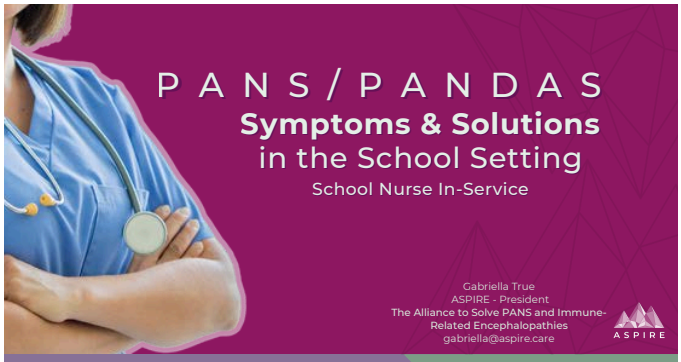

PANS/PANDAS
Symptoms & Solutions in the School Setting
School Nurse In-Service

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Disclosure Statement

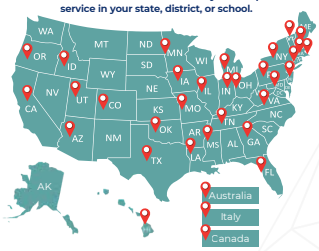
I have no relevant financial relationships or conflicts of interest to disclose.

Learning Objectives

1. Will be able to describe the PANS diagnostic criteria
2. Will be able to provide an overview of diagnostic and treatment approaches of PANS
3. Will be able to discuss strategies for working with a student with PANS

ASPIRE School In-Service Lectures

ASPIRE has provided 300 school in-service lectures in 30 +states and countries. Contact us today to set up an in-service in your state, district, or school.



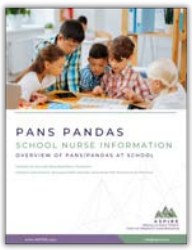
ASPIRE provides lectures on PANS/PANDAS via Zoom to school staff and school nurses, along with a new asynchronous training option for added flexibility. After the training, we provide toolkits and lecture slides to support implementation. We remain available for questions and follow-up throughout the year. Live sessions are typically scheduled for 2 hours (a 1.5-hour lecture plus Q&A), but shorter options are available. Schools can choose the format that best fits their needs, whether live, recorded, or a combination of both.

Contact ASPIRE to schedule a virtual in-service on PANS PANDAS More info: https://aspire.care/treating-pans/pans-at-school

PANS PANDAS Comprehensive Educator Toolkit

https://aspire.care/families-parents-caregivers/comprehensive-school-toolkit/

School Nurses & PANS



"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."

PANDAS in the School Setting by Kathy O'Rourke, MA (School Nurse News-2003)

School Nurses & PANS

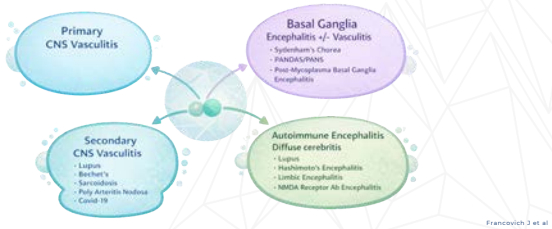
"The school nurse, as a member of a multidisciplinary team, benefits from an awareness of these disorders, the resulting impact on school performance, and the recommended treatment."

- Kathy Bagian, MSN, RN, CSN, Sheila Q. Hartung, PhD, RN, Is It PANS, CANS, or PANDAS? Neuropsychiatric Pediatric Disorders That Are Not Black and White —Implications for the School Nurse

- Bridge communication between staff, parents, and outside providers
  - Develop and monitor Individual Healthcare Plans (IHP/IHCP)
  - Provide guidance to the team in developing 504 & IEP plans
- Educate the school community on PANS/PANDAS
  - Share information via newsletter, website, meetings, staff meetings, etc.
  - Refer students and families to resources like ASPIRE or to their providers
- Provide emotional support to parents and students.

Inflammatory Brain Conditions with Psychiatric Symptoms

Medical conditions may initially present with neuropsychiatric symptoms, reflecting an underlying medical cause.



