April 13, 2026

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

On behalf of the Alliance to Solve PANS and Immune-Related Encephalopathies (ASPIRE), we, the members of the ASPIRE Professional Advisory Board, write to express our strong support for **NYS Assembly Bill A9659 and NYS Senate Bill S2655A - Requires health insurance policies to cover costs for pediatric acute-onset neuropsychiatric syndrome rehabilitation treatment**. This bill will significantly improve the health and well-being of patients with PANS and ease the financial and emotional burdens on their families.

Pediatric Acute-Onset Neuropsychiatric Syndrome (PANS) is characterized by the abrupt and dramatic onset of obsessive-compulsive symptoms, restricted intake of food or fluids (sometimes to the point of starvation or dehydration), anxiety, depression and suicidality, emotional lability, personality changes, sensory hypersensitivity, cognitive deficits, and physical symptoms such as arthralgias, urinary dysfunction, and severe insomnia. As its name implies, PANS affects patients, primarily those pediatric patients. However, adults can also have PANS/PANDAS; it is not solely a pediatric disorder. A viral or bacterial infection triggers most cases; when Group A streptococcal infections (such as strep throat or impetigo) trigger symptoms, the disorder is known as Pediatric Autoimmune Neuropsychiatric Disorders Associated with Streptococcal Infections (PANDAS). In recent months, a number of studies have demonstrated that PANS/PANDAS is a form of autoimmune encephalopathy—or inflammation of the brain. Treatment of PANS/PANDAS involves a three-pronged approach that utilizes psychiatric medications to provide symptomatic relief, antibiotics to eliminate the source of neuroinflammation, and immune-modulating therapies to treat disturbances of the immune system. When these therapies are instituted promptly, many patients recover completely and return to full functioning.

Delays in obtaining treatment not only prolong the patient's suffering needlessly but also increase the risk that PANS/PANDAS

symptoms will become entrenched, leading to long-term psychiatric, neurologic, and cognitive dysfunction.

Unfortunately, there are currently several barriers that delay or prevent treatment of PANS/PANDAS. At the outset, families are confronted with a paucity of physicians available to treat PANS/PANDAS. Insurance coverage for PANS/PANDAS would address this concern through efforts to educate providers and raise awareness about PANS/PANDAS. Without such measures, many families must travel long distances to access treatment at great emotional and monetary expense. For others, the inability to travel due to financial circumstances or the severity of a child's illness postpones or precludes therapeutic interventions entirely.

Lack of insurance coverage for PANS/PANDAS further delays or, in some cases, completely prevents access to treatment. Particular difficulties are experienced with obtaining reimbursement for intravenous immunoglobulin (IVIG) and other immunotherapies. Insurers routinely deny coverage, and a lengthy cycle of repeated denials and appeals frustrates both healthcare providers and families. More importantly, the denials-and-appeals process prolongs patient suffering and family trauma and increases the risk of serious neurological and psychological harm, long-term disability, or even loss of life. Faced with continual denial of care, many families attempt to self-pay for treatment, forcing them to take on heavy credit card debt, deplete retirement or college funds, or sell their homes to raise funds to pay for care that should be covered by insurance.

While we acknowledge that the cost of immunotherapies (particularly IVIG) is substantial, it is small in comparison with the cost of emergency interventions, inpatient psychiatric treatment, and/or pediatric hospitalizations for complications of severe PANS/PANDAS, such as starvation, dehydration, aggressive behaviors, self-injury, or suicidality. Delayed or denied care also carries a risk of long-term care for serious neurological, emotional, and behavioral disabilities. In addition to increased medical expenditures, untreated PANS/PANDAS also increases education-related costs, as children often require specialized, individualized instruction and significant accommodations for cognitive, neuropsychological, and psychological dysfunction.

Since 2017, there have been several critical advances in research. In 2017, the PANS Research Consortium (PRC) published treatment guidelines in the *Journal of Child and Adolescent Psychopharmacology*. These guidelines are divided into four sections and represent best-practice recommendations: Overview; Part I—psychiatric and behavioral interventions; Part II—use of immunomodulatory therapies; and Part III—treatment and prevention of infections. In 2017 and 2020, two papers from Columbia University explained the mechanism of PANDAS by elucidating how autoantibodies enter the central nervous system due to persistent microglial

activation as a result of multiple Group A Streptococcus infections. In 2020, a double-blind study from Yale demonstrated that antibodies from children with PANDAS bind specifically to striatal cholinergic interneurons and alter their activity. “These findings provide strong evidence for striatal CINs as a critical cellular target that may contribute to pathophysiology in children with rapid-onset OCD symptoms, and perhaps in other conditions.” A 2020 study on IVIG for PANS provides further support for IVIG use in a small but significant subset of children who meet diagnostic criteria. These studies represent only a small sample of the scientific advancements being made in PANS/PANDAS research.

In closing, we ask that you alleviate the burdens placed on families, physicians, and community members striving to meet the critical needs of patients with PANS/PANDAS. Please enable physicians to make appropriate medical decisions free from administrative and time constraints imposed by insurance denials. We urge you to join your fellow legislators in Arkansas, California, Colorado, Delaware, Georgia, Illinois, Indiana, Louisiana, Maryland, Massachusetts, Minnesota, New Hampshire, Oregon, Rhode Island, Tennessee, and Virginia who require insurance coverage for PANS/PANDAS treatment. Your leadership on this important issue will help ensure that patients with PANS/PANDAS receive appropriate treatment, enabling them to experience childhood fully and reach their full potential.

Thank you for your time and consideration. Please do not hesitate to contact us if we can provide additional information or answer any questions that may arise.

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