





THE STATE OF PANS AND PANDAS POLICY IN 2024

Pediatric Acute-onset Neuropsychiatric Syndrome (PANS) and Pediatric Autoimmune Neuropsychiatric Disorders Associated with Streptococcal Infections (PANDAS)



Children and young adults who suffer from neuroimmune disorders PANS and PANDAS endure devastating, life-altering symptoms, including severe OCD, tics, joint pain, gastrointestinal distress, sleep disturbance, separation anxiety, disordered eating, irritability and more as a result of immune system dysfunction. Since 2017 state legislators have continued to reduce barriers to care for these extremely ill, but often overlooked patients. As of August 2024, Arkansas, Colorado, Delaware, Illinois, Indiana, Maryland, Massachusetts, Minnesota, New Hampshire, Oregon and Rhode Island state statutes require individual and group health insurance coverage for treatments such as antibiotics, anti-inflammatories and immunomodulatory therapies.

2024 PANS/PANDAS ACTION

MEASURES CONSIDERED





How can you help these vulnerable patients? Policy options to consider include:

- Continuing Medical Education (CME) requirements
- Insurance coverage protections
- Pharmacist authorization to test for and treat strep infections



According to the National Alliance of State Pharmacy Associations at least six states provide such direct prescribing authority.

PANS AND PANDAS

And Infection-Associated Chronic Conditions and Illnesses

PANS and PANDAS are increasingly recognized as one of several infection-associated chronic conditions and illnesses (IACCIs) such as myalgic encephalomyelitis/chronic fatigue syndrome, postural orthostatic tachycardia syndrome (POTS), chronic Lyme disease, and Long COVID. The National Institutes of Health recently released a groundbreaking Notice of Intent to Publish a Funding Opportunity Announcement for Towards a Better Understanding of the Neurological Effects of Infection-Associated Chronic Illnesses, including PANDAS, that have long been suspected to have an infectious trigger in a certain subset of individuals.

Interested in learning more? Check out The Alex Manfull Fund's podcast.

Untangling PANDAS & PANS: Conversations about Infection-Associated, Immune Mediated Neuropsychiatric Disorders.



Scan me!



Help Spread the Word. Share the Neuroimmune Foundation's extensive clinician resources with health care professionals.



You can provide access to diagnostic and treatment guidelines, CME courses, instructions for submitting a case to an expert consultation panel and more.

GRATEFUL FOR THE SUPPORT OF STATE POLICYMAKERS

PANS and PANDAS advocacy organizations recognize the leadership of state legislatures in crafting public policies to improve the lives of this often neglected group of patients. Our community appreciates your support.

Questions about PANS and PANDAS public policies? Please contact Alissa Johnson, patient advocate and public policy consultant, at ajohnson@policyconsult.com or by phone at 202-258-5529.

