



PANS PANDAS

LEGISLATIVE ACTION

PANS PANDAS Information for Legislators

Pediatric Acute-onset Neuropsychiatric Syndrome

Pediatric Autoimmune Neuropsychiatric Disorders Associated With Streptococcal Infections

Updated: February 2026



ASPIRE
Alliance to Solve PANS &
Immune-Related Encephalopathies

WHAT ARE PANS/PANDAS

PANS and PANDAS are clinical conditions defined by the acute onset of Obsessive Compulsive Symptoms (OCD) and/or severe eating restrictions concurrent with at least two symptoms from the following seven cognitive, behavioral, or neurological categories

- Anxiety/Separation Anxiety
- Emotional Lability and/or Depression
- Irritability, Aggression, Severe Oppositional Behavior
- Behavioral/Developmental Regression
- Deterioration in school performance (Loss of math skills, handwriting changes, & ADHD-like behaviors)
- Sensory or motor abnormalities, including tics
- Somatic symptoms, including sleep disturbances, enuresis or urinary frequency

+ Symptoms are not better explained by a known neurologic or medical disorder

+ Age requirement – None

doi: [10.1089/cap.2014.0084](https://doi.org/10.1089/cap.2014.0084)

PREVALANCE

The true number of individuals affected by PANS and PANDAS is unknown due to underdiagnosis and misdiagnosis, and the absence of nationwide data collection further obscures the scope of need. Available prevalence research suggests the condition may affect approximately 1 in 11,765 children ages 3–12, though this likely underestimates the true prevalence, and incidence in adults has not been systematically studied. doi: [10.3389/fped.2023.1170379](https://doi.org/10.3389/fped.2023.1170379)

COST IMPACT

An analysis conducted by the Virginia Board of Insurance estimated the cost of mandated insurance coverage for PANS and PANDAS at \$0.0046 per member per month, or less than half a cent. This finding demonstrates that coverage does not represent a meaningful financial burden to insurers or employers. While cost estimates vary by state, Virginia's analysis is consistent with actuarial findings in other states that have evaluated similar mandates, showing minimal impact when spread across the insured population.

INSURANCE COVERAGE FOR PANS AND PANDAS

Insurance denials delay medically necessary care.

- Patients with PANS and PANDAS are frequently denied coverage for physician-prescribed treatments, resulting in delayed or incomplete care.

Delayed treatment causes preventable long-term harm.

- Misdiagnosis and psychiatric-only care increase the risk of ongoing neuroinflammation, permanent impairment, and missed opportunities for recovery.

Untreated illness increases public dependence.

- Delayed or denied care can result in lifelong neurological or functional disability and long-term reliance on public services.

The human consequences are severe.

- Delayed or denied care has been associated with death by suicide among pediatric and adult patients and, in some cases, their parents, as well as severe medical complications.

Families bear overwhelming economic costs.

- Care demands often force parents to leave the workforce, deplete savings, and rely on public benefits to meet medical needs.

Costs shift to emergency and crisis systems.

- Without timely treatment, patients cycle through emergency care, law enforcement involvement, and hospitalization, increasing costs without addressing the underlying illness.

Diagnostic & Treatment Guidelines

The National Institute of Mental Health (NIMH), led by Dr. Susan Swedo, has studied PANS for nearly thirty years. The PANS Research Consortium (PRC), a group of clinicians and researchers from leading universities and hospitals, fields of immunology, infectious disease, microbiology, neuroimmunology, neurology, pediatrics, psychiatry, and rheumatology lead the way by continuing with research and writing clinical diagnostic and treatment guidelines. The PRC published a consensus of diagnostic criteria in the Journal of Child and Adolescent Psychopharmacology in 2015.

In 2017, the PRC published treatment guidelines in the Journal of Child and Adolescent Psychopharmacology. The treatment guidelines were developed by experts from over 24 academic institutions, including Georgetown, Columbia, Yale, Harvard, and Stanford, and pooled data and clinical experience from over 1000 PANS patients. These guidelines represent best practice recommendations. The guidelines are divided into four sections: Overview, Part I- psychiatric and behavioral interventions, Part II- use of immunomodulatory therapies, and Part III- treatment and prevention of infections.

