

NEW ENGLAND
PANS/PANDAS
ASSOCIATION

PANS/PANDAS IN THE SCHOOL SETTING:
From Symptoms To Supports

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NE PANS/PANDAS Association

Who We Are

New England PANS/PANDAS Association is a group of parent and medical volunteers focused on raising awareness of Pediatric Autoimmune Neuropsychiatric Disorder Associated with Streptococcal Infections (PANDAS) and Pediatric Acute-onset Neuropsychiatric Syndrome (PANS).

Our Mission is Simple

- ✧ To raise awareness of PANS/PANDAS in our community and beyond
- ✧ To support the medical community in their mission to heal children suffering from PANS/PANDAS
- ✧ To look for ways to expand the medical care available
- ✧ To create opportunities to assist families searching for solutions



What is PANS & PANDAS

PANS

Pediatric Acute-onset Neuropsychiatric Syndrome

PANDAS

Pediatric Autoimmune Neuropsychiatric Disorders Associated with Streptococcal Infections

PANS and PANDAS is a condition in which a subset of children and adolescents who experience an encephalitic-like onset of neuropsychiatric symptoms following exposure to a trigger such as Strep, Pneumonia, Mononucleosis, Environmental Factors and other. In simple terms, antibodies created to fight the infection become misdirected and attack a small area of the brain known as the basal ganglia. This autoimmune reaction results in an acute onset of neuropsychiatric symptoms. Both PANS and PANDAS are clinical diagnoses. PANDAS is a subset of PANS. The initial trigger of PANDAS is Strep however secondary triggers are not relegated to only strep. The initial triggers for PANS can include Pneumonia, Mononucleosis, other pathogens, Environmental Factors and other factors.



Overview of PANS in School

“Increased awareness [in PANS], however, has not yet translated into readily-available school and community supports, resulting in significant difficulties for students with PANDAS or PANS, and their families throughout the educational process. Our special education processes, often, rely on the assumption that students will make progress throughout the year. In contrast, students with PANDAS or PANS may **demonstrate rapid shifts in their social, emotional or academic functioning as their systems react to, then recover from, illness.** Teachers may, understandably, be baffled that **the student who was passing math last week is now failing the class and acting out daily.** Frequently, students with PANDAS or PANS experience such **heightened anxiety that it is difficult to attend school** at all, and **their immune systems may not be able to tolerate exposure to peers** during the height of cold and flu season. Teachers already juggling new curriculum, new tests and new evaluation rules may find it virtually impossible to also learn about new neurological disorders and how to accommodate them in the classroom.”



What is PANS & PANDAS

PANS Criteria

- ✧ Sudden onset of OCD or severely restricted food intake.
- ✧ Symptoms not better explained by a known medical or neurologic disorder. It is a “diagnosis of exclusion”.
- ✧ At least 2 of the following severe and acute symptoms from the following categories:
 - Anxiety - including separation anxiety
 - Emotional Lability, Depression
 - Aggression, Irritability, Oppositional Behavior
 - Behavioral (Developmental) Regression
 - Deterioration of Learning Abilities related to ADHD (memory deficits, cognitive changes)
 - Sensory & Motor Abnormalities
 - Somatic Signs- sleep disturbances, enuresis, urinary frequency
- ✧ Symptoms may also include: terror, separation anxiety, regress behavior-temper tantrums or baby talk, and deterioration of fine motor and handwriting skills

Additional Notes on PANS:

- ✧ Children with PANS
 - Are extremely ill
 - Can have extreme compulsions (licking shoes, barking)
 - Can have Motor & Phonic tics (whooping, wringing hands)
 - Can have terrifying episodes of extreme anxiety or aggression.
- ✧ PANS symptoms overlap with psychiatric disorders, such as OCD, Tourette’s syndrome, ADHD, depression, and bipolar disorder. However PANS is only diagnosed when these symptoms present acutely at the same time.
- ✧ Some children with PANS have visual or auditory hallucinations thus symptoms can seem to be identical to the psychotic symptoms seen in conditions such as schizophrenia, bipolar disorder, and lupus cerebritis.