Francovich J et al

DSM-5 TR Differential Diagnosis

1. Ruling out Malingering and Factitious Disorder
2. Ruling out a substance etiology
3. Ruling out an etiological medical condition
4. Determining the specific primary disorder(s)
5. Differentiating Adjustment Disorder from the residual Other Specified and Unspecified conditions
6. Establishing the boundary with no mental disorder

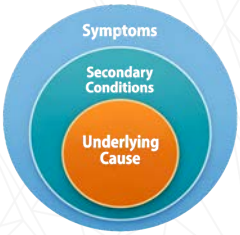
3 Ruling IN a medical issue

Exclude general medical conditions that could explain the symptoms (e.g., thyroid issues causing anxiety).

Primary vs Secondary Conditions

Why the distinction is critical

- Correct diagnosis drives appropriate treatment
- Addressing the underlying condition is essential for recovery
- Treatment approaches can differ significantly for secondary conditions
- Psychiatric and psychological interventions can vary significantly but have some overlap to manage some symptoms



PANS and PANDAS

PANS

Pediatric Acute-onset Neuropsychiatric Syndrome

PANS is a clinical condition defined by the sudden onset or worsening of obsessive-compulsive symptoms and or severe eating restrictions and at least two concurrent cognitive, behavioral, or neurological symptoms. PANS has multiple etiologies and disease mechanisms.

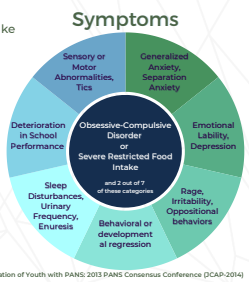
PANDAS

Pediatric Autoimmune Neuropsychiatric Disorder Associated with Streptococcal infection

PANDAS is a subset of PANS that requires a temporal relationship to Group A Streptococcal infections.

PANS Diagnostic Criteria

1. **Abrupt, acute new onset or newly worsening of**
   - Obsessive-compulsive disorder or severe restricted food intake
2. **Concurrent presence of additional behavioral or neurological symptoms with similarly acute onset and severity from at least two of the seven categories:**
   1. Anxiety, separation anxiety
   2. Emotional lability or depression
   3. Irritability, aggression, and/or oppositional behaviors
   4. Behavioral or developmental regression
   5. Deterioration of school skills (math skills, handwriting changes, ADHD-like behaviors)
   6. Sensory or motor abnormalities, tics
   7. Somatic signs: sleep disturbances, enuresis, or urinary frequency
3. **Diagnosis of Exclusion**
4. **Age requirement – None**



Clinical Evaluation of Youth with PANS: 2013 PANS Consensus Conference (JCAP-2014)

Who Gets PANS/PANDAS?

- How many have PANS/PANDAS:
  - True incidence is unknown
  - Not rare—rarely diagnosed
- Average age of diagnosis: 3–13 years
- Peak age of onset: 4–9 years (≈69%)
- Sex distribution:
  - Below age 8: ~4.7 boys : 1 girl
  - Above age 8: ~2.6 boys : 1 girl
- No age requirement:
  - Symptoms can continue into adulthood
  - Adult-onset can occur
- Family history:
  - ~70% of PANDAS families report autoimmune or strep-related illness

What is Happening with These Families?

"Imagine your capable, confident, verbal child turning into what appears to be a mentally ill, non-functional person you cannot recognize nearly overnight! The trauma to the PANDAS/PANS child and their family is profound and life-changing. This is a family diagnosis that can tear entire families apart! It often takes everything and everyone to wrestle the child back from the attacking antibodies!"

Understanding the Impact of Symptoms, A Psychologists View - Dr. Lisa Scholder, LP

Caregiver Burden Index

"High levels of caregiver burden are reported in the Stanford PANS clinic. Interventions for PANS/PANDAS may be enhanced by including the CBI as part of routine clinical assessment and by providing targeted resources to parents where appropriate."

