making these children more susceptible; but, this is not incurable illness!

Youth can heal with treatments that are available but treatment is extremely costly to families without insurance coverage. Insurance coverage is critical because the expense of treatment together with debilitating, daily symptoms make lack of coverage inhumane and devastating financially to families. Early recognition of illness onset of PANDAS-PANS has the best chance of assuring children a rapid and substantial recovery. The average age of onset is between ages 4-10.

The untreated child will often struggle with lifelong neurological and psychological problems. Families and social services will incur financial costs potentially well into the hundreds of thousands of dollars and strains many underfunded systems in society.

TESTIMONY EXCERPTS

Alexander Nweeia, Sr.

CT Resident - Parent

As a finance professional, I value disciplined budgeting, risk assessment, and evidence-based decision-making. I never expected to consider leaving Connecticut to secure medically necessary care for my children, yet this became necessary when treatment for PANS and PANDAS was recommended, and insurance coverage was unavailable. When access to care depends on state lines, the policy framework is failing.

The economic impact is clear. Denying or delaying treatment does not eliminate costs; it shifts and increases them through prolonged special education, out-of-district placements, emergency psychiatric care, lost wages, and reduced long-term earning potential. Massachusetts, Rhode Island, and New Hampshire, along with many other states, have mandated PANS and PANDAS coverage. Rhode Island’s data shows that utilization and costs are measurable and contained. These mandates have not destabilized insurance markets.

Aetna, a national insurer, now recognizes PANS and PANDAS and provides IVIG and other immune-modulating treatments when medically necessary, but only for pediatric patients, even though PANS has no defined age limit. This discrepancy must be addressed.

Adults who were not treated appropriately as children, as well as those with adult-onset disease, need comprehensive coverage. They should not be denied care or face discrimination based on age when the medical condition persists beyond childhood.

Beyond economics, there is a fundamental moral issue. Denying or delaying medically recommended care for deteriorating patients, including those at risk of suicide, is unacceptable. The state should not adopt policies that fail to protect patients.

Mary Mennillo

Rhode Island Resident - parent

Rhode Island’s mandate has worked. The 2024 report from the Office of the Health Insurance Commissioner confirmed that the premium impact of this coverage has been minimal — measured in pennies or fractions of pennies per member per month. The law did not destabilize our insurance system. It simply ensured that families like mine could access medically necessary care without financial ruin or prolonged appeals.

It is hard to understand why families in Connecticut, just miles away, should not have the same protection and access. Medical necessity does not stop at a state line. I respectfully urge you to pass HB5374 so that Connecticut families can have the same chance at recovery that my daughter had. Please take serious consideration in helping Connecticut families save their children and provide them with a promising future.

Emily Klein

Rhode Island Resident - parent

In December 2024, the Rhode Island Office of the Health Insurance Commissioner released its review of the mandate. While the report was limited to examining short-term insurer savings, it confirmed that the premium impact of coverage has been minimal — measured in pennies or fractions of pennies per member per month. Importantly, the report did not identify destabilizing cost growth. In other words, the mandate has not harmed our insurance market.

It is difficult to understand why families just across the state line in Connecticut should face less consistent access to care for the same medical condition. Geography should not determine whether a patient can receive medically necessary treatment.