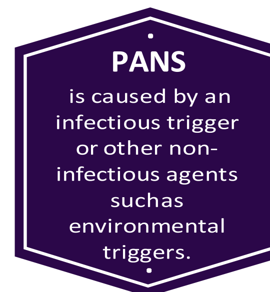
# Understanding PANS/PANDAS

## ▶ *Resources for General Pediatricians*

## What are PANS & PANDAS?

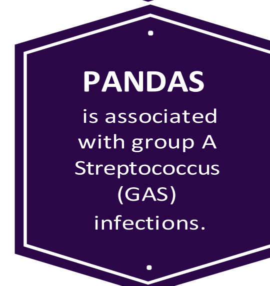
**PANS = *Pediatric Acute-onset Neuropsychiatric Syndrome***

PANS is a clinical diagnosis based on history and physical examination. PANS diagnostic criteria require an acute onset of OCD and/or eating restrictions, with concurrent symptoms in at least two of seven neuropsychiatric and somatic categories. Infections, metabolic disturbances, other inflammatory reactions and stress can trigger PANS. Infectious triggers include upper respiratory infections, influenza, strep, mycoplasma pneumoniae, and lyme borreliosis, among others.




**PANDAS = *Pediatric Autoimmune Neuropsychiatric Disorder Associated with Streptococcal Infections***

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.




**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. 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 diagnosed with a psychiatric illness and prescribed 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 psychological support (CBT, ERP and/or psychotropic medication), antimicrobial treatment, and immunomodulation.

## Diagnostic Criteria for Pediatric Acute-onset Neuropsychiatric Syndrome

1. **Abrupt, acute onset of obsessive-compulsive disorder or severe restricted food intake**

2. **Concurrent presence of additional behavioral or neurological symptoms with similarly acute onset and severity from at least two of the seven following categories:**
   - Anxiety, separation anxiety
   - Emotional lability or depression
   - Irritability, aggression, and/or oppositional behaviors
   - Behavioral or developmental regression
   - Deterioration in school performance (loss of math skills, handwriting changes, ADHD-like behaviors)
   - Sensory or motor abnormalities, tics
   - Somatic signs: sleep disturbances, enuresis, or urinary frequency

3. **Symptoms are not better explained by a known neurologic or medical disorder.**

4. **Age: The typical age of onset is between 4 and 14, but post-pubertal cases do occur.**

## 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. ***Tics are not always present.*** While tics were part of the original PANDAS diagnostic criteria, they are not required for a PANS diagnosis.

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 (ARFID) 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. ***Children may experience recurrence of episodes.*** Some children with PANS/PANDAS experience remission of symptoms after treatment with no recurrence, while a portion experience subsequent exacerbation (relapse) incited by a variety of triggers.

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 non-streptococcal 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.

**For further information, contact**

Children's Postinfectious Autoimmune Encephalopathy Center

**Website** ***www.peds.arizona.edu/cpae***
**Email** ***cpae@bannerhealth.com***
**PO Box 245073**
**Tucson, Arizona 85724**

*The Children's Postinfectious Autoimmune Encephalopathy (CPAE) Center of Excellence at the University of Arizona Steele Center, developed in partnership with Banner University Medicine and in cooperation with the NIH/NIMH, is the first in the U.S. to implement an integrated model of basic science, clinical research, clinical care, and teaching to address a spectrum of neuro-psychiatric disorders that are often misdiagnosed, underdiagnosed, and undiagnosed in children.*