- **37** — Median CBI during first PANS/PANDAS flare = 37
- **50%** — Stanford PANS Clinic - 50% of families, during first flare,exceed score to determine need for respite
- **-3.5** — CBI score predicted to decrease each year family is in an established clinic = -3.5 points per year; 95% CI, -2.4 to -4.6
- **+.7** — CBI mean score predicted to improve in families with shorter time between PANS onset & entry into multidisciplinary clinic = .7 points per year squared; 95% CI, 0.1 to 1.3

- ↑ Higher CBI than in Alzheimer's
- = Equal to CBI in Rett Syndrome

Presentation: PANS Diagnosis & Assessment, Thienemann MD, Willett MD Phd
Farmer C et al, Psychometric Eval. CBI in Children & Adolescents w/PANS. 2018

Factor Structure of the CBI

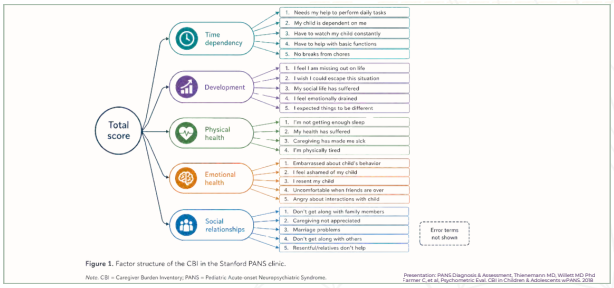


Figure 1. Factor structure of the CBI in the Stanford PANS clinic.

Note. CBI = Caregiver Burden Inventory; PANS = Pediatric Acute-onset Neuropsychiatric Syndrome.

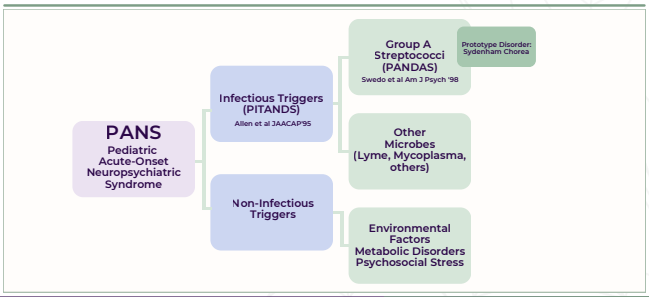
Presentation: PANS Diagnosis & Assessment, Thienemann MD, Willett MD Phd
Farmer C, et al, Psychometric Eval. CBI in Children & Adolescents w/PANS. 2018

Clinical Urgency to Improve Outcomes

Clinical Urgency

- PANS/PANDAS is treatable
  - Early identification and appropriate treatment improve outcomes
  - Early, targeted treatment of infection may reduce severity and recurrence
- Families see an average of 8 physicians over 3 years before correct diagnosis
- Delayed or missed treatment can lead to:
  - Neural injury
  - Developmental disruption
  - Long-term disability
  - Inappropriate psychiatric medications
  - Restrictive psychiatric placements
- Delays in care have real and serious consequences—including loss of life

PANS Flow Chart

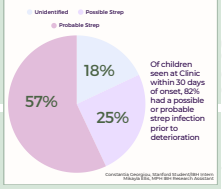


PANS Triggers

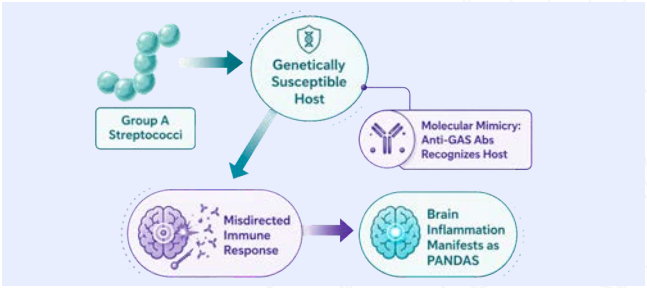
Post-infectious Autoimmunity and/or Neuroinflammation are found in more than 80% of PANS cases.
Below are some of the most known triggers. It is not meant to be a comprehensive list and does not mean another infection may have triggered PANS symptoms.

