

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

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.