What is PANS & PANDAS

PANDAS Criteria

- ✧ Significant OCD, and/or Tic disorders such as Tourette Syndrome
- ✧ Pediatric Onset
- ✧ Episodic course of symptom severity associated with association with Streptococcal-A (GABHS) infection
- ✧ Neurologic abnormalities (motoric hyperactivity, choreiform movement)

Additional Notes:

- ✧ Relapsing-remitting courses of OCD and/or tic severity that get suddenly worse (typically after strep infection) and gradually better rather than consistent levels with good and bad weeks.
- ✧ Often experience one or more of the following in conjunction to OCD and/or tics
 - Separation anxiety
 - Mood changes
 - Sleep Disturbance
 - Night time bed wetting and/or urinary frequency
 - Fine and/or Gross Motor changes
 - Joint Pains



Identification of PANS at School

Could it be PANS?

It is not always easy to identify if a child has PANS. Knowing the PANS Diagnostic Criteria is a good place to start but you really have to look at the whole picture. It often takes a collaborative effort to identify a child with PANS.

“The identification of PANDAS symptoms in the school setting requires a cooperative effort. Any teacher who comes in contact with a child should be alert for **sudden behavioral changes.** Young children frequently exhibit striking behavior changes, including those due to trauma or significant life changes. **Scrupulous observation and careful deliberation** are sometimes needed to assess causes. **Open and ongoing home — school communication may be essential.**

The school nurse, equipped with medical information, is in a valuable position to assist in the identification of possible PANDAS cases. She may be the significant professional in a school setting who is first able to link a recent or recurring strep infection with sudden atypical behavior. **The perceptive school nurse will also be able to identify and consider any variety of confounding medical symptoms.**



PANS in a School Setting

Manifestations of PANS Symptoms in the School Setting

BEHAVIORAL Symptoms

- Obsessive Compulsive Disorder
- Obsessive Thinking (Inappropriate Thoughts/Rigid Thinking/Perfectionism)
- Eating Issues (Limited Menu/Fear of Choking/Anorexia)
- Anxiety (Separation Anxiety/School Refusal)
- Aggression (Defiance/Rages)
- Age Regression/Immaturity (Tantrums/"Baby Talk")
- ADHD (Fidgeting/Outbursts/Poor Impulse Control)
- Sensory Issues

PHYSICAL Symptoms

- Tics (Motor/Vocal)
- Eye Issues (Dilated Pupils, Vision Issues, Hallucinations)
- Eating Issues (Limited Menu/Fear of Choking/Anorexia)
- Frequent Urination (Trips to the Bathroom)
- Unusual Gait
- Balance Issues
- Chapped Hands or Lips/Mouth
- Trichotillomania (Hair Pulling/Skin Picking)
- Enuresis

ACADEMIC Symptoms

- Loss of Math Skills
- Decline in Handwriting Skills (Dysgraphia)
- Unable to Make Simple Decisions
- Poor Short-Term Memory
- Decline in Creative Work (Art, Creative Writing)
- Avoidance of High Sensory Environments (Art, Music, Cafeteria, Physical Ed, etc...)
- Loss of Focus on a Single Task
- Work Refusal (School Work/Homework/Writing Assignments)
- Perfectionism (Erasing through paper, Needing to start over)

EXECUTIVE FUNCTION Symptoms

- Difficulty with Working Memory and Holding Information
- Poor Organizational Skills
- Time Management Issues
- Difficulty Planning/Prioritizing Attention on a Single Task
- Difficulty Making Decisions



Before & After PANS

<u>Before PANS</u>	<u>After PANS</u>
<p>"A 4 year old with attention and behavior difficulties. Initial testing in June revealed mild visual perceptual and fine motor issues, but no sensory processing problems. He began occupational therapy in September."</p>	<p>"[Later], Luis' mother reported that he refused to don his socks and complained that the waistband of his pants hurt. In occupational therapy, Luis demonstrated regression in drawing and was no longer able to write the letters of his name legibly."</p>
<p>"An easygoing 15-year-old 10th grader, has always been a good student who has many friends and takes mostly honors classes. John has always been excellent in math."</p>	<p>"Following the flu..., John suddenly developed eye blinking tics and erratic behavior; he became anxious, argumentative with his teachers and parents, and suicidal, resulting in hospitalization....he suddenly missed relatively easy questions on math tests. He developed obsessions, such as pacing, setting the volume button on electronics to multiples of 5, and having everything "just so"."</p>



