April 13, 2026

Dear New York State Assembly Insurance Committee and Assemblyman Weprin; New York State Senate Insurance Committee and Senator Bailey,

I am writing to urge you to support **NYS Assembly Bill A9659 and NYS Senate Bill S2655A - Requires health insurance policies to cover costs for pediatric acute-onset neuropsychiatric syndrome rehabilitation treatment.** Passage of this bill will have a meaningful and immediate impact on patients and families affected by Pediatric Acute-Onset Neuropsychiatric Syndrome (PANS).

Early and comprehensive treatment is critical to achieving optimal outcomes. Patients who receive appropriate care within the first year of symptom onset often experience significant recovery. In contrast, when treatment is delayed or denied, symptoms can worsen, and patients may require more invasive interventions. Due to the lack of insurance coverage for PANS, families frequently face prolonged cycles of denials and appeals that delay or prevent access to medically necessary immune-based treatments. These delays can result in worsening brain inflammation, increased symptom severity, and, in some cases, long-term disability. Without appropriate treatment, patients may remain neurologically and psychiatrically affected throughout childhood and into adulthood.

It is fiscally responsible to identify and treat this illness early rather than allow it to progress into a condition requiring years—or even a lifetime—of care. Failure to treat PANS places an extraordinary burden not only on patients, but also on families, schools, and community systems. We must act now to reduce the financial, emotional, and physical toll of this disease by ensuring insurance coverage for PANS and PANDAS.

Current research demonstrates that PANS has multiple etiologies and is increasingly understood as a form of autoimmune encephalopathy—characterized by inflammation of the brain—often triggered by common infections such as streptococcal infections or mycoplasma pneumonia. Physicians are already prescribing medically necessary and evidence-supported treatments for PANS/PANDAS, which may include long-term antibiotics, steroids, intravenous immunoglobulin (IVIG), and, in rare, severe cases, plasmapheresis. IVIG is used in a small subset of patients with severe symptoms and is considered disease-modifying, with the potential to halt the autoimmune process. When diagnosed and treated appropriately, many patients can recover using the least invasive interventions available, allowing them to return to healthy, functional lives.

The Alliance to Solve PANS & Immune-Related Encephalopathies (ASPIRE) speaks with physicians, therapists, families, and educators every day. While PANS is considered a rare condition, its impact on affected children, families, schools, and communities is profound.

We routinely hear from families who are forced to sell their homes, exhaust savings, and accumulate significant debt to access care. The disease disrupts family life through severe symptoms such as obsessive-compulsive behaviors, separation anxiety, rage, restricted eating, sleep disturbances, and more. In some families, multiple children are affected. Caregivers are often forced to leave the workforce to provide full-time care for a medically ill child.

The consequences of untreated PANS extend into the education system as well. Children commonly miss substantial amounts of school and require extensive supports upon return. Symptoms often include regression in handwriting, fine motor skills, and math abilities, as well as school refusal and behavioral difficulties. Without treatment, children may require long-term special education services through IEPs or 504 plans, rather than short-term supports during recovery.

Please support **NYS Assembly Bill A9659 and NYS Senate Bill S2655A** as it will allow physicians to treat patients according to their clinical judgment without placing the burden of insurance appeals on already overwhelmed families. Prolonged denials and delays place children at risk of further deterioration and long-term disability. This legislation supports both good medicine and responsible stewardship of healthcare resources.

Critically ill patients with PANS and PANDAS in New York need your help to access appropriate medical care. Families cannot wait. While we remain hopeful that one day all insurers will recognize and cover PANS, the children affected today require action now. It is imperative that you and your fellow legislators support and pass **NYS Assembly Bill A9659 and NYS Senate Bill S2655A**. This is a bipartisan issue, and your constituents deserve access to insurance coverage when faced with the serious medical challenges PANS presents.

Please feel free to contact me with any questions or for additional information. Thank you for your time, consideration, and continued efforts to support families in our community so that children can heal, grow, and reach their full potential.

Best regards,

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