Epidemiology

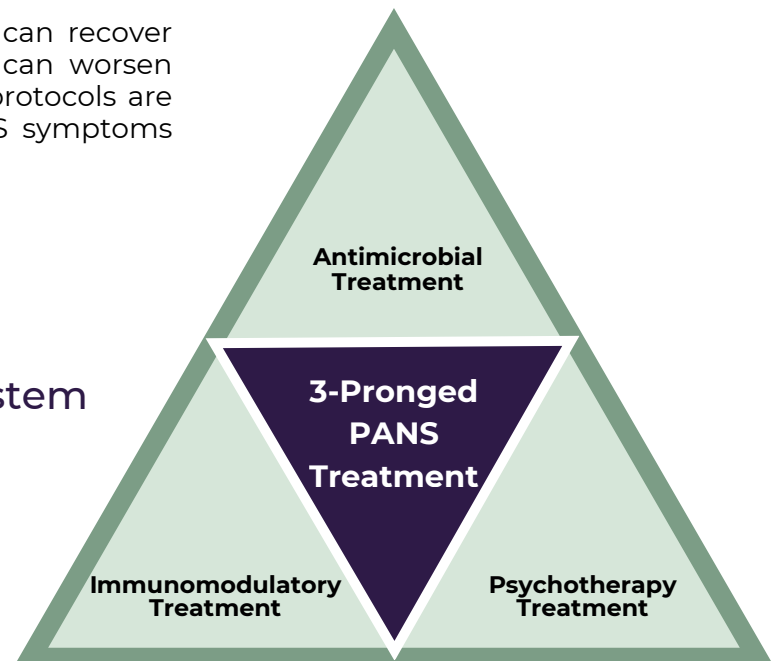
- Peak age at onset = 6.5 years
- Boys outnumber girls approximately 2:1
- 1 in 250 children have impairing symptoms (estimates from clinic populations)
- 5 – 10% of grade-school aged children have observable GAS-related neurologic and behavioral symptoms
- Average age of diagnosis is between 4-13 years of age
- Nationwide, 33% of children see more than five doctors before being correctly diagnosed

Three Complimentary Modes of Intervention

PANS treatment involves a three-pronged approach that uses psychiatric medications as needed to provide relief of symptoms, antibiotics to remove the source of neuroinflammation if the trigger is infectious in nature, and immune-modulating and anti-inflammatory therapies to treat immune system disturbances. Physical examination, laboratory testing results, and the course and severity of PANS symptomatology impact the specific treatment choices. Primary care providers can treat most PANS symptoms with guidance from the published treatment recommendations. Experienced PANS/PANDAS clinicians may need to treat patients with complex clinical presentations or severe or life-threatening symptoms.

If treated promptly and appropriately, patients can recover completely; if not, neuropsychiatric symptoms can worsen and become chronic. Individualized treatment protocols are dependent on the severity and course of PANS symptoms along with a physical exam and lab testing.

- **Remove inflammatory source**
with antimicrobial treatments or other treatments depending on trigger
- **Treat dysregulated immune system**
with immune-modulating and/or anti-inflammatory interventions
- **Alleviate symptoms**
with psychotherapeutic treatments, including psychotherapies and psychotropic medications as needed



Overview of Treatment of PANS-JCAP Vol27, 2017
Swedo, MD, Frankovich, MD, MS, Murphy, MD, MS

INSURANCE COVERAGE FOR PANS/PANDAS: FISCAL EVIDENCE FROM OTHER STATES

A primary consideration for legislatures evaluating insurance mandates is whether such policies will significantly increase premiums. Fiscal analyses from multiple states examining similar legislation consistently indicate that the cost impact of covering PANS/PANDAS treatment is minimal.

EVIDENCE FROM OTHER STATES

Independent fiscal analyses in California, Virginia, and Nebraska assessed the potential costs associated with mandating insurance coverage for PANS/PANDAS treatment, including intravenous immunoglobulin (IVIG) and related immune-directed therapies. Although different modeling approaches were employed, each state reached similar conclusions regarding the fiscal impact. Across states, these analyses consistently demonstrate that the cost of coverage amounts to only a few cents per month per insured member.

