

PANDAS
PHYSICIANS
NETWORK

Seeing Your First Child with **PANS/PANDAS**

An overview of the clinical presentation, diagnostic evaluation, and expected outcomes of immune mediated neuroinflammatory conditions PANS and PANDAS.

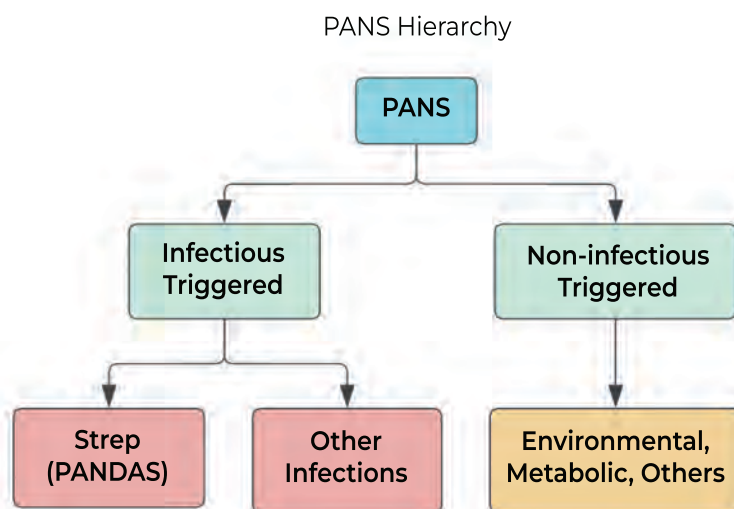


What is PANS/PANDAS?

Pediatric Acute-onset Neuropsychiatric Syndrome (PANS) is a clinical condition characterized by the abrupt onset of Obsessive-Compulsive Disorder (OCD) and/or Avoidant/Restrictive Food Intake Disorder (ARFID).

While PANS can be triggered by many factors, the syndrome is thought to result from an abnormal immune reaction to physiological stressors. These may include infections with group A *Streptococcus* (GAS), *Mycoplasma pneumonia*, influenza, upper respiratory infections, sinusitis, and psychosocial stressors.

Pediatric Autoimmune Neuropsychiatric Disorder Associated with Streptococcal infections (PANDAS) is a specific subset of PANS. In PANDAS, symptom onset and exacerbations are specifically linked to streptococcal infection.



The diagnosis of PANS/PANDAS should be considered whenever symptoms of OCD, eating restrictions, and/or tics emerge suddenly, and are accompanied by other emotional and behavioral changes, frequent urination, motor abnormalities, and/or handwriting changes.

Proposed Pathogenesis

Current research suggests that PANS/PANDAS results from inflammation and dysfunction within the basal ganglia (specifically, the caudate, putamen and globus pallidus). One leading theory proposes that serum antibodies produced by the immune system cross the blood brain barrier and interact with neuronal antigens, leading to disruptions in basal ganglia functions.¹ Another theory suggests an immune-mediated activation of neuroglial immune cells that incite basal ganglia inflammation. The basal ganglia consist of a group of deep brain structures involved in regulating motor function, emotion, behaviors, procedural learning, cognition, and sensory processing.²



In cases of PANDAS, the mechanism is thought to be similar to Sydenham chorea, a neurological manifestation of acute rheumatic fever (ARF). Approximately 30% of ARF patients have Sydenham chorea; of those, up to 70% develop OCD symptoms within months of the movement disorder.³ In Sydenham chorea, cross-reactive antibodies target the brain, producing a variety of neurologic and psychiatric manifestations. This process—known as molecular mimicry—may also underlie the neuropsychiatric symptoms seen in PANDAS.

Diagnostic Criteria for PANS/PANDAS

PANS Diagnostic Criteria

The PANS diagnostic criteria were developed by a consortium of experts and are considered a “working draft” that may be changed as more is learned.

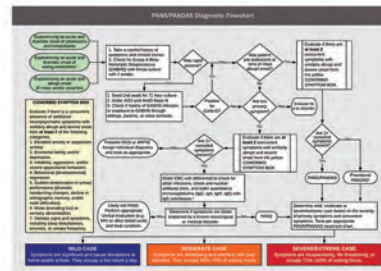
- Abrupt onset or abrupt recurrence of OCD and/or severely restricted food intake
- Concurrent presence and acute onset of neuropsychiatric symptoms from at least 2 categories: (1) anxiety, (2) emotional dysregulation, (3) irritability, aggression, and/or oppositional behaviors, (4) behavioral regression, (5) academic deterioration, (6) motor/sensory abnormalities, and (7) somatic abnormalities
- Symptoms are not better explained by a known neurologic or medical disorder

PANDAS Diagnostic Criteria

PANDAS is a subtype of PANS that requires the symptoms to be associated with a recent untreated strep infection.

