



PLEASE SUPPORT HCR 78

TASK FORCE TO INVESTIGATE DEVASTATING PEDIATRIC DISEASE AFFECTING KENTUCKY FAMILIES

We seek your support for the A CONCURRENT RESOLUTION establishing the Kentucky Pediatric Autoimmune Neuropsychiatric Disorder Associated with Streptococcal Infections (PANDAS) and Pediatric Acute-Onset Neuropsychiatric Syndrome (PANS) Task Force.

Quick Facts about PANDAS AND PANS in this State

- NIMH estimates approximately **5,000 children are impacted in Kentucky.**
- NIMH researcher Dr. Susan Swedo believes **25-30% of all childhood mental health disorders** are a direct result of PANDAS/PANS*.
- Approximately **500 children require advanced treatment** intravenous immunoglobulin (IVIG)
- Kentucky has **0 pediatricians willing to diagnose and treat** in the state.

What is PANDAS/PANS?

- PANDAS/PANS is a post-infectious neuro-immune encephalitis. (**brain inflammation after an infection or virus**)
- **A misguided immune response attacks the brain following streptococcal infection or other common illnesses. It results in disturbing and debilitating neurological and behavioral changes in children.**
- PANDAS/PANS begins with **abrupt and dramatic onset** of obsessive-compulsive disorder, emotional outbursts, inappropriate behaviors, severe separation anxiety, behavior regression, motor and/or vocal tics like stuttering, sneezing, and coughing. Children experience the inability to eat and sleep, they have emotional rages including physical aggression and in later stages: hallucinations and delusions.

Impact on Kentucky Children and Families

- **Children Unable to Attend School - Truancy and Absentee Issues** - Children refuse to leave their homes, they cannot attend school or engage in learning activities because brain inflammation.
- **Families in Crisis at Home** - Family life is **intensely disrupted** due to a child's compulsive ritual behaviors, restricted eating, aggression toward parents and siblings, and sleep disturbances.
- **Economic Impact on Families** - 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 the child needing around the clock care.
- **Overuse of Emergency Services and Hospitalizations** - Emergency room visits and psychiatric hospitalizations are often needed due to sudden aggressive behaviors when the child is capable of harm to self or others.

Kelly Joplin, MSW. KY Committee Lead – Southeastern PANDAS Association
kelly@sepans.org (606) 875-6521