



**ASPIRE Professional
Advisory Board**

Susan Swedo, MD

Scientist Emerita
National Institute of
Mental Health

Dritan Agalliu, PhD

Assistant Professor
Departments of
Neurology and Pathology
& Cell Biology Columbia
University

Margo Thienemann, MD

Co-Director PANS Clinic
and Director Psychiatric
Services, Stanford
University

Mark Pasternack, MD

Unit Chief, Pediatric
Infectious Disease, Mass
General for Children

**Fern Aaron Zagor,
LCSW, ACSW**

Principal Consultant,
Fern Zagor

**Nancy H. O'Hara, MD,
MPH, FAAP**

Integrative Pediatrics,
New England Center of
Health

Sydney Rice, MD, Msc

Developmental
Pediatrics, Co-Director
Childhood Autoimmune
Encephalopathy Clinic,
University of Arizona

**Anu French, MD, FAAP,
ABIM**

Integrative Pediatrician
SSM Health Cardinal
Glennon Pediatrics

Shannon L. Delaney, MD

Psychiatry, Child &
Adolescent Psychiatry
Private Practice

Christina Hift, MD, FAAP

Infectious Disease &
Pediatric Rheumatology,
Private Practice

January 30, 2026

Dear members of the Banking, Commerce and Insurance Committee,

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 **LB762, Require Insurance Coverage of Pediatric Autoimmune Disorders**. This bill will significantly improve outcomes for patients with Pediatric Acute-Onset Neuropsychiatric Syndrome (PANS) and reduce the financial and emotional burdens on their families.

PANS is characterized by the abrupt 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. While PANS primarily affects pediatric patients, adults can also have PANS/PANDAS; it is not solely a pediatric disorder. Most cases are triggered by infection. When Group A streptococcal infections trigger symptoms, the disorder is known as Pediatric Autoimmune Neuropsychiatric Disorders Associated with Streptococcal Infections (PANDAS).

A growing body of research demonstrates that PANS/PANDAS is a form of autoimmune encephalopathy, characterized by inflammation of the brain. Treatment involves a three-pronged approach: psychiatric medications for symptom relief, antibiotics to address infectious triggers, and immune-modulating therapies to treat immune dysfunction. When treatment is initiated promptly, many patients recover and return to full functioning. Delays in treatment unnecessarily prolong suffering and increase the risk that symptoms will become entrenched, leading to long-term psychiatric, neurologic, and cognitive impairment. Unfortunately, families face significant barriers to care. There is a limited number of clinicians experienced in treating PANS/PANDAS, often requiring families to travel long distances at great personal and financial cost. Lack of insurance coverage



further delays or prevents access to treatment, particularly immune-based therapies such as intravenous immunoglobulin (IVIG). Insurers routinely deny coverage, forcing families into prolonged cycles of appeals that increase the risk of serious neurological and psychological harm, long-term disability, or even loss of life. Many families attempt to self-pay, depleting savings, accruing debt, or selling their homes to obtain medically necessary care.

While the cost of immunotherapies can be substantial, it is small compared to the cost of emergency care, inpatient psychiatric hospitalization, or pediatric admissions for complications of severe PANS/PANDAS, including starvation, dehydration, aggression, self-injury, or suicidality. Untreated illness also increases long-term educational costs, as children often require extensive accommodations and special education services.

Since 2017, major advances in research have strengthened the evidence base for PANS/PANDAS, including published treatment guidelines from the PANS Research Consortium and peer-reviewed studies from Columbia University and Yale elucidating disease mechanisms and immune targets. These findings support the medical necessity of immune-based treatments for appropriately selected patients.

In closing, we urge you to alleviate the burdens placed on families and physicians by supporting LB762. This bipartisan legislation will allow clinicians to provide appropriate care without unnecessary administrative barriers and ensure that patients with PANS/PANDAS receive timely, effective treatment.

Sincerely,

On behalf of the ASPIRE Professional Advisory Board
Susan Swedo, MD
Scientist Emerita
National Institute of Mental Health

Contact Information:
Gabriella True, PAB Secretary and Board President
Email: gabriella@aspire.care Mobile: 562-480-7560

Sources:

- 1 - Swedo SE, Frankovich J, Murphy TK. Overview of treatment of pediatric acute-onset neuropsychiatric syndrome. *J Child Adolesc Psychopharmacol*. 2017;27:562-5. <https://doi.org/10.1089/cap.2017.0042>
- 2 - Thienemann M, Murphy T, Leckman J, et al. Clinical management of pediatric acute-onset neuropsychiatric syndrome: Part I- psychiatric and behavioral interventions. *J Child Adolesc Psychopharmacol*. 2017;27:566-73. <https://doi.org/10.1089/cap.2016.0145>
- 3 - Frankovich J, Swedo S, Murphy T, et al. 2017. Clinical management of pediatric acute-onset neuropsychiatric syndrome: Part II—use of immunomodulatory therapies. *J. Child. Adolesc. Psychopharmacol*. 2017;27:574-93. <http://doi.org/10.1089/cap.2016.0148>
- 4 - Cooperstock MS, Swedo SE, Pasternack MS, Murphy TK for the PPC. Clinical Management of pediatric acute-onset neuropsychiatric syndrome: Part III—treatment and prevention of infections. *J Child Adolesc Psychopharmacol*. 2017;27:594- 606. <http://dx.doi.org/10.1089/cap.2016.0151>
- 5 - Maryann P. Platt, Kevin A. Bolding, Charlotte R. Wayne, Sarah Chaudhry, Tyler Cutforth, Kevin M. Franks, Dritan Agalliu. Th17 lymphocytes drive vascular and neuronal deficits in a mouse model of postinfectious autoimmune encephalitis. *Proceedings of the National Academy of Sciences* Mar 2020; 117 (12) 6708-6716; DOI: 10.1073/pnas.1910971117
- 6 - Cutforth, Tyler & Platt, Maryann & Agalliu, Dritan. Hello from the Other Side: How Autoantibodies Circumvent the Blood-Brain Barrier in Autoimmune Encephalitis. (2017). *Frontiers in Immunology*. 8. 10.3389/fimmu.2017.00442.
- 7 - Antibodies Bind to Striatal Cholinergic Interneurons and Alter Their Activity
Jian Xu, Rong-Jian Liu, Shaylyn Fahey, Luciana Frick, James Leckman, Flora Vaccarino, Ronald S. Duman, Kyle Williams, Susan Swedo, and Christopher Pittenger. *Am Jnl of Psychiatry* 16 Jun 2020 DOI: 10.1176/appi.ajp.2020.19070698
- 8 - Isaac Melamed, Roger Kobayashi, Maeve O'Connor, Ai Lan Kobayashi, Andrew Schechterman, Melinda Heffron, Sharon Canterbury, Holly Miranda, Nazia Rashid. Benefits of IVIG in Pediatric Acute-Onset Neuropsychiatric Syndrome. *Neurology* Apr 2020, 94 (15 Supplement) 2411