RE: Requires health insurance policies to cover costs for pediatric acute-onset neuropsychiatric syndrome rehabilitation treatment.

April 14, 2026

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

My name is Jennifer Vitelli, Executive Director of the Look. Foundation, a nonprofit dedicated to supporting children and young adults affected by PANS and PANDAS, as well as their families.

PANS and PANDAS are medical conditions often triggered by infections such as strep, Lyme disease, COVID-19, or other pathogens that cause inflammation in the brain. The symptoms can look exactly like mental illness: sudden-onset OCD, eating restriction, rage, tics, severe anxiety, depression, and even suicidal thoughts. But these are symptoms of immune-mediated brain inflammation.

With proper diagnosis and appropriate medical treatment, children and young adults can heal.

The stakes are enormous. Roughly 1 in 5 children experiences a mental health disorder each year, and suicide is the second leading cause of death among young people ages 10 to 24. When a treatable medical condition is left unrecognized or untreated, the consequences can be devastating.

Despite consensus treatment recommendations from the PANS Research Consortium and other multidisciplinary experts, families frequently encounter insurance denials for immune-modulating therapies recommended by qualified physicians. The appeals process often lacks review by clinicians with specific expertise in these conditions, leaving treating providers unable to meaningfully discuss medical necessity with knowledgeable peers.

Prolonged denials delay initiation of critical immune therapies. During that time, inflammation may persist, symptoms may worsen, and children may experience further functional decline. When treatment is delayed, the burden does not disappear. It shifts to families and to the state through increased emergency department visits, psychiatric hospitalizations, educational disruption, and long-term support needs.

Intravenous immunoglobulin, or IVIG, is considered only in a small subset of the most severely affected children, approximately 10 percent, often those with extreme impairment or life-threatening symptoms. When medically indicated, access to this therapy can be pivotal in stabilizing and restoring a child's functioning.

On a personal note, three of my four children developed PANS and PANDAS at ages 4, 5, and 9. It was a long, terrifying, and extraordinarily expensive journey back to wellness. Today, they

are thriving, now 16, 22, and 23, because they were properly diagnosed and treated. Recovery is possible when children are afforded appropriate care.

Gaps in coverage for immune therapy leave severely ill children waiting for necessary intervention. Prolonged barriers to care can contribute to worsening symptoms, increased reliance on emergency and inpatient psychiatric services, and, in some cases, tragic loss of life.

NYS Assembly Bill A9659 and NYS Senate Bill S2655A (*Requires health insurance policies to cover costs for pediatric acute-onset neuropsychiatric syndrome rehabilitation treatment)* address this gap by ensuring that decisions about medically necessary treatment for children with PANS and PANDAS remain grounded in clinical judgment between patients and their medical providers. Aligning insurance coverage with current medical understanding supports timely care and improves outcomes for children whose conditions are treatable.

New York's children deserve access to the full range of medically appropriate care when it is recommended by their physicians.

Thank you for your time and consideration.

Respectfully submitted,

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Executive Director

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