- California estimated that statewide coverage would increase total health expenditures by approximately \$2.99 million annually, equating to about one cent per member per month.
- Virginia projected an annual impact of approximately \$1.6 million for its state employee health plan, corresponding to approximately \$0.20 to \$0.30 per member per month.
- Nebraska estimated the premium impact at approximately \$0.03 to \$0.25 per member per month and noted that the number of patients expected to require treatment each year is very small.

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.)

WHY THE COST IMPACT IS SMALL

PANS/PANDAS is a severe neuroimmune condition. Only a small subset of patients require immune-directed treatments such as IVIG. Because the number of affected individuals is small relative to the overall insured population, the financial impact on premiums remains minimal when costs are spread across the insurance pool.

THE COST OF INACTION

Although the premium impact of coverage is minimal, untreated or inadequately treated PANS/PANDAS can result in significant downstream costs, including:

- psychiatric hospitalizations
- emergency department visits
- residential treatment programs
- intensive special education services
- loss of workforce participation for caregivers
- long-term disability care

These costs are frequently borne by schools, families, long term psychiatric care, disability systems, and other components of the public infrastructure, rather than the health insurance system. In the absence of timely treatment, expenses are often shifted to the most costly and least effective sectors of the system.

CONCLUSION

Fiscal analyses across multiple states demonstrate that requiring insurance coverage for PANS/PANDAS treatment results in a very small premium impact, typically measured in a few cents per member per month.

For Connecticut policymakers, this indicates that the proposal does not create a substantial new insurance liability. Rather, it distributes the cost of treating a small number of severely ill patients across the insurance pool and helps prevent significantly higher downstream costs in psychiatric care, special education, and long-term disability systems.

ON TREATMENT & THE USE OF IVIG

Source: Massachusetts H947 S613 Point Paper and MEDICAL EFFICACY UPDATE: AN ACT RELATIVE TO INSURANCE COVERAGE FOR PANDAS/PANS (H.947/S.613)

- Mild to moderate cases of PANDAS/PANS are often managed successfully with antibiotic and nonsteroidal anti-inflammatory therapy.
- More severely afflicted patients frequently require prednisone and psychotropic medications.
- A small but significant subset, an estimated 10% of referred children, fail to improve with these conventional measures and require treatment with intravenous immunoglobulin (IVIG).
- IVIG therapy has been recommended in the 2017 guidelines prepared by the PANS Research Consortium immunomodulatory task force (PRC-ITF), comprised of immunologists, rheumatologists, neurologists, infectious disease experts, general pediatricians, psychiatrists, nurse practitioners, and basic science experts in neuroimmunology.
- Although IVIG is found to be effective in the majority of treated patients and is often sufficient to restore a meaningful recovery with a return to school and normalization of household life, administration of IVIG has been extraordinarily difficult to attain.

WHY PASSAGE OF LEGISLATION IS CRITICAL

Source: Massachusetts H947 S613 Point Paper and MEDICAL EFFICACY UPDATE: AN ACT RELATIVE TO INSURANCE COVERAGE FOR PANDAS/PANS (H.947/S.613)

- Despite the consensus recommendation of the PANS Research Consortium, IVIG for the treatment of severe PANDAS and PANS patients is almost universally denied by insurers. The appeals process is not structured to include a physician who is an expert in the management of these conditions, and clinicians are frustrated by their inability to discuss IVIG approval objectively with an expert.
- The protracted denial and appeals process of insurance coverage delays and often derails the initiation of critical immune therapy for these children. Tragically, this puts them at risk of further decline and potential long-term disability as their brain inflammation remains untreated.
- The family and the state inevitably shoulder the burdens of delayed treatment in terms of significant costs associated with social services, medical treatments, and educational support.
- IVIG therapy, which is considered in a small subset of the most ill PANDAS/PANS patients, many of whom have extreme impairments or life-threatening symptoms, is not currently covered by insurance in Massachusetts. At this time, families often travel to providers in Illinois, New York, New Jersey, or Washington D.C. for therapy, adding to the families' expense and logistical difficulty.
- The Center for Health Information Analysis (CHIA) of the Commonwealth of Massachusetts conducted an actuarial assessment in 2015. It concluded, "requiring coverage for this benefit by fully-insured health plans would result in an average annual increase, over five years, to the typical member's monthly health insurance premiums of between \$0.003 (0.001%) and \$0.039 (0.008%) per year."
- A recent Medical Efficiency Update summarized literature published in the past four years. These peer-reviewed studies, systematic reviews, and international guidelines recommend IVIG to treat a subset of patients with PANDAS and PANS and support its efficacy.

