August 14, 2025

Dear Rep. Luke Meerman and the House Subcommittee on Child Welfare System,

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 a bill that would ensure coverage for PANS/PANDAS similar to the Senate Bil - SB447 Insurance: insurers; coverage for certain pediatric autoimmune neuropsychiatric disorders. This bill will significantly improve the health and well-being of patients with PANS and ease the financial and emotional burdens of 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 aged 4 - 9 years. Please note that adults can have PANS PANDAS; it is not just a pediatric disorder. A viral or bacterial infection triggers most cases; when Group A streptococcal infections (such as strep throat or impetigo) triggers symptoms, the disorder is known as Pediatric Autoimmune Neuropsychiatric Disorders Associated with Streptococcal Infections (PANDAS). In recent months, a number of studies have proven 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 the

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 insurance coverage, and a lengthy cycle of repeated denials and appeals frustrates both healthcare providers and families. More importantly, the denials/appeals process prolongs the patients' 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 the treatments, forcing them to take on heavy credit card debt, deplete retirement/college funds or sell their homes to raise funds to pay for a treatment 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, in-patient psychiatric treatment, and/or pediatric hospitalizations for the complications of severe PANS/PANDAS, such as starvation/dehydration, aggressive behaviors, and 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 the increased expenditures for medical care, 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. (7, 8, 9, 10) These guidelines are divided into four sections and represent best practice recommendations: Overview (1), Part I-psychiatric and behavioral interventions (2), Part II-use of immunomodulatory therapies (3), and Part III-treatment and prevention of infections (4). In 2017 and 2020, two papers from Columbia University explain the mechanism of PANDAS by

elucidating how the autoantibodies enter the CNS due to persistent microglial activation as a result of multiple Group A Streptococcus infection (5,6). In 2020, a double-blind study out of 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.” (7). A 2020 study on IVIG for PANS provides further support of IVIG use for a small but significant subset of children who meet the criteria. (8) These studies are only a small sample of the scientific advancements being made in PANS PANDAS.

In closing, we ask that you alleviate the burdens placed on families, physicians, and other community members who strive to serve the critical needs of patients with PANS/PANDAS. Please enable their doctors to make appropriate medical decisions free from administrative and time constraints posed by insurance coverage 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 require insurance coverage for PANS/PANDAS treatment. Your leadership on this important issue will help ensure patients with PANS/PANDAS receive appropriate treatment, enabling them to experience all the joys of childhood and reach their full potential.

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

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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 syn- drome: 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.1911097117
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 Jrnl 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 Canterberry, Holly Miranda, Nazia Rashid. Benefits of IVIG in Pediatric Acute-Onset Neuropsychiatric Syndrome. Neurology Apr 2020, 94 (15 Supplement) 2411