- Abrupt onset of OCD and/or tics
- A relapsing-remitting, episodic symptom course
- Symptom onset prior to puberty (average of 6–7 years)
- Presence of neurologic abnormalities
- Temporal association between symptom onset and group A *Streptococcus*

PANS/PANDAS Flowchart



The PANDAS Physicians Network flowcharts for diagnosis and treatment are available to help clinicians navigate the process of evaluating and treating their patients. Scan the QR code or visit www.pandasppn.org/flowchart for more information.

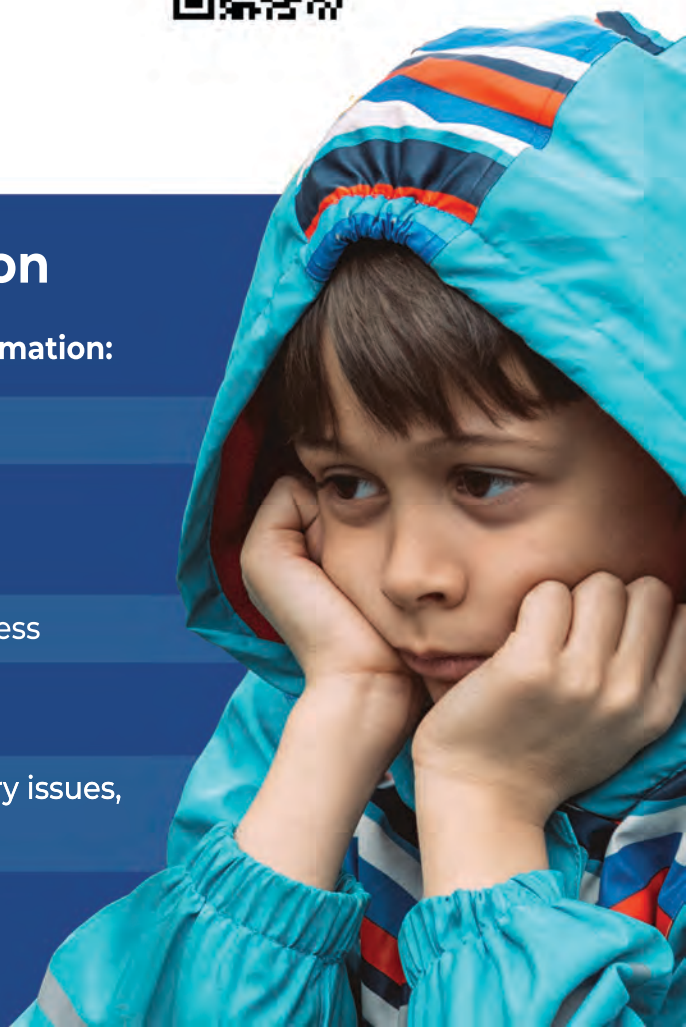


Effects of Basal Ganglia Inflammation

Basal Ganglia Function:

Potential Symptoms of Inflammation:

Mood and emotion	➡	OCD, mood lability, anxiety
Behavior	➡	OCD, rage episodes, developmental regression
Procedural learning	➡	Handwriting changes, clumsiness
Motor movements	➡	Tics, choreiform movements
Cognition	➡	Slow processing speed, memory issues, learning deficits (often math)
Sensory processing	➡	Sensitivity to light, sounds, smells, tastes, textures



Description of PANS/PANDAS Symptoms



PANS/PANDAS-related OCD is marked by an abrupt and dramatic onset typically from mild or no symptoms to debilitating.

Treatment options for PANS/PANDAS differ from traditional OCD and may include antibiotics, anti-inflammatory medications, and immunomodulatory therapies such as IVIG.

Obsessive Compulsive Disorder (OCD)

OCD affects an estimated 1–4% of children and adolescents.⁴ In traditional OCD, symptoms emerge gradually and become more involved and burdensome over time; symptoms tend to be persistent with minor variance. In contrast, PANS/PANDAS-related OCD is marked by an abrupt and dramatic onset typically from mild or no symptoms to debilitating. Parents often recall the exact date of symptom onset, and frequently describe it as coming “out of the blue.”

Diagnosing OCD in children can be challenging, as compulsions may resemble oppositional behavior, particularly when children react strongly to being prevented from performing rituals. Compulsions may be covert and difficult to observe (e.g., mental rituals) or appear as exaggerated versions of normal behavior (e.g., excessive hand washing). Common OCD rituals include washing/grooming, checking (e.g., locks, door), counting, ordering/symmetry, restrictive eating, and repetitive questioning. Clinicians typically use the Children’s Yale-Brown Obsessive Compulsive Checklist and Scale (CY-BOCS) to assess symptom severity.