ADDRESSING INSURANCE COVERAGE GAPS FOR PANS AND PANDAS

Mandated Insurance Coverage for PANS/PANDAS

PANS/PANDAS are immune-mediated conditions characterized by sudden onset or newly worsening of severe neuropsychiatric symptoms, including obsessive-compulsive symptoms, restricted eating, anxiety, aggression, cognitive impairment, and functional decline. Without timely diagnosis and appropriate medical treatment, these conditions can become profoundly disabling and, in some cases, permanently life-altering.

Actuarial analysis has shown that mandated insurance coverage for PANS and PANDAS can be provided at minimal cost, measured in fractions of a cent per member per month, while preventing far greater long-term medical, educational, and public-system costs.

The Issue

PANS/PANDAS patients frequently face insurance denials for physician-prescribed treatments, including immune-based therapies, even when those treatments are medically indicated and supported by clinical expertise. Inconsistent recognition of PANS and PANDAS across insurance policies contributes to delayed diagnosis and treatment and reinforces gaps in clinician education.

Because these conditions are often under or misdiagnosed, the true number of affected individuals remains unknown, and the absence of nationwide data collection obscures the scope of the need. Without clear coverage standards, patients may endure prolonged misdiagnosis, inappropriate psychiatric-only treatment, and delayed care, increasing the risk of ongoing neuroinflammation, long-term disability, and unnecessary reliance on emergency services, inpatient hospitalization, special education systems, and public benefits.

Families and adult patients are frequently forced to pay out of pocket, deplete savings, or forgo treatment entirely, resulting in inequitable access to care based on financial means rather than medical necessity.

The Solution

Mandated insurance coverage for PANS/PANDAS ensures that medically necessary, physician-prescribed care is accessible and reviewable under clear standards rather than categorically excluded.

Insurance mandates allow coverage determinations to be based on medical necessity, peer-reviewed evidence, and clinical judgment, rather than blanket denials. This approach supports timely treatment, improves outcomes, and reduces long-term costs associated with delayed or inappropriate care.

The Precedent

Insurance coverage for PANS/PANDAS has already been established in multiple states through legislation or policy. Coverage exists in at least the following states: 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 by state and insurer.

These actions reflect growing acknowledgment that early and appropriate treatment reduces long-term disability, educational disruption, and public system burden.

THE NEED FOR MANDATED INSURANCE COVERAGE FOR PANS AND PANDAS

The Cost of Inaction

Medical System Impact

- Early identification and appropriate treatment of PANS/PANDAS often result in less costly interventions that may only be needed for a limited time. Not all PANS and PANDAS patients require high-cost immunomodulatory treatment.
- Delayed or denied care drives higher overall healthcare utilization and long-term costs by shifting care from recovery-focused treatment to ongoing symptom management.
 - Repeated emergency visits, unnecessary hospitalizations, and prolonged psychiatric treatment
 - Increased likelihood of intensive or lifelong interventions
 - Involvement of police, emergency responders, and crisis services as symptoms escalate

Long-Term Disability

- Missed treatment windows can turn a treatable illness into a lifelong disorder. Delays in diagnosis and treatment increase the risk of:
 - Permanent neurological, cognitive, or functional impairment
 - Lifelong dependence on public services, disability supports, and specialized care

Educational System Burden

- Delayed or denied medical care frequently prevents students from accessing the curriculum, causing educational disruptions that may persist for years but are often avoidable with timely treatment.
- Most students require formal accommodations, such as 504 plans and IEPs.
- Many need prolonged homebound or hospital-based instruction.
- Some require outplacement, specialized tutoring, or alternative educational settings.

