

PANDAS, PANS, SYDENHAM CHOREA

What is it?

Pediatric Autoimmune Neuropsychiatric Disorders Associated with Streptococcal infections (PANDAS) occurs when a strep infection triggers a misdirected autoimmune response causing brain inflammation. Children and adolescents will quickly exhibit symptoms like Obsessive Compulsive Disorder (OCD), tics, anxiety, sensory sensitivity, and restrictive eating. These symptoms are sudden and intense but could appear as late as 4-6 months post strep infection because antibiotics did not eradicate the bacteria. PANDAS typically first appears in childhood from age 3 to puberty. Reactions to strep infections after age 12 are considered rare.

Pediatric Acute onset Neuropsychiatric Syndrome (PANS) is a newer term used to describe a larger class of acute and abrupt onset OCD. PANS is associated with a variety of different infections.

Sydenham chorea (SC) is a neurological disorder of childhood resulting from infection via Group A beta-hemolytic streptococcus (GABHS), the bacterium that causes rheumatic fever. SC is characterized by rapid, irregular, and aimless involuntary movements of the arms and legs, trunk, and facial muscles. It affects girls more often than boys and typically occurs between 5 and 15 years of age. Symptoms can occur gradually or appear rapidly.

According to The PANDAS Network, neurologists believe both illnesses, PANDAS and Sydenham Chorea, affect the basal ganglia of the brain. These illnesses may be renamed '*basal ganglia encephalitis*' by a consortium in 2019-2020.

What are the symptoms?

PANDAS and PANS are episodic; meaning symptoms may disappear for extended periods before reappearing when stimulated by a later exposure to bacteria or viruses. Symptoms may grow increasingly severe with multiple recurrences. The signs and symptoms of the OCD can present in many types but are abrupt and acute with dramatic onset. Children are often misdiagnosed with a psychiatric illness. A child's possible symptoms may vary in exacerbation and severity but could include:

- OCD manifesting in a variety of forms
- Restrictive eating
- Anxiety, fear
- Increased ADHD symptoms
- Sleep disturbance
- Motor disturbance
- Sensory sensitivity
- Aggression
- Irritability
- Short term memory issues
- Mood changes
- Emotional and development regression
- Depression
- Changes in handwriting
- Joint pain

What is the treatment?

Treatment for acute episodes means treating the infection causing the symptoms if present. Antibiotics for one or more symptoms will be prescribed and in some cases used prophylactically.

Other treatments include use of steroids, probiotics, Omega 3, IVIG, and plasmaphoresis. Children with OCD symptoms could also additionally benefit from SSRI medication and cognitive behavioral therapy (CBT). Children with PANDAS are unusually sensitive to side effects of SSRIs and other medications so it is important to start with a low dose and slowly increase over time.



Kennedy Krieger Institute

The Specialized Health Needs Interagency Collaboration (SHNIC) program is a collaborative partnership between the Kennedy Krieger Institute and the Maryland State Department of Education.

Suggested school accommodations

A student that has been diagnosed with PANDAS/PANS might find attending school to be difficult especially as it relates to leaving home and experiencing a decline in school performance. Planning for the student is essential so that the student may receive the supports that they might need when the condition exacerbates or changes. Supporting students with these conditions in the school require educators and parents/guardian to work as a team. Some accommodations to consider for a 504/IEP could include:

- Modified or flexible school day
- Plan for absences and make-up work
- Rest periods or frequent breaks
- Extended time
- Copies of notes
- Use of computer for classwork or scribe
- Executive function accommodations
- Communication plan with parents/guardians concerning any abrupt changes in behavior, eating habits, school performance
- Sensory supports
- Modify tasks involving motor control
- "Safe space" to use related to behavioral difficulties/tics
- Advance planning for health related absences
- Emotional support for student
- Behavioral supports
- Staff education/training as appropriate
- Emergency Evacuation Plan (EEP)

Specific health issues for Individualized Healthcare Plan

- Diagnosis
- Student specific characteristics, behaviors, etc.
- Current medication list including PRN medications
- Monitor for signs and symptoms of strep outbreak and notify caregivers
- Consider that student may have other immunosuppression concerns or diagnoses
- Support and resources for family
- Communicate with school staff, parents/guardian, and provider any changes or concerns about the disease
- Emergency Care Plan(s) (ECP) related to medical needs in the school setting and staff education/training as appropriate for each

Resources & Manuals

National Institute of Health (NIH)- PANDAS-Questions and Answers
<https://www.nimh.nih.gov/health/publications/pandas/index.shtml>

PANDAS Network
<http://pandasnetwork.org/>

New England PANS/PANDAS Association
<http://www.nepans.org/>