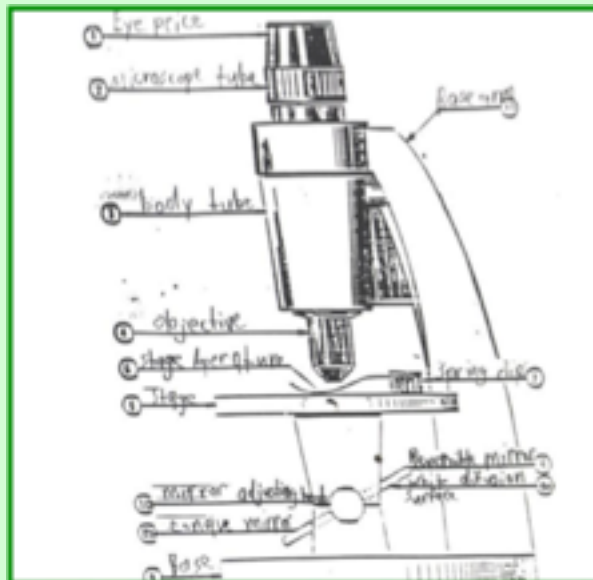
Before & After PANS

<u>Before PANS</u>	<u>After PANS</u>
<p>"A bright, well-adjusted third-grade girl... The school psychologist ruled out the possibility of recent trauma, reporting that the "intact family was wonderfully close and supportive." School friendships were numerous, with no identified social problems. The girl rated her teacher as a "favorite" and was not overwhelmed by missed schoolwork, which she described as "easy.""</p>	<p>"who returned to school after a strep infection suddenly appeared acutely school phobic. Yet morning after morning the child became intensely anxious, refused to get on the school bus, and had to be driven to school. She crouched in the car, sobbing and clinging to the seat. No amount of coaxing or prodding seemed to alleviate her severe yet unspecified anxiety."</p>
<p>"A second-grade student.... This boy, previously studious and industrious in the classroom,"</p>	<p>"The child had contracted strep during a family vacation [and] became so hyperactive and disorganized that his teacher became quite alarmed. His inability to remain seated, resist calling out, and complete even simple tasks by himself were beyond comprehension."</p>

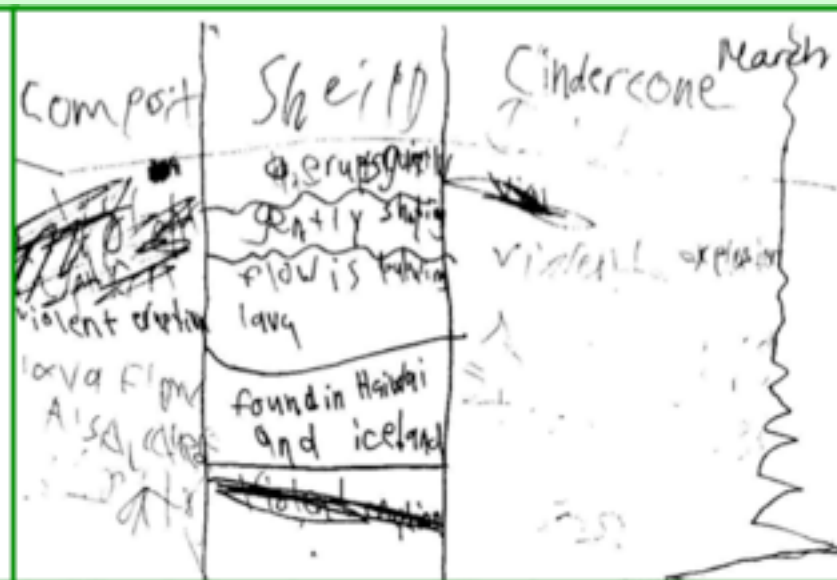
Before & After PANS

Hand writing changes correlated with increase in neuropsychiatric symptoms

Before Acute Onset



After Acute Onset



Before & After PANS

Behavioral Regression correlated with increase in neuropsychiatric symptoms

Acute Illness

Demonstrates
Behavioral
Regressive
Self-Portrait



Convalescence

Demonstrates
Age Appropriate
Self-Portrait





Road Blocks to Diagnosis

In the Medical Setting

PANS is often not diagnosed right away by medical professionals.

- ✧ Not all practitioners are PANS literate.
- ✧ There are doctors that still believe that PANS doesn't exist. Fortunately more studies are coming from the NIH and the PANS Consortium to provide enough evidence as seen with the JCAP.
- ✧ Infectious triggers and symptoms are not always immediately linked.
- ✧ Sometimes the infection is treated immediately so initial symptoms are not as severe; therefore not flagged.
- ✧ Medical testing is only one facet of diagnosis.
- ✧ Symptoms aren't linked together or blamed on age or another diagnosis.
- ✧ Symptoms often relapse and remit from year to year so big picture is hard to see.