Infectious Triggers	• Strep – (PANDAS) • Mycoplasma Pneumonia • COVID-19 • Tick-borne disease ◦ lyme, bartonella, babesia • Coxsackie virus • Upper respiratory infections • Epstein Barr virus • Sinus infections • Influenza
Non-Infectious Triggers	• Mold • Environmental toxins • Metabolic imbalances • Endocrine imbalances • Psycho-Social stress

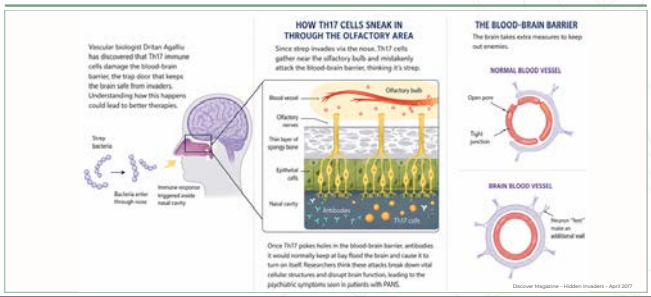
Strep Association in Stamford Cohort



PANDAS Disease Mechanism



Blood-Brain Barrier



Effects of Basal Ganglia Inflammation

Basal Ganglia is a relay station through which run neurons that control:	Inflammation in the Basal Ganglia may cause:
Mood & Emotion	• OCD • Mood Lability • Anxiety
Cognition	• Slow Processing Speed • Memory Issues • Learning Deficits eg Math
Sensory	• Sensitivity to: • Light, Sounds, Smells, Textures, Tastes
Motor Movements	• Tics • Choreiform Movements
Procedural Learning	• Handwriting Changes • Clumsiness
Behavior	• OCD • Rage • Developmental Regression

PANDAS PPN – Seeing Your First Child with PANDAS

Neuroimmune Symptoms vs. Behaviors

What we normally see as "behaviors" may be PANS/PANDAS symptoms

- Symptoms are not the same as behavior, even if they look similar
- Not all behavior is choice-based—neuroinflammation can drive involuntary responses
- Follow the principle:
  - "Children do well when they can." Ross Greene, Ph.D.
- Neurologically driven symptoms may not respond to traditional behavior approaches

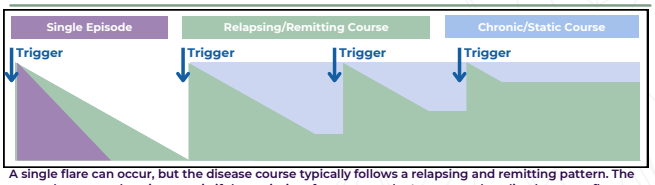
Reframe the Lens:
From "behavior problem" → to "neuroimmune symptom"

Symptom Severity

Mild	Moderate	Severe

• Symptoms interfere with daily life but not in all settings
• Able to attend school but with separation anxiety
• OCD occupies 1-2 hours a day without escalating to obsessional fears
• Other symptoms vary from patient to patient and from flare to flare but are not incapacitating
• Symptoms require some school accommodations
	• OCD occupies 50%-70% of the waking day. Impacts daily activities severely but not fully disabling
	• Other symptoms are also moderate; impact daily life but not incapacitating
	• School attendance may be affected, but the patient may be able to engage in other activities
	• Symptoms require increased school accommodations and supports
		• Neuropsychiatric symptoms can result in life-threatening situations
		  • Hazardous impulsivity and/or regression
		  • Weight loss (>10%-15% of body mass) due to obsessional food restrictions
		• OCD, anxiety, and fears occupy 80%-100% of waking day
		• Unable to attend school due to OCD and separation anxiety
		• Irritability, depression, aggression, and other symptoms can be equally present

Symptom Course



A single flare can occur, but the disease course typically follows a relapsing and remitting pattern. The course becomes chronic or static if the majority of symptoms don't return to baseline between flares.

Remittance
- Can be gradual – Saw tooth recovery (good and bad weeks)
- A few symptoms may not return completely to baseline in between flares
  - Symptoms become chronic/static if the majority of symptoms don't return to/close to baseline.

