



# WHAT IS **PANS/PANDAS?**



**PANS/PANDAS** are misdirected immune responses, often with an encephalitic onset, that result in acute onset of OCD, tics and/or restricted food intake, along with other neuropsychiatric and somatic symptoms.

**PANS is a clinical diagnosis based on history and physical examination.** PANS diagnostic criteria are based on the acute onset of OCD and/or eating restrictions, with concurrent symptoms in at least 2 of 7 neuropsychiatric and somatic categories. PANS can be triggered by infections, metabolic disturbances, and other inflammatory reactions; infectious triggers include strep, upper respiratory infections, influenza, mycoplasma pneumonia, and lyme borreliosis, among others.

**PANDAS, a subset of PANS, is associated with group A Streptococcus (GAS) infections.** Not all patients have a positive strep throat culture, and examination must be followed by ASO and ADB immune responses. Onset of symptoms can occur within days of contracting strep, or within several months of the inciting infection.

After the initial onset, **PANS/PANDAS** symptoms follow a relapsing/remitting course. Initial triggers may differ from secondary triggers. During each recurrence, symptoms can worsen, and new symptoms may manifest. Symptoms can range from mild to severe. In mild cases, children might function well enough to continue to attend school. In severe cases, symptoms can become life-threatening due to extreme food restriction and/or suicidality.

Many children with **PANS/PANDAS** are misdiagnosed with a psychiatric illness and prescribed only psychotropic medications rather than being evaluated and treated for an underlying infection. According to a consortium of experts convened by the National Institute of Mental Health, appropriate treatment for these disorders is a triad that incorporates psychotherapeutic interventions, antimicrobial treatment, and immunomodulation and/or anti-inflammatories.

## Consider an evaluation for **PANS/PANDAS**

### If you see an unusually abrupt and acute onset of

- Obsessive-compulsive symptoms and/or severe eating restrictions

### And at least two comorbid cognitive, behavioral, or neurological symptoms

- Anxiety
- Emotional lability or depression
- Irritability, aggression, and/or oppositional behaviors
- Tics
- Behavioral or developmental regression
- Deterioration in school performance (Loss of math skills, handwriting changes, & ADHD-like behaviors)
- Sensory or motor abnormalities
- Sleep disturbances
- Enuresis or urinary frequency

# 10 things you should know about PANS/PANDAS

- 1 Strep throat is NOT the only infectious trigger. Although group A streptococcal (GAS) infections are associated with PANDAS, PANS is a broad-spectrum syndrome that can result from a variety of disease mechanisms and multiple etiologies.
- 2 Acute onset can be preceded by milder episodes. Mild cases have been documented, and symptoms might look like behavioral problems, isolated tics, and sensory issues, among other issues that require awareness on the part of the parent and provider. These children should be clinically evaluated for PANS/PANDAS.
- 3 Children with PANS/PANDAS may experience recurrence of episodes. Some children experience remission of symptoms after treatment with no recurrence, while a portion experience subsequent exacerbation (relapse) incited by a variety of triggers.
- 4 OCD symptoms vary. While the mean age of OCD in children is between the ages of 9 and 10, in children with PANS/PANDAS it can start much earlier. OCD presentation is acute and disruptive to child's normal functioning.
- 5 Restrictive eating can be a primary symptom. Some children with PANS/PANDAS present with Avoidant Restrictive Food Intake Disorder without OCD or tics. A child with severe food restriction resulting in dramatic weight loss or who refuses fluid intake should be examined for PANS/PANDAS.
- 6 Tics are not always present. While tics were part of the original PANDAS diagnostic criteria they are not required for a PANS diagnosis.
- 7 Prevalence is unknown, due to poor diagnosis. PANS/PANDAS affects as many as 1 in 200 children each year according to the PANS/PANDAS consortium.
- 8 Scientific studies strongly support PANS/PANDAS diagnosis. Diagnostic guidelines published by the Journal of Child and Adolescent Psychopharmacology (July 2017) and a recent nationwide study in the Netherlands designed to test PANDAS hypothesis demonstrated that individuals with a positive streptococcal test have an increased risk of neuropsychiatric disorders. The study also demonstrated an increased risk with nonstreptococcal throat infections.
- 9 Early diagnosis and treatment lead to improved outcomes. According to NIMH, "preliminary data suggest that with appropriate treatment early in the course of illness, and effective use of antibiotic prophylaxis, we may be able to prevent up to 25-30% of childhood mental illnesses."
- 10 Pediatricians CAN diagnose and treat PANS/PANDAS. The 2017 JCAP Treatment Guidelines issued by the PANS Physician Consortium are designed to provide practical clinical guidelines for the management and treatment of children diagnosed with PANS/PANDAS.

## We aspire to **improve.**

Who is ASPIRE? We are experienced leaders in the PANS advocacy community, who together believe collaboration and empowered action are the keys to the world we seek: one where no one suffers through PANS and immune-related encephalopathies without access to a knowledgeable provider, insurance coverage for standard-of-care treatments, or the support that comes with public awareness.

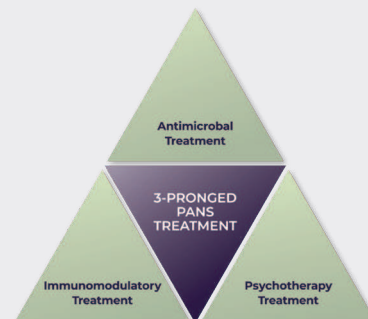


Alliance to Solve PANS & Immune-Related Encephalopathies  
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## PANS/PANDAS treatment utilizes three complementary modes of therapies:

If treated promptly and appropriately, patients can recover completely; if not, neuropsychiatric symptoms can worsen and become chronic. Individualized treatment protocols are dependant on the severity and course of PANS symptoms along with physical exam and lab testing.

- Remove the inflammatory source with **antimicrobial treatments**.
- Treat the disrupted immune system with **immune modulating** and/or anti-inflammatory interventions.
- Alleviate symptoms with **psychotherapeutic treatments**, including psychotherapies.



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