



**ASPIRE Professional  
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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  
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