Treatment options for PANS/PANDAS differ from traditional OCD and may include antibiotics, anti-inflammatory medications, and immunomodulatory therapies such as IVIG. As with traditional OCD, patients with PANS/PANDAS benefit from behavior therapy to assist with symptom management. It is important to note that some children with PANS/PANDAS may be unable to participate in behavioral intervention during acute phases due to the severity of symptoms and/or an inability to connect with a clinician. Understanding the unique onset and progression of PANS/PANDAS-related OCD is essential for appropriate interventions to be implemented.

PANS/PANDAS may manifest as an abrupt onset of multiple symptoms, which may range in severity from mild to life-threatening.

Eating Restriction

Children with PANS/PANDAS may refuse food for several reasons, such as fear of vomiting or choking; sensory sensitivity to taste, smell, and texture; or concerns that food is contaminated, spoiled, or poisoned. In some cases, the restricted eating is directly related to body image distortions, including concerns about being overweight, regardless of the child's actual weight.

Anxiety

Anxiety may present as persistent generalized anxiety or age-inappropriate separation anxiety.

Sensory Amplification

Children with PANS/PANDAS may become uncharacteristically and intensely bothered by smells, tastes, sounds, and textures. These sensitivities can interfere with everyday activities, such as brushing teeth, riding in a car, eating, or dressing.

Motor Abnormalities

Children with PANS/PANDAS may exhibit motor and vocal tics, handwriting deterioration, and/or clumsiness.

Urinary Symptoms

Urinary frequency is a common early complaint. A careful history will often expose additional symptoms, such as polyuria (urinating many times per hour), frequent urges to urinate, and/or day and night secondary enuresis. These urinary symptoms are not due to UTI, anxiety, or OCD type worries.

Deterioration in School Performance

Psychological testing of children with PANDAS has found challenges in visual-spatial memory, executive functioning, and fine motor skills. Children with PANS/PANDAS may also struggle with reduced processing speed, memory difficulties related to executive function, challenges in math, and fluctuating performance. For instance, a child's printing ability might shift dramatically—from a third-grade level to a first-grade level within a week—only to return to the third-grade level a month or two later.

Mood Disorder

During a PANS/PANDAS exacerbation, children may exhibit depression, mania, irritability, emotional lability, and rage. Children may experience rapid mood shifts (e.g., happiness to sadness to anger within moments). They may also experience episodes of intense, reactive rage (as opposed to predatory rage) that may start instantaneously and resolve just as quickly, often leaving the child feeling remorseful or confused.

Behavioral Regression

Children with PANS/PANDAS may display regressed behaviors, such as baby talk, refusal to carry out age-appropriate grooming activities, tantrums, and/or clinginess.

Sleep Disturbances

Polysomnographic studies have revealed a variety of sleep abnormalities in children with PANS/PANDAS, including initial and middle insomnia, REM behavior disorder, parasomnias, and/or sleep phase shifting.



Recommendations for Initial Workup

PANS and PANDAS are clinical diagnoses.

There is currently no definitive laboratory test to confirm or exclude either condition. However, targeted testing may help identify infectious triggers, rule out alternative diagnoses, and guide treatment planning. The scope of testing should be informed by the clinical presentation and severity of symptoms. Initial testing recommendations appear below. For additional information, visit www.pandasppn.org/testing.



1

2

3

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5

Evaluate for Group A Streptococcal (GAS) infection.

Rule out acute rheumatic fever (ARF).

Check for other infections.

Exclude non-infectious triggers.

Refer to a specialist.

Evaluate for Group A Streptococcal (GAS) infection.

Inquire about recent exposures to streptococcal infections, and symptoms of GAS infection (sore throat, headaches, and abdominal pain), rashes, and perianal itching. If inappropriate to the office situation, refer to the primary care provider for the following exam and specimen collection. Examine and vigorously swab the throat and nose. Examine skin for a scarlatina or perianal rash. If symptoms and physical exam suggests, swab perianal and vaginal areas.

If the rapid strep test is negative, the swab should be sent for a 48-72 hour GAS culture. Perianal culture orders should indicate that evidence of strep is sought. If the clinical encounter is within 2 weeks of symptom onset, check for rising antibody titers (ASO, Anti-DNAse B) by obtaining an initial set of titers and repeating after 4-6 weeks. Since elevated titers are common in grade-school aged children, anti-streptococcal titers are only helpful when a two-fold rise in titers is observed.

Because GAS infections are contagious and often spread back and forth among family members, if the child with PANS/PANDAS tests positive, it may also be appropriate to test close family members. Identifying and treating asymptomatic carriers may decrease the risk for subsequent GAS infections in the child.

