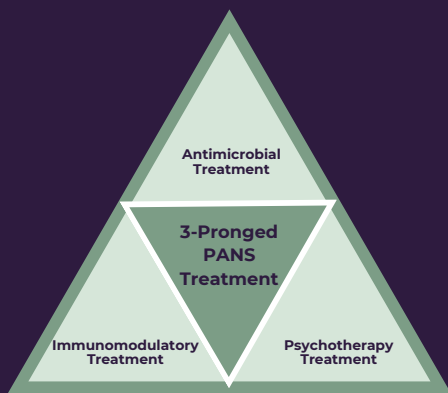




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Alliance to Solve PANS & Immune-Related Encephalopathies

## PANS Criteria

1. Abrupt, acute onset or worsening
  - Obsessive-compulsive disorder or severe restricted food intake
2. Concurrent presence of additional neuropsychiatric symptoms from at least 2 of the 7 categories:
  1. Anxiety, separation anxiety
  2. Emotional lability or depression
  3. Irritability, aggression, and/or oppositional behaviors
  4. Behavioral regression
  5. Deterioration in school performance (loss of math skills, handwriting changes, ADHD,)
  6. Sensory or motor issues, tics
  7. Somatic signs: enuresis, or urinary frequency, sleep disturbances
3. Symptoms are not better explained by a known neurologic or medical disorder
4. Age requirement – None



Overview of Treatment of PANS-JCAP Vol27, 2017  
Swedo, MD, Frankovich, MD, MS, Murphy, MD, MS

## Treatment Overview

“Treatment of PANS involves a three-pronged approach that utilizes psychiatric medications when appropriate to provide symptomatic relief, antibiotics to eliminate the source of neuroinflammation, and anti-inflammatory and immune modulating therapies to treat disturbances of the immune system.”

- 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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# PANS PANDAS IN THE SCHOOL SETTING

## PANS Pediatric Acute-onset Neuropsychiatric Syndrome

PANS is a clinical diagnosis based on history and physical examination. PANS diagnostic criteria require an acute onset or sudden worsening of OCD and/or restrictive eating, 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. The average age of onset is between 3 and 13, but post-pubertal cases do occur. There is no requisite age of symptom onset for a PANS diagnosis.

## PANDAS Pediatric Autoimmune Neuropsychiatric Disorder Associated with Streptococcal Infections

PANDAS, a subset of PANS, in which symptom onset is triggered by Group A Streptococcus (GAS) infections.

## SCHOOL OVERVIEW

### PANS is a Medical Condition

- Treatment includes medical protocols and therapeutic practices
- School supports are a component of appropriate treatment
- Essentially a spectrum disorder - symptoms and severity varies

### Impacts Multiple Areas of Learning

- Affects a student's ability to learn & attend school
- Effects physical, psychological, neurological, behavioral, and developmental health
- All students will need some degree of accommodation and support
- Need to weave together layers of support

### Behavior Intervention

- Due to the inflammation in the Basal Ganglia, not all behaviors are choice-based. Differentiate between choice-based behaviors and neurological symptoms
- Positive reinforcement tends to work better - Don't blame the student for illness
- Manage environment and antecedents

### Flexibility

- Relapsing and remitting disease course
- Functioning can change rapidly. Need a fluid flow in and out of services and rapidly react to change in symptoms
- Supports must be individualized per student and per flare

### Attendance

- Nature of illness greatly impacts attendance. Not typical school refusal
- The goal is to get students to attend full time, but flexibility is required
- Pushing too hard for normalcy may result in a backslide
- Provide tutoring & create opportunities for a partial day, online learning, or homebound
- Gradually increase expectations when the student is able to return to school

### Communication & Collaboration

- A team approach is needed
- Inform families of exposure to infectious triggers in the classroom
- Work with families and providers to
  - Determine level of support needed
  - Determine what is and is not choice-based behavior
- The caregiver burden is extreme and affects the whole family, including siblings so, please partner well with family and providers



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## Multiple Domains of Learning Impacted

