Connecticut PANS/PANDAS Partnership

April 13, 2026

Dear Members of the New York State Assembly Insurance Committee and Senate Insurance Committee,

As a Connecticut-based PANS/PANDAS advocacy steering committee, we express our strong support for **New York State Assembly Bill A9659 and Senate Bill S2655A**, which would require health insurance policies to cover treatment for Pediatric Acute-Onset Neuropsychiatric Syndrome (PANS).

In supporting families across state lines, we witness the consequences when insurance coverage is unavailable for this condition. PANS is a serious immune-mediated disorder marked by the sudden onset of severe neuropsychiatric symptoms, such as obsessive-compulsive behaviors, restricted eating, anxiety, cognitive decline, and functional impairment. Without timely and appropriate treatment, patients may face prolonged illness, significant disability, and, in some cases, life-threatening complications.

Early intervention is essential. When treatment is accessible, many patients improve and return to typical functioning. Delayed or denied care leads to worse outcomes and requires more intensive, costly interventions over time.

Lack of insurance coverage creates unnecessary barriers to care. Families often face repeated denials and appeals, delaying treatment during the most critical period for recovery. Many must pay out of pocket for medically necessary care, resulting in financial hardship, loss of income, and long-term instability.

The impact extends beyond the healthcare system. Untreated PANS leads to increased use of emergency services, psychiatric hospitalizations, and long-term educational supports. Denying care does not eliminate costs; instead, they shift to families, schools, and public systems, often resulting in significantly higher long-term expenses.

New York would not be acting alone. Several states have already implemented PANS/PANDAS insurance mandates or coverage policies, demonstrating that these measures are both feasible and responsible. Actuarial analyses consistently show that the cost of mandated coverage is minimal, while the cost of inaction is substantial.

This legislation is a practical and necessary step to:

- Ensure access to medically necessary care
- Reduce long-term disability and system-wide costs
- Promote equity across insurance plans and patient populations
- Allow medical decisions to be made by treating clinicians

We urge you to support and advance A9659 and S2655A. Families should not have to fight their insurance company while their child's condition worsens. Access to care should not depend on location or financial means.

Thank you for your time and consideration, and for your commitment to improving outcomes for patients and families impacted by PANS and PANDAS.

Sincerely,

Lisa Williams
On behalf of the Connecticut PANS/PANDAS Advocacy Steering Committee

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