



Massachusetts Coalition for PANDAS/PANS Legislation  
Post Office Box 30  
Marshfield Hills, MA 02051  
(617)797-7145  
(781)254-2820  
[masspandasbill@gmail.com](mailto:masspandasbill@gmail.com)

## **PLEASE SUPPORT PASSAGE OF S.2935 AN ACT REQUIRING CERTAIN INSURANCE COVERAGE FOR PANDAS/PANS**

We seek your support for passage of the insurance coverage for PANDAS/PANS Act S.2935. This bill provides for insurance coverage for doctor-recommended therapies for children suffering from Pediatric Autoimmune Neuropsychiatric Disorder Associated with Streptococcus (PANDAS) and Pediatric Acute-Onset Neuropsychiatric Syndrome (PANS).

### **WHAT ARE PANDAS AND PANS?**

- PANDAS and PANS are post-infectious neuroimmune disorders believed to result from a misguided immune response which attacks the brain following streptococcal infection or other common illnesses. The resulting inflammatory process leads to debilitating neurological and behavioral changes in children.
- PANDAS and PANS frequently begin with acute and dramatic onset of obsessive-compulsive disorder, emotional lability, severe separation anxiety, and motor and/or vocal tics.
- Many children experience eating restriction, rage behaviors including physical aggression, sleep difficulties, and a number of additional debilitating symptoms such as hallucinations and delusions.

### **THE IMPACT ON CHILDREN AND THEIR FAMILIES**

- Children suffering from these conditions frequently cannot attend school for extended intervals or engage in meaningful learning activities when they are in the classroom.
- Home life is profoundly disrupted due to compulsive ritual behaviors, restricted eating, aggression toward parents and siblings, and sleep disturbances.
- It is not unusual for multiple siblings in a single household to be affected, presumably due to the combination of mutual exposure to infectious agents within the same household and to their shared genetic backgrounds.
- Many families of PANDAS/PANS children must choose between full-time employment and caring for their child. Often, one parent must leave a job and remain at home, or both parents may need to reduce working hours to support extended days out of school due to physical and psychiatric symptoms.
- Emergency room visits are often needed due to sudden aggressive behaviors which put patients as well as their family members at risk of physical injury. Psychiatric hospitalization is often required for severely afflicted children. Suitable inpatient and partial hospitalization programs are in very short supply, with resulting months-long delays in appropriate psychiatric therapy.

### **DEFINING THE PROBLEM**

- Mild to moderate cases of PANDAS/PANS are often managed successfully with antibiotic and nonsteroidal anti-inflammatory therapy.
- More severely afflicted children frequently require prednisone and psychotropic medications.
- A small but significant subset, an estimated 10% of referred children, fail to improve with these conventional measures and require immunomodulatory therapy with intravenous immunoglobulin (IVIG).
- IVIG therapy has been recommended in the 2017 guidelines prepared by the PANS Research Consortium immunomodulatory task force (PRC-ITF), which was comprised of immunologists, rheumatologists, neurologists, infectious disease experts, general pediatricians, psychiatrists, nurse practitioners, and basic science experts in neuroimmunology.
- Although IVIG is found to be effective in the majority of treated children and is often sufficient to restore a meaningful recovery with return to school and normalization of household life, administration of IVIG in the Commonwealth has been extraordinarily difficult.

### **WHY PASSAGE OF THIS BILL IS SO IMPORTANT**

- Despite the consensus recommendation of the PANS Research Consortium, IVIG for the treatment of severe PANDAS and PANS patients is almost universally denied by Massachusetts insurers. The appeals process is not structured to include a physician who is an expert in the management of these conditions, and clinicians are frustrated by their inability to objectively discuss IVIG approval with a knowledgeable expert.
- The protracted denial and appeals process of insurance coverage delays and often derails initiation of critical immune therapy for these children. Tragically, this puts them at risk of further decline and potential long-term disability as their brain inflammation remains untreated.
- The burdens of delayed treatment are inevitably shouldered by the family and the state in terms of significant costs associated with social services, medical treatments, and educational supports.
- IVIG therapy, which is considered in a small subset of the most ill PANDAS/PANS patients, many of whom have extreme impairment or life-threatening symptoms, is not currently covered by insurance in Massachusetts. At this time, families often travel to providers in Connecticut, New Jersey, or Washington D.C. for therapy, adding to the families' expense and logistical difficulty.

### **Please support passage of the insurance coverage for PANDAS/PANS Act S.2935**

Today, severely ill children wait indefinitely for appropriate medical intervention due to the gap in coverage for immune therapy in Massachusetts. Now is the time to change the clinical outcomes for children by ensuring that a full range of treatment options is widely available,

**We urge you to support passage of this essential legislation.**