### Academic/Cognitive Symptoms

- Loss of math skills
- Decline in handwriting skills
- Reduced concentration
- Perfectionism
- Work refusal
- Reduced memory
- Avoidance of high sensory settings
- Decline in creativity
- Inability to make decisions
- Reduced ability to focus
- Poor organizational skills
- Time management problems
- Difficulty in planning & prioritizing
- Visual processing difficulties
- Processing delays

### Physical/Sensory/Motor Symptoms

- Restricted food intake: fear of contamination, choking, sensory
- Tics: Vocal and/or motor
- Urinary frequency & involuntary urination
- Unusual gait & Balance issues
- Hair pulling and skin picking
- Dilated pupils
- Stomach pain
- Fatigue
- Hallucinations
- Selective mutism
- Frequently sick
- Low tone

### Behavioral Symptoms

- Obsessive thoughts: rigidity, perfectionism, inappropriate Compulsive actions
- Anxiety: separation, school refusal, general
- Depression & emotional lability
- Aggression: oppositional behavior, rages
- Regression: immaturity, baby talk
- ADHD: poor impulse control, fidgeting, outbursts
- Sensory issues: defense and seeking

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# PANS PANDAS IN THE SCHOOL SETTING

## IMPACT ON STUDENTS

A hallmark of PANS PANDAS is a well-rounded student who goes from solid grades and many friends to barely able to function, attend school, or engage in activities. Imagine what it feels like to be this student whose life is hardly recognizable. It is scary, frustrating, maddening, confusing, isolating, exhausting, painful, and depressing. Imagine what these symptoms do to the entire family. They are utterly unprepared for their new reality; they want their life back. They need support.

## 1 IN 200 STUDENTS

PANS PANDAS affects an estimated 1 in 200 kids. An elementary school with 400 to 600 students may have 2 to 3 students with PANS PANDAS. This number may include students who have yet to be correctly diagnosed therefore are not receiving appropriate treatment. Schools must learn about PANS PANDAS to appropriately support their currently diagnosed students and help identify students who have these devastating but treatable disorders.

At first glance, PANS PANDAS may resemble other disorders: Tourette's syndrome, ADHD, OCD, Generalized Anxiety Disorder, Autism, Oppositional Defiance Disorder, etc. Do not rule out PANS PANDAS if a student already has another diagnosis. Since PANS PANDAS is a neuroimmune medical condition, treatment requires a different approach than managing "typical" OCD, ADHD, or anxiety. One cannot only treat symptoms psycho-therapeutically. Instead, one needs to take both a medical and therapeutic approach.

## SUPPORTING STUDENTS

PANS PANDAS is a medically complex condition. Symptoms affect multiple areas of learning: academic, cognitive, behavioral, and physical, impacting their ability to learn, function, and attend school. Some PANS students will be affected more severely than others; some will have a small concentration of symptoms, while others will exhibit symptoms across all domains.

All students will need some degree of school support ranging from classroom supports to IEPs. Early diagnosis and treatment, coupled with support, communication, and collaboration at school, can minimize the impact of the illness on the student's education and life.

First and foremost, we need to understand these behaviors and symptoms are due to brain inflammation, specifically in the Basal Ganglia, essentially causing it to malfunction and override choice-based behavior during a flare. Positive reinforcement strategies are more effective for managing behaviors.

Due to the relapsing-remitting nature of the disease, expect rapid changes in functioning. It is critical to be flexible and to try different approaches with responsive strategies. Attendance can be significantly impacted; this is not typical school refusal. Nearly all PANS PANDAS students will miss more than the maximum unexcused days; supportive plans should be implemented. Thi

The more that PANS PANDAS students are in classrooms that are sensitive and responsive to their experiences, the more prepared schools can support the needs that are a function of this illness. Supports can help PANS/PANDAS students remain functional in school during a flare. Remedial support after flares can help the student regain skills lost. Supports often look similar to accommodations and strategies that teachers may already use for disparate conditions (ADHD, OCD, executive functioning, urinary issues). Due to the numerous symptoms typical of PANS PANDAS, teachers may need to layer" or utilize multiple layers of accommodations.