

DID YOU KNOW THAT INFECTIONS CAN TRIGGER NEUROPSYCHIATRIC DISORDERS, OFTEN REFERRED TO AS PANS/PANDAS?

- Common infections can set in motion a misdirected immune response that can trigger brain inflammation, resulting in deterioration in psychological, emotional, cognitive, motor, sensory, and social functioning.
- PANDAS and PANS are the well-known immune-mediated neuropsychiatric disorders. These neuroimmune disorders are also known by the names autoimmune encephalitis (AE) and basal ganglia encephalitis (BGE).
- Immune-mediated neuropsychiatric symptoms occur in a small percentage of children, adolescents and young adults, and are often misdiagnosed.
- Early recognition of these disorders is imperative because early diagnosis and appropriate treatment offer the best prognosis. If not treated appropriately, the impact on the patient, family, and community can be devastating.

INFECTIOUS TRIGGERS

PANDAS

Group A Streptococcus

PANS

Bacteria such as mycoplasma pneumonia (walking pneumonia), Borrelia burgdorferi (Lyme disease), and other tick-borne bacteria (e.g., Borrelia miyamotoi and Bartonella).

Viruses such as the Epstein-Barr virus (mononucleosis), herpes simplex virus (HPV), Coxsackie (hand, foot and mouth disease), influenza, and Sars-CoV-2 (the coronavirus that causes COVID-19,) are among other infectious triggers.

In addition to infections, metabolic disturbances and other inflammatory reactions are thought to be triggers.

SYMPTOMS

Obsessions and compulsions, tics, and eating restrictions are the characteristic symptoms of PANDAS and PANS. Other symptoms or behaviors are listed below and may range from mild to severe:

- Anxiety (especially separation anxiety).
- Increased irritability
- Severe mood swings and temper tantrums.
- · Personality changes
- Sleep disturbances (e.g., night terrors, sleepwalking).
- Extreme fatigue (never feeling rested)
- Increased urinary frequency and/or enuresis (urinary incontinence, especially at night).
- Dilated pupils (mydriasis)
- Hyperactivity, inattention
- · Difficulty concentrating
- Sensory problems
- · School refusal
- Deterioration of handwriting and drawing
- · Loss of previously learned math skills
- Explosive rage
- Extreme impulsivity
- Self-injurious behavior
- Suicidal ideation

COURSE

The onset of these symptoms is usually (but not always) associated with an infection. Symptoms may appear so abruptly that caregivers remember the exact day they began. The severity of symptoms usually oscillates over time, presenting with ups and downs.

Tragically, people with PANDAS/PANS may have persistent and intrusive thoughts of self-injury or death. They may impulsively engage in behaviors that inadvertently -- without intention or awareness of what they are doing -- result in serious injury or even death.

DIAGNOSIS

Because immune-mediated neuropsychiatric disorders such as PANDAS and PANS have symptoms very similar to those of traditional mental illnesses, they are often misdiagnosed and treated only with psychotherapy and psychiatric drugs, which can be ineffective.

The diagnosis of PANDAS/PANS is based on clinical criteria, which means that your doctor will ask you many questions to determine if your case fits the diagnostic criteria. A physical examination and laboratory tests will likely also be included.

TREATMENT

Effective treatment of these disorders includes:

- Treatment of the active infection(s): antibiotics and antivirals
- Treatment of the brain inflammation caused by the infection(s): non-steroidal antiinflammatory drugs - such as ibuprofen or naproxen - and corticosteroids
- Treatment of the immune system itself (IVIG, plasmapheresis, and Rituximab)

Given the likely relationship between the gut microbiome and the brain, dietary modification should also be considered. Cognitive behavioral therapy (CBT) and psychiatric drugs may also be beneficial.

If you think you or a family member may have PANDAS or PANS, contact your primary care physician or pediatrician. Prepare detailed notes about onset, symptoms, any infections, and personal and family medical history. Take this booklet and inform your physician about PANDAS/PANS (https://www.pandasppn.org/).



Visit TheAlexManfullFund.org to learn more about Alex, PANDAS and PANS, the POND Brain Bank, and how you can help. TAMF is a 501(c)(3) nonprofit organization. All donations are tax-deductible as allowed by law. References for the information in this brochure are also available on our website.

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