Economic Impact on Families and Workforce

- Many families require at least one parent to leave or reduce employment to provide full-time care.
- Loss of household income reduces tax revenue and economic participation, may require unemployment benefits or family leave, and increases reliance on public benefits.
- Long-term financial instability: Families sell homes, deplete savings, incur substantial debt, and exhaust retirement accounts, permanently eliminating future financial security.
- Adult patients may be unable to sustain employment and ultimately rely on disability benefits.

Disparities and Inequity

- Lack of mandated coverage disproportionately harms low-income and marginalized families.
- Access to care depends on finances rather than medical necessity.
- Delayed diagnosis and poorer outcomes reinforce racial, economic, and educational inequities.

Human Cost

- PANS/PANDAS can cause severe, debilitating neuropsychiatric symptoms, including OCD, restricted eating, anxiety, aggression, and suicidality.
- Delayed diagnosis and treatment can erase a child's childhood, which cannot be recovered.
- Adult life trajectories are permanently altered, affecting education, employment, relationships, independence, and quality of life.
- Family systems are profoundly disrupted, often resulting in secondary trauma for siblings.
- Caregiver burden is exceptionally high, rivaling other severe chronic conditions.
- Delayed or denied care has been associated with death by suicide among pediatric and adult patients and, in some cases, their parents, as well as severe medical complications, including those secondary to anorexia.

WHY STATE-MANDATED COVERAGE FOR PANS/PANDAS IS NOW EVEN MORE JUSTIFIED

Aetna's Update Medical Policy

Aetna has updated its medical policy to recognize PANS/PANDAS and to cover IVIG when medically necessary for patients who meet specific diagnostic and clinical criteria. This decision is significant not only for Aetna members, but also for states considering whether to require insurance coverage for PANS by law.

Aetna's policy affirms that PANS/PANDAS are serious, immune-mediated medical conditions rather than solely psychiatric disorders. Delayed or denied treatment can cause significant and lasting harm. By requiring clear diagnostic criteria, documentation of disease progression, prior treatment attempts, and objective outcome measures, **Aetna shows that coverage can be responsible, evidence-based, and clinically appropriate.**

The Equity Problem State Mandates Must Solve

Currently, access to care depends largely on a child's insurance provider. Some families can obtain disease-modifying treatment such as IVIG, while others in the same state with the same diagnosis cannot. This results in a two-tiered system where:

- Children with identical clinical presentations receive vastly different care
- Families are forced into medical debt, prolonged suffering, or repeated hospitalizations
- Outcomes worsen simply because coverage is inconsistent
- Lower-income patients and families are disproportionately affected. Those unable to pay out of pocket are more likely to experience delayed care, incomplete treatment, and poorer long-term outcomes when coverage is denied.

State-mandated coverage is designed to address this disparity. When a major national insurer recognizes medical necessity and others do not, legislatures have both the authority and responsibility to intervene.

Aetna's Policy Sets a Practical, Replicable Standard

Aetna's criteria demonstrate to lawmakers that mandated coverage does not allow for unrestricted treatment. Coverage is based on:

- Established diagnostic criteria from expert consensus
- Objective symptom measurement tools
- Demonstrated clinical response to therapy
- Documentation that other causes have been ruled out

States can adopt this framework to ensure appropriate access while maintaining necessary clinical safeguards.

The Broader Policy Implication

When a national insurer acknowledges that immune-targeted treatment for PANS/PANDAS can be medically necessary and potentially lifesaving, it challenges the argument that such care is "experimental" or inappropriate for coverage. **Insurance mandates now serve to align policy with current medical practice.**

The Bottom Line for Legislators

- Aetna's policy confirms medical legitimacy
- Inconsistent coverage creates inequity and harm
- State mandates ensure fair, timely access to care
- Clear criteria already exist to guide coverage responsibly

WHY STATE-MANDATED COVERAGE FOR PANS/PANDAS IS NOW EVEN MORE JUSTIFIED

PANS Is Not Limited to Childhood and Coverage Must Reflect That Reality

Although PANS was initially described in pediatric populations, its diagnostic criteria do not specify an age limit.

Restricting insurance coverage based on age, rather than diagnostic criteria and medical necessity, creates an arbitrary barrier to care that is not supported by the diagnostic framework for PANS.

