

IMPROVING THE LIVES OF PATIENTS WITH NEUROIMMUNE DISORDERS *THE ROLE OF STATE LEGISLATURES*

What are PANS and PANDAS?

Pediatric acute-onset neuropsychiatric syndrome (PANS) and pediatric autoimmune neuropsychiatric disorders associated with streptococcal infections (PANDAS) are neuroimmune disorders that produce devastating, life-altering symptoms in children and young adults. Patients may endure severe OCD, tics, joint pain, gastrointestinal distress, extreme sleep disturbance, separation anxiety, disordered eating, irritability and more as a result of immune system dysfunction.

Barriers to Proper Care and Treatment

Lack of physician awareness and understanding of PANS and PANDAS persists, despite treatment guidelines and mounting evidence of the biological mechanisms behind these conditions. Families often experience years of misdiagnosis, delay in treatment and heavy financial burdens due to insurer denial of prescribed treatments.



Progress Through Policymaking

State legislatures have taken the lead in efforts to improve the lives of patients with PANS and PANDAS. Legislators in ten states—Arkansas, Delaware, Illinois, Indiana, Maryland, Massachusetts, Minnesota, New Hampshire, Oregon and Rhode Island—have enacted measures to require insurance coverage for the treatment of PANS and PANDAS, which may include antibiotics, steroids, intravenous immunoglobulin (IVIG), and other immunomodulatory therapies. The Kansas state employee health insurance plan also provides coverage. Thus far in 2023, state legislators have considered at least 28 bills, of which nine were enacted. California Assembly members also passed a bill to require insurance coverage which currently resides in the Senate.

Continuing to Curb Suffering Through Creative Solutions

In addition to private insurance and Medicaid coverage requirements, policymakers introduced legislation in 2023 to tackle the hardships facing families affected by PANS/PANDAS through state advisory councils, studies, funding to support a



Resources

Neuroimmune Foundation

www.neuroimmune.org

The Alex Manfull Fund

<https://thealexmanfullfund.org/>

For an example of much needed comprehensive care that PANS/PANDAS families hope to have accessible across the country one day, please visit Stanford's Immune Behavioral Health Clinic at med.stanford.edu/pans.html

For more information on the extreme challenges affected families endure, please visit LunaDNA's blog at www.lunadna.com/panspanda/

Questions about current state laws and legislation pertaining to PANS and PANDAS?

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PANS/PANDAS clinic, and screening for PANS/PANDAS by physicians per recommendations developed by a medical professional consortium. Other tools that state policymakers may want to consider as they strive to provide better access to quality care for patients with neuroimmune disorders include:

- ◆ Required surveillance of PANS/PANDAS cases by state health departments via existing programs;
- ◆ Required screening for PANS/PANDAS in state mental health programs serving youth upon first onset of psychosis;
- ◆ Medical education requirements for physicians; and
- ◆ State funding of PANS/PANDAS research and fellowships.

Such measures would alleviate the substantial burden on health care systems, schools, patients and families as a result of delayed diagnosis. In doing so, it is critical that legislation to advance the care and treatment of PANS and PANDAS takes into account the complexity of the illness, and, therefore, is formulated in consultation with experts in the field and the patient community to avoid unintended harmful consequences.

Looking Toward the Future of Care: PANS, PANDAS and the Spectrum of Infection-Associated Conditions

With millions of Americans battling long COVID, experts in the field increasingly recognize common, overlapping biological factors across infection-associated conditions, including long COVID, myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS), chronic Lyme, postural orthostatic tachycardia syndrome (POTS) and PANS/PANDAS. In June 2023 the National Academies of Sciences, Engineering, and Medicine held a workshop to explore these factors and the development of a common research agenda for infection-associated illnesses. State policymakers' efforts to help the PANS/PANDAS community today are preparing our health care system to implement advances in the care and treatment of these illnesses and, in turn, ensure a brighter future for these children and young adults.