Relapse
- Triggered by new infection, exposure to infection, environmental challenges, stress, injury, etc.
- The severity of flares will vary, don't ignore the less severe relapses
- Flares can occur often or spread out by months or years

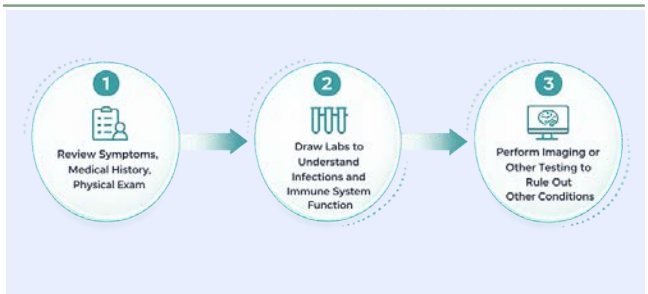
Roadblocks to Diagnosis & Treatment

There are many roadblocks to a PANS PANDAS diagnosis and treatment. The list below includes some of the most common roadblocks but are not all-encompassing.

- Not all practitioners are PANS literate
- Long waiting lists for literate providers
- Not all states have mandated insurance coverage
- Not all providers take insurance no matter if the condition is covered
- Infectious triggers & symptoms are not always immediately linked

- Sudden onset or worsening can be missed
  - If symptoms are low severity
  - Blamed on age or another diagnosis
  - Acute infection is treated so symptoms may seen as a "blip"
- Not all comorbid health conditions may be identified
- Not all triggers may be identified

Clinical Diagnostic Process



Clinical Diagnosis

Differential Diagnosis

- Sydenham Chorea
- Forms of Autoimmune Encephalitis
- Acute disseminated encephalomyeltis (ADEM)
- Sjorjen's, Behcet's, Anti-phospholipid Ab, Others
- Central nervous system vascultis
- Guillain Barre syndrome
- Rapid Responsive Encephalitis with Thyroiditis
- Systemic lupus Erythematosus

Clinical Diagnosis

Physical Signs

- **Symptoms** – Current and Past Symptoms
- **Family History** – including Grandparents - high rates of OCD, SC, Rheumatic Fever and Autoimmune disease
- **Physical Exam**
  - **Physical signs of strep** - Peeling skin on hands or feet, red anal ring, strawberry tongue – NOT just in the throat
  - **Physical signs of other infection** – Bartonella striae, warts, molluscum, ringworm, recalcitrant sinus infections, etc.
  - **Eyes** - dilated or constricted (deer in the headlight), vision issues including distortions, hallucinations of bugs, colors, people
  - **Rheumatology** - 80% have arthralgias, myalgias, and other evidence of inflamed joints and muscles
  - **Neurology** – evaluate for SC - Choreiform Movements vs Piano Fingers

Choreiform Movements

https://aspire.care/featured/sensory-motor-abnormalities-tics-pans-pandas/

Psychiatric Deterioration & Arthritis

When psychiatric symptoms are abrupt and severe, musculoskeletal inflammation may be present — even if the physical exam looks normal.

- 28% of children with PANS developed chronic inflammatory arthritis
- Arthritis was often "dry" — minimal swelling, detected mainly on imaging
- Common findings: enthesitis, inflammatory back pain, sacroiliac tenderness
- Arthritis often appeared years after psychiatric onset but onset may have been missed due to severity of neuropsychiatric symptoms
- Suggests a possible shared systemic inflammatory process affecting brain and joints

Ma et al., 2023 | Whelan, 2024

Testing & Antibiotic Usage for GAS in PANS & PANDAS

https://aspire.care/clinicians/toolkit-testing-antibiotic-usage-for-gas-in-pans-pandas/