Adults can meet these criteria, and many adults living with PANS today either:

- Experienced onset in childhood and remains symptomatic due to delayed or inadequate treatment, or
- Experience acute-onset neuropsychiatric symptoms later in life following infection or immune activation

The consequences of this gap are significant. Adults with untreated or undertreated PANS often face:

- Recurrent or persistent OCD and severe anxiety
- Functional impairment affecting employment, education, and independent living
- Repeated psychiatric hospitalizations that fail to address the underlying immune driver of symptoms

As with children, delayed or denied access to appropriate medical treatment in adults increases long-term disability and overall healthcare costs.

Why This Matters for Insurance Mandates

Many insurance policies and some proposed legislation implicitly or explicitly frame PANS as a pediatric-only condition. This approach is increasingly inconsistent with clinical reality and leaves adults without access to medically necessary care, even when they meet established diagnostic and clinical criteria.

State-mandated coverage must therefore:

- Tie eligibility to diagnosis and medical necessity, not age
- Ensure continuity of care for individuals diagnosed in childhood as they transition into adulthood
- Prevent coverage loss solely due to aging out of pediatric benefit structures

Aligning Policy with Medical Practice

Recognizing PANS across the lifespan strengthens, rather than weakens, coverage standards. A consistent, criteria-based approach ensures that patients are evaluated on clinical presentation, objective measures, and documented response to treatment, regardless of age.

Medical necessity does not change with age. State insurance mandates should reflect the full scope of PANS as a treatable, immune-mediated condition affecting both children and adults.

UNDERSTANDING RHODE ISLAND'S PANS/PANDAS INSURANCE REPORT

The Rhode Island Office of the Health Insurance Commissioner (OHIC) released an insurance report in December 2024 evaluating the state's mandate for PANS and PANDAS. As the report is cited in policy discussions, it's important to clarify its scope and limitations. Download report: https://ohic.ri.gov/sites/g/files/xkgbur736/files/2025-01/PANDAS_PANS%20Report%20to%20the%20Legislature%20December%202024.pdf

Legislative Takeaway

- The OHIC report was required to answer a narrow statutory question about short-term insurer savings, not whether PANS/PANDAS coverage is medically necessary or beneficial to families.
- The report does not find insurer savings, but it also finds that mandated coverage has only a minimal impact on premiums, consistently measured in pennies or fractions of pennies per member per month.
- Claims data is inherently unreliable due to the lack of specific diagnostic codes, making it difficult to draw firm conclusions about utilization or cost trends.
- The analysis does not evaluate the cost of delayed or denied care, including psychiatric hospitalizations, school disruption, long-term disability, or family financial strain.
- Repealing the mandate would not meaningfully reduce premiums, but would likely reintroduce coverage denials, delayed treatment, and inequitable access, particularly for families unable to pay out of pocket.

Policy implication: The report supports maintaining mandated PANS/PANDAS coverage as a low-cost, access-protecting benefit rather than rolling it back based on an analysis that was never designed to measure the full cost of the condition.

What The Report Measured

OHIC was required by law to answer a very specific question:

Does mandated PANS/PANDAS coverage produce direct cost savings for insurers or policyholders?

This narrow focus is significant. The law restricts what OHIC can analyze. **The scope of the report is determined by statute, not by medical or family need.** The report does not address:

- The cost of delayed or denied treatment
- Psychiatric hospitalizations or emergency care
- Special education services
- Long-term disability or public assistance
- Lost parental income or family financial strain

OHIC acknowledges these limitations throughout the report. **In other words, the analysis was never designed to capture the full cost of PANS/PANDAS or the cost of failing to treat it early.**

UNDERSTANDING RHODE ISLAND'S PANS/PANDAS INSURANCE REPORT

What OHIC found

Within this limited framework, OHIC concluded there is no evidence that mandated PANS/PANDAS coverage results in *net savings* for insurers.