In the School Setting

There are some kids that are easily identified with sudden onset of symptoms that all manifest at school. But more than likely you will see students that are more complicated to identify.

- ✧ Not all symptoms manifest at school.
- ✧ Children often work extremely hard to cover up anxiety, sensory issues, rage, and/or emotional changes at school.
- ✧ Communication between School and Parents is often not extensive enough.
- ✧ Student already has a 504 or IEP for ADHD, Autism, or Other Health Impairment so symptoms are only seen as behavioral or part of the previously diagnosed disorder.
- ✧ Student switched schools and history not fully communicated.



Support in the School Setting

“therapy can be instrumental in negotiating exacerbation, but doing so requires a paradigm shift. Children often lose skills during exacerbation, and traditional remedial intervention may be ineffective. Greater benefit may be found with adaptation and compensation for problems during exacerbation, followed by remediation of ongoing problems during remission.”

Basic School Supports

Student needs and performance may vary widely from week to week.

- ✧ Behavioral & Sensory supports
- ✧ Reduce student’s stress.
- ✧ Plan for acute symptom exacerbations.
- ✧ Plan for periods when less intensive supports are needed.
- ✧ Homework Accommodations
- ✧ Plan for frequent absences and tardiness.
- ✧ Encourage student to avoid germs, clean tables, wash hands, etc

Communication Supports

Students benefit from strong and proactive school communication

- ✧ Report any abrupt changes in behavior, eating habits, or school performance to family.
- ✧ Inform parents of any communicable illness in classrooms.
- ✧ Parents will inform school nurse of any health changes.



Support Accommodations

Symptom	Accommodation/Support
OCD	Redirection Depends on what/when/where
Mood Changes	Calming Techniques "Safe Space"
Anxiety	Relaxation Techniques
ADHD	Extended Time Frequent Breaks & Exercise Breaks Redirection Written Directions Preferential Seating
Sensory	Sensory Supports: proprioception, pressure, weighted vests Sensory Seeking: varying tactile input Sensory Defense: low light, quiet space
Language Issues	Extra Time Assisted Technology Speech Therapy
Lateness	Late slip on file Temporary later start time
Mobility Issues	Adaptive PE Physical Therapy Field Trip accommodations/support

Symptom	Accommodation/Support
Tics	Nurse Breaks Reading/Writing: Assistive Technology Vocal Tics: Less reading aloud Testing Modifications
Urinary Frequency	Low Key Bathroom Access Tracking
Fatigue	Time to rest Healthful snack
Math Regression	Math Facts, Formula Sheets, Calculator Extended Time, Shortened Assignments Manipulatives
Dysgraphia	Keyboard/Assistive Technology Built-Up pencils Graph paper/raised line paper
Memory	Management: Lists, Timers, Calendars, Repetition of Information Review Time Recording devices
Organization	Assignment books/Homework Binder Long Term School Project Plans Projects broken down into segments



Excused Absences

Students with PANS are medically fragile. As such, students with PANS may be absent from school more than 9 times a year. Therefore, when absences are medically necessary, they can obtain excused medical absences from their doctor. They should not be counted as truant. Some students will be absent sporadically while others will need to be absent from school for longer period of times. The School Nurse, staff, parent, medical doctor should collaborate to determine plans for frequent but sporadic missed days as well as extended absences. Please note that under some circumstances extended absences will require Homebound instruction.

For the tenth absence and all absences thereafter, **a student's absences from school are considered excused for the following reasons:**

1. **student illness** (Note: all student illness absences must be verified by an appropriately licensed medical professional to be deemed excused, regardless of the length of absence)

Districts can take some of the following steps to improve overall attendance and compliance to attendance policies:

1. **Leveraging school nurses: *School nurses can be a great resource in dealing with medical related absences.*** Using their expertise can especially benefit those students who have limited access to medical professionals.



Home Bound Instruction

Students with PANS are medically fragile. As such, students with PANS may be absent from school more for more than 9 consecutive days and may require Home Bound instruction. Home Bound Instruction is considered the most restrictive placement. Students with PANS may require this placement when a) they are too sick to attend school for extended periods b) require a non-infections environment that the school can't provide. Instruction is designed to ensure the continuity of educational services between school and home placement. The goal is to facilitate the return to the school setting, as it is a temporary placement.

