

Key Areas of PANS PANDAS Research

Causes and Mechanisms

- Ongoing studies suggest that infections, like streptococcal bacteria, may trigger an abnormal immune response that affects the brain.

Immune System Role

- Researchers are exploring how the immune system might mistakenly attack the brain, leading to sudden neuropsychiatric symptoms.

Diagnosis and Biomarkers

- Efforts are underway to improve diagnostic criteria and find reliable tests, such as blood work and imaging, to distinguish PANS/PANDAS from other disorders.

Treatment Approaches

- Researchers are exploring different treatment strategies, such as antibiotics, anti-inflammatory drugs, immunotherapy, and supportive therapies to find the most effective ways to manage symptoms and promote recovery.

Long-Term Outcomes

- Studies are examining the long-term outcomes of PANS/PANDAS, including the potential for chronic illness and the impact on mental health, cognitive function, and quality of life.

Collaborative Research Efforts

- Research on PANS/PANDAS often involves collaboration between neurologists, immunologists, psychiatrists, and other specialists. Multidisciplinary approaches are critical for advancing understanding and treatment.

Awareness and Advocacy

- There is also a focus on raising awareness and advocating for more research funding and resources to support children and families affected by PANS/PANDAS.

PANS/PANDAS research is a dynamic and evolving field, with the potential to significantly improve diagnosis, treatment, and outcomes for affected individuals.



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PANS PANDAS Guide for Providers

PANDAS Pediatric Autoimmune Neuropsychiatric Disorders Associated with Streptococcal Infections

PANS Pediatric Acute-onset Neuropsychiatric Syndrome

What are PANS and PANDAS?

In PANDAS, the immune system mistakenly attacks the brain after a Strep infection. PANS is a broader term that includes cases triggered not just by Strep but also by other infections, toxins, or stress.

Diagnostic Criteria for PANS

PANDAS: OCD and/or tics
PANS: OCD and/or eating restrictions

Includes at least two of the following symptoms:

- Anxiety or separation anxiety
- Emotional lability or depression
- Irritability, aggression, or severe oppositional behaviors
- Behavioural regression or developmental setbacks
- Decline in school performance
- Motor or sensory abnormalities
- Somatic symptoms such as sleep disturbances, enuresis, or frequent urination

Age of Onset

PANDAS was once believed to start between ages 3 and 13, but it can also begin in older teens and adults. The average onset is 7.5 years, with boys being twice as likely to be affected as girls.

Sudden Onset (Sometimes Gradual)

Surveys of parents and physicians show that 88% of cases have a sudden onset, with symptoms escalating within three days. In some cases, the onset is more gradual.

Relapsing & Remitting

The cyclical nature of these conditions, where symptoms can flare up (relapse) and then improve or disappear (remit) over time. This pattern can be unpredictable and challenging for both the affected child and their family.

Understanding the relapsing and remitting nature of PANS/PANDAS helps families and healthcare providers create a flexible, responsive treatment plan.

Initial Testing for PANS PANDAS

The initial tests for diagnosing PANS PANDAS focus on identifying underlying infections, excluding other potential causes, and evaluating the child's overall health. Below is a summary of the first steps in the diagnostic process:

Clinical Evaluation

- **Medical History:** A thorough medical history is taken, focusing on the sudden onset of symptoms like OCD, tics, or eating restrictions, often after an illness.
- **Physical Examination:** A comprehensive physical exam to check for signs of infection, inflammation, or other neurological issues.



Infection Screening

- **Throat Swab and Rapid Strep Test:** To check for current or recent streptococcal infections, which is crucial for PANDAS. Testing all family members is also recommended. Note that a negative result doesn't rule out PANDAS, as strep bacteria can remain dormant and react to external triggers.
- **Blood Tests for Infections:**
 - **Anti-Streptolysin O (ASO) Titer:** Measures antibodies produced in response to a strep infection.
 - **Anti-DNase B Titer:** Another antibody test for detecting recent streptococcal infections.
 - **Tests for Other Infections:** Depending on symptoms, tests for Mycoplasma pneumoniae, Lyme disease, Epstein-Barr virus, or other pathogens may be conducted.

Inflammatory Markers

- **C-Reactive Protein (CRP):** Indicates inflammation in the body.
- **Erythrocyte Sedimentation Rate (ESR):** Another test to detect inflammation.

Autoimmune Testing

- **Anti-Nuclear Antibody (ANA) Test:** To rule out other autoimmune conditions that could cause neuropsychiatric symptoms.
- **Other Autoimmune Panels:** Depending on the child's symptoms and history, further testing may be done.

Neurological and Psychiatric Assessment

- **Neuropsychiatric Evaluation:** An assessment of the child's mental and emotional state, including OCD, tics, anxiety, and behavioral changes. Ensure that the psychologist or psychiatrist conducting the evaluation is familiar with PANS PANDAS.
- **Standardized Psychiatric Questionnaires:** Tools like the Children's Yale-Brown Obsessive Compulsive Scale (CY-BOCS) may be used to quantify the severity of OCD symptoms.

Basic Blood Work

- **Complete Blood Count (CBC):** To assess overall health and look for signs of infection or anemia.
- **Metabolic Panel:** To check for electrolyte imbalances, kidney, and liver function.

Imaging and Additional Tests (If Indicated)

- **Brain MRI:** To rule out other neurological conditions that could mimic PANS/PANDAS symptoms.
- **Electroencephalogram (EEG):** If seizures are suspected.

How is PANS PANDAS treated?

Treatment for PANS and PANDAS typically involves a multi-faceted approach, addressing both the underlying triggers and the symptoms. Here are the main treatment strategies:

Antibiotics

- **PANDAS:** If a streptococcal infection is identified as the trigger, antibiotics are often prescribed to eradicate the infection. Penicillin, amoxicillin, or azithromycin are commonly used.
- **PANS:** Antibiotics may also be used if other infections like mycoplasma pneumonia, Lyme disease, or others are identified as triggers.
- In some cases, a longer course of antibiotics may be required.

The treatment approach is often tailored to the individual child, with adjustments based on their response to various therapies. Regular follow-up with healthcare providers specializing in PANS/PANDAS is essential for effective management.

Anti-Inflammatory Treatments

- **Non-Steroidal Anti-Inflammatory Drugs (NSAIDs):** Medications like ibuprofen may be used to reduce inflammation and alleviate symptoms.
- **Corticosteroids:** Short courses of corticosteroids, like prednisone, may be used to quickly reduce inflammation and immune system overactivity.

Immune-Modulating Therapies

- **Intravenous Immunoglobulin (IVIG):** IVIG therapy may be considered for children with severe or refractory cases, helping to modulate the immune response.
- **Plasmapheresis:** In cases where IVIG is ineffective, plasmapheresis (a procedure that filters the blood to remove harmful antibodies) may be used.

Supportive Therapies and Psychiatric Interventions

- **Supportive Therapies:** educational support and psychoeducation is often recommended to help manage OCD, anxiety, and other neuropsychiatric symptoms associated with PANS/PANDAS.
- **Medications:** Psychiatric medications, such as SSRIs or other anxiolytics, may be prescribed to manage symptoms like anxiety, OCD, or depression.

Supportive Care

- **Education and Family Support:** Providing education to the family and school about the disorder, along with support for the child, is crucial.
- **Nutritional and Lifestyle Support:** Ensuring the child maintains a healthy diet, regular sleep, and stress management can support overall treatment efforts.

Treatment of Co-occurring Conditions

- If the child has other conditions like tics, ADHD, or autoimmune issues, these may require specific treatments.