

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.