BofE shall provide Homebound "instruction to a child in public schools"... "when such child is unable to attend school due to a verified medical reason"

The physician's statement must state: "That the child's treating physician has consulted with the school health supervisory personnel and has determined that attendance at school with reasonable accommodations is not feasible;" and that "the child will be absent from school for at least 10 consecutive days or that the child's condition is such that the child may be required to be absent for short, repeated periods of time during the school year"

The physician's statement must state: "That the child's treating physician has consulted with the school health supervisory personnel and has determined that attendance at school with reasonable accommodations is not feasible"- *Sec. 10-76d-15*



Individual Health Care Plans

An individualized health care plan is a detailed and orderly program of action designed to monitor, prevent, reduce or eliminate identified health problems in order to maintain or improve a student's health status and level of wellness and to promote his or her learning and positive coping. The process of planning requires a team approach and includes the establishment of care priorities, a clear understanding of student specific goals, prescription of appropriate interventions, and delineation of measurements for goal achievement.

National Association of School Nurses, 2008

Health care plans identify solutions for diagnosed health problems (actual or potential); communicate the student's specific health needs, and the prescribed nursing and collaborative interventions for directing and evaluating the care given; and provide a mechanism for demonstrating accountability.

SDECT – Clinical Procedure Guidelines for CT School Nurses

IHCPs are usually developed for students with special health needs or whose health needs require daily intervention. These plans describe how to meet an individual child's daily health and safety needs in the school setting. IHCPs include:

- functional health issues (nursing diagnoses);
- student objectives (expected outcomes) for promoting self-care and age-appropriate independence;
- responsibilities of parents, school nurses, teachers, students and administration, as appropriate

SDECT - Guidelines for Managing Life-threatening Food Allergies



Sample IHCP

Below is a small portion of a sample Individual Health Plan culled from IHPs of several students. Link to full sample is in Resources.

Assessments:

- ✧ Infection: Possibility of exposure to contagious infectious agents could result in symptoms associated with PANS.
- ✧ Medical Conditions: PANS, Immune Deficiency

Nursing Diagnosis:

- ✧ Ineffective Coping – Related to knowledge deficit of school resources, possible reluctance to seek help.
- ✧ Fear – Related to inability to predict or control symptoms.
- ✧ Increased susceptibility from contact with any contagious disease. PANS manifests in OCD, ADHD, ODD behaviors, motor and vocal tics, depression, etc.

Goals:

- ✧ Student will identify sources of anxiety and fear.
- ✧ Student will identify his support systems at school and will be willing to use them.
- ✧ School Nurse will inform parents of any communicable illness in classrooms.
- ✧ School Staff and School Nurse will recognize signs of PANS episode.
- ✧ School Staff to encourage infection control measures in the classroom.
- ✧ School Staff will implement an ANYTIME Nurse/Bathroom pass not to be used by other students.
- ✧ Parents will inform school nurse of any health changes.
- ✧ School Staff will understand that Student might require snacks between meals in order to sustain energy.



Sample IHCP

Intervention	Who	When	Why
Share/exchange health information with parent with regard to communicable diseases in classroom	Nurse	As needed	To promote health and well-being. Potential for flare related to compromised immune system
Notify parent of any changes in student's condition	Nurse	As needed	To promote health and well-being
Classroom support for tics that are bothering student—permit student to go to School Nurse	School Staff/ Nurse	As needed	Minimize disruptions to class and embarrassment of student over symptoms
Check in with student when Student shows signs of frequent bathroom breaks, putting face in hands, picking at own hands or other different behaviors	School Staff	As needed	These could be indications of stress. Stress needs to be minimized.
Student shuts down or is unable to speak—send to nurse	School Staff	As needed	To promote health and well-being
Student becomes sad or angry without due cause—send to nurse	School Staff	As needed	To promote health and well-being
Student's symptoms are not resolving, he is not able to work to school expectations, and he is upset—notify parents ASAP	Nurse	As needed	To promote health and well-being
Fatigue; student may require time to rest or a healthful snack	School Staff	As needed	To promote health and well-being



Closing Thoughts

- ✧ Kids Can Get Better
- ✧ Earlier diagnosis and treatment equals better outcomes

- ✧ PANDAS/PANS is essentially a spectrum disorder
- ✧ Not all students will have all of the symptoms

- ✧ Symptoms are relapsing and remitting
- ✧ Create fluid access in and out of services

- ✧ Be a partner with the family
- ✧ It takes a whole team

- ✧ Don't blame the child for his/her illness
- ✧ It is Medical. The symptoms are not behavioral