This finding is often misunderstood. It does **not** mean:

- The coverage is expensive
- The treatment is ineffective
- The mandate was a mistake

It simply reflects that the law defines “benefit” primarily as short-term insurer savings, excluding areas where early treatment could prevent significantly higher costs. **Those excluded areas are often where families, schools, and public systems bear the greatest burden.**

What the Report Shows About Premium Impact

Although OHIC did not find insurer savings, it consistently found that mandated PANS/PANDAS coverage has only a minimal impact on insurance premiums across carriers and comparison states, one of the report’s clearest conclusions.

Across insurers and comparisons with other states:

- Estimated costs range from fractions of a cent to a few cents per member per month
- UnitedHealthcare described the cost as “immaterial” and did not include it in rate filings
- Cigna estimated \$0.01–\$0.02 per member per month
- Analyses from Massachusetts, California, and Maine also found similarly negligible impacts.

Limits of the Available Claims Data

The report also makes clear that the available data is flawed, through no fault of families or clinicians. OHIC is transparent about these limitations.

There are still **no specific diagnostic billing codes** for PANS or PANDAS. As a result:

- Claims are often coded as autoimmune encephalitis or broad immune disorders
- Data likely over-includes non-PANS cases and misses true PANS/PANDAS patients
- One insurer noted that its data included children under age 2 and adults over age 50
- Small numbers make year-to-year trends unreliable

OHIC repeatedly cautions against drawing definitive conclusions from these numbers. This makes it difficult to use claims data alone to assess utilization, outcomes, or cost trends related to PANS/PANDAS.

UNDERSTANDING RHODE ISLAND'S PANS/PANDAS INSURANCE REPORT

How the Mandate Changed Access

In many cases, treatments such as IVIG were already covered before the mandate. The law did not create an entirely new benefit from scratch. The law often:

- Standardized access
- Reduced discretionary denials
- Provided clarity for families and providers

Importantly, insurers did not report significant increases in utilization after the mandate took effect. This suggests the law primarily improved consistency and access, rather than driving overuse or unnecessary treatment.

What the report does not measure: the cost of inaction

The report does not examine the consequences of untreated or delayed PANS/PANDAS. It does not capture:

- Psychiatric crises and hospitalizations
- School failure and long-term educational impact
- Family financial collapse
- Long-term dependence on public systems

OHIC explicitly states that these outcomes are outside the scope of the analysis, even though they often represent the highest and most lasting costs. These are also the costs most frequently described by families living with PANS/PANDAS.

Policy Implications

Taken together, the report supports a straightforward conclusion:

- Mandated PANS/PANDAS coverage does not produce measurable insurer savings under a very narrow definition of “benefit.”
- It also does not meaningfully raise insurance premiums
- This places PANS/PANDAS coverage alongside many long-standing mandated benefits that are medically necessary and ensure equitable access, not because they save insurers money.

Repealing the mandate would not significantly lower premiums. However, it would increase the risk of coverage denials, delayed care, and unequal access, especially for families unable to pay out of pocket. For many families, that gap in access can determine whether a child receives timely medical care or spirals into crisis.

Our Mission

To improve the lives of children and adults affected by PANS, PANDAS, and immune-related encephalopathies.

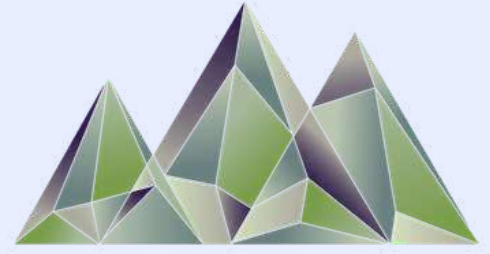
Our Vision

We aspire to create a world where children and adults affected by PANS, PANDAS and related encephalopathies obtain a timely diagnosis from informed providers and receive effective, proven and affordable treatments and support in all areas of daily living, without discrimination.

Who We Are

We are experienced leaders in the PANS advocacy community. We are parents, providers and experts in our field who believe collaboration and empowered action are the keys to the world we seek: one where no one suffers through PANS and immune-related encephalopathies without access to a knowledgeable provider, insurance coverage for standard-of-care treatments or the support that comes with public awareness.

We work collaboratively to improve the quality of life for those affected by PANS, PANDAS and immune-related encephalopathies. We focus our efforts on empowering and connecting our community with tools and resources for advocacy, education, support, and awareness.



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