

WHAT ARE PANS/PANDAS?

PANS - Pediatric Acute-Onset Neuropsychiatric Syndrome

PANDAS - Pediatric Autoimmune Neuropsychiatric Disorder Associated with Streptococcal Infections

Inflammatory Brain Disorders triggered by infections, metabolic disturbances, and other inflammatory reactions--OCCUR WHEN THE IMMUNE SYSTEM ATTACKS THE BRAIN

PANS/PANDAS Symptoms

- **OCD**
- **FOOD RESTRICTION**
- **TICS**
- ADHD
- Sensory seeking / avoiding
- Developmental regression
- Decline in school performance
- Anxiety
- Emotional lability
- Depression
- Irritability
- Aggression
- Balance / gait issues
- Urinary frequency / urgency
- Sleep disturbance
- Fatigue
- Hallucinations
- Selective mutism

LEGISLATION INTRODUCED - HB513 & HB514

HB 513 - Calls for insurance coverage for the diagnosis and treatment of PANS/PANDAS

HB 514 - Calls for the reinstatement of the PANDAS/PANS Council.

WHY DO WE NEED PANS/PANDAS LEGISLATION?

- Virginia health insurance companies routinely deny doctor-prescribed treatments, including antibiotics, anti-inflammatories, IVIg and other immune therapies.
- Patients frequently endure months, if not years, of misdiagnosis, resulting in irreversible brain inflammation with associated profound disabilities.
- Permanent neurological damage may result in permanent dependence on the state.
- Suicides have occurred, in both affected individuals and their despondent parents.
- Most of the time, at least one parent must stop working to care full-time for the ill child. Desperate families sell their homes to pay for medicine out-of-pocket.
- Police, ER, and child protective services are commonly involved as symptoms become increasingly erratic. Patients may be hospitalized medically or psychiatrically, resulting in more costs and unnecessary suffering due to inappropriate medical treatment.

EXPEDITE THE HIRC REVIEW

VIRGINIA'S YOUTH CANNOT WAIT ANY LONGER...

Another brain at Georgetown University's POND Brain Bank should not be collateral damage of a two-year HIRC study. Please expedite the HIRC review of HB513.

*Note: The true incidence of PANS/PANDAS is not known. We only have clinical references to use as a guide. Cleveland Clinic lists PANS/PANDAS as a rare condition: <https://my.clevelandclinic.org/health/diseases/23553-pandas-syndrome>. California's Health Commission studied the bill AB907, with Stanford University expert inputs, and determined an incidence of **1/10,000**. The Texas PANS/PANDAS Advisory Council describes it as 1/10 of kids with OCD (1/200), which would be about **1/2,000 children**.*



VOTE YES ON HB513 AND HB514