Recommendations for Initial Workup

Evaluate for Group A Streptococcal (GAS) infection (continued).

There is strong evidence from studies of acute rheumatic fever that abrupt onset OCD symptoms can result from otherwise asymptomatic GAS infections. Similarly, children with PANS/PANDAS do not always present with “classic strep throat” despite colonization and infection. Accurate detection of GAS requires a thorough throat swab, with attention to the tonsils and posterior oropharynx. Importantly, more than 37% of children with positive GAS cultures may not show elevated titers with ASO and Anti-DNAse B, even when tests are correctly timed. These findings reinforce the importance of comprehensive evaluation, including careful lab testing, review of symptom history, and examination of the skin. All identified GAS infections should be appropriately treated.

Rule out acute rheumatic fever (ARF).

Careful auscultation for a murmur should be done for every child. If the child has a history of polymigratory joint complaints, frank chorea, erythema nodosum or erythema migrans, it is imperative that the child be referred to a pediatric cardiologist to assess for rheumatic carditis.⁵

Check for other infections.

Evaluate for other infections as indicated by the child's history and physical. Check mycoplasma IgM for active mycoplasma infection. IgG is not particularly helpful. Mycoplasma pneumonia titers are less accurate than Mycoplasma PCR. Recurrence of PANS/PANDAS symptoms may also be precipitated by viral illnesses. A CBC with differential may be used to check for other infections.

If urinary symptoms are present, obtain a urinalysis. In children with PANS/PANDAS, a negative result is common and may suggest that symptoms such as urinary urgency, frequency or secondary enuresis are manifestations of PANS/PANDAS, rather than a urinary tract infection. If the child has been on antibiotic therapy, evaluate for *Candida Albicans* as it can exacerbate symptoms.

Exclude non-infectious triggers.

Non-infectious triggers, such as drug ingestion or exposure to toxins (e.g., heavy metals or other environmental agents), should be ruled out based on clinical context and history.

Refer to a specialist.

Primary care providers can typically diagnose and treat PANS/PANDAS. Children with a moderate to severe onset or a complex presentation may require referral to an experienced multi-disciplinary team or a provider with expertise in PANS/PANDAS. Refer parents and caregivers to a pediatric psychologist to begin CBT/ERP once appropriate and consider other relevant specialists as needed, such as cardiology, rheumatology, immunology, neurology, sleep medicine, otolaryngology, and/or infectious disease.

Seeing Your First Child with PANS/PANDAS: Setting Expectations



Medical and Longer-Term Expectations

- PANS/PANDAS has a relapsing remitting course. Most children will experience at least one recurrence of symptom onset following a trigger. Families should be counseled that recovery is a process, and there is no “quick fix.”
- Unlike traditional OCD, which shows a waxing and waning course with modest changes in severity, OCD associated with PANS/PANDAS is relapsing-remitting, with dramatic, abrupt exacerbations of OCD and ancillary symptoms.
- Antibiotic treatment may lead to improvement of symptoms within 2-6 weeks, especially when initiated early in an exacerbation. Adjunctive use of anti-inflammatory agents may lessen the duration of the exacerbation. Each symptom may respond at a different rate and recovery can be uneven.
- Residual OCD symptoms may persist even after treatment of the underlying infection and inflammation, as well as after other medications or behavioral therapy. A 1999 study using aggressive immunomodulatory treatment showed patients improved on average 45%. Cognitive behavioral therapy, specifically exposure with response prevention, can be helpful in treating symptoms of PANS/PANDAS. Psychiatric medications can also be used in combination with CBT, and studies indicate to “start low and go slow.”
- Moderate to severe cases may require intravenous immunoglobulin (IVIG). Refer to guidelines for details.

Home and School Expectations

- PANS/PANDAS-related OCD is still OCD. Family education and support is critical, particularly in the early stages of illness. Providing material on treating and managing childhood OCD is an important step.
- Communication with schools helps alleviate stress and establishes a better understanding between faculty and student. Parents and caregivers may request to be informed of documented strep within the classroom and ask that good hygiene practices are enforced. Clinicians, parents, and caregivers might also volunteer to provide an informative lecture to class, parents, and teachers, and/or request a 504 Plan, IEP, or SST.

Helping families understand the nature and progression of PANS/PANDAS is essential for supporting a child both at home and in school. Providing accurate, evidence-based information and guidelines, such as those developed by the PANDAS Physicians Network and the PANS Research Consortium, ensures that families are guided by reliable sources. Setting realistic expectations regarding the medical course and daily impact of the disorder can improve outcomes and reduce stress.

LEARN MORE

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