Clinical Diagnosis

Labwork

- Infectious Disease workup – Don't chase titers
  - Group A Streptococcal eval: Swab throat, anus, and sometimes skin; ASO, ADNaseB
  - Mycoplasma Pneumonia IgM and IgG, Tick-Borne Illness, Sinus infections, etc
- Immunology Panel (IgE, IgM, IgA and IgG; IgG subclasses)
- Cunningham Panel/Moleculera - antibody test
- CBC, Comp Metabolic, Thyroid, Iron, Copper, etc.
- 80% have pain in joints and muscles:
  - screen with ANA, CRP, ESR.
- Depending on Symptoms and Severit y -
  - MRI (rule out ADEM), EEG, Lumbar Puncture (To look for AE in CNS on very sick patients, Swallowing Study, Sleep Study

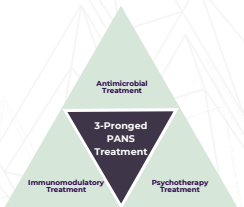
Three-Pronged Treatment Guidelines

PANS treatment utilizes three complementary modes of intervention to treat the patient completely.

Inflammatory Source:
- Remove the inflammatory source with **antimicrobial treatments**.

Immune Dysregulation:
- Treat the disrupted immune system with **immune modulating** and/or **anti-inflammatory** interventions. The protocol depends on the severity and disease course.

Symptomatic Relief:
- Alleviate symptoms with **psychotherapeutic treatments**, including therapy & medications as appropriate to each symptom if needed.

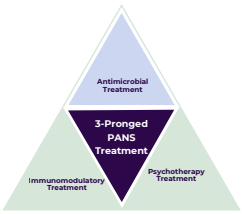


Overview of Treatment of PANS-JCAP Vol27, 2017
Swedo, MD, Frankovich, MD, MS, Murphy, MD, MS

Individualized Treatment Plans

- **Individualized per patient, per flare, per symptom course** – Not one size fits all
- **Evaluate** treatment efficacy at frequent intervals
- **Modify as needed** - depending on symptom worsening/improvement
- **Taper or stop** treatments as symptoms resolve
- **Reintroduce** treatments as needed in relapses

Monitoring & Treating Infections



Overview of Treatment of PANS-3CAP Vol27, 2017
Swedo, MD, Frankovich, MD, MS, Murphy, MD, MS

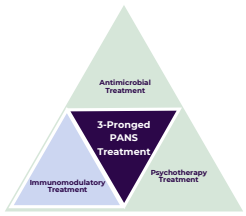
- Test for GAS even without strep throat symptoms.
  - Strep – not just in the throat
  - Some may be asymptomatic for strep throat but still culture-positive. Testing can be inaccurate
  - Test family for strep and other infections even if asymptomatic
- Closely monitor for other infections. Treat according to guidelines
- Antibiotic use
  - At diagnosis - Initial course of Antibiotics is recommended even without a documented infection.
  - 3-4 weeks of antibiotics at initial diagnosis
  - Prophylaxis only if clear evidence of GAS trigger as done for Acute Rheumatic Fever - Prevent neural injury
- Lasting remission can happen from antibiotics alone in some cases.

Infection Control & Flare Prevention

- Provide ideas for reducing infection spread in the classroom
  - Must be Consistent & Classroom Wide
  - Follow prevention for comorbid health conditions
  - No sharing supplies
  - Proper station/desk cleaning
  - Repeated Handwashing
- Communicate with family and school community about strep and other infectious illness
  - Inform parents of PANS/PANDAS students if strep or a particular illness is going around the school
  - Request that the school community inform the School Nurse's office of strep or other illness.

Immuno-Modulatory/Anti-Inflammatory Therapy

Treatment Guidelines for Immuno-Modulatory interventions are dependent on Symptom Severity and Co-Morbid Conditions



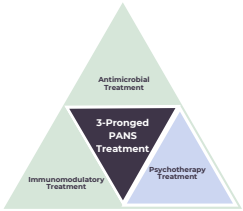
Overview of Treatment of PANS-3CAP Vol27, 2017
Swedo, MD, Frankovich, MD, MS, Murphy, MD, MS

Mild
- Antibiotics, therapy, "tincture of time"
- Anti-inflammatory treatment
  - (NSAIDs for 6 weeks, short oral corticosteroid burst)
- Intravenous Immunoglobulin (IVIG) if indicated

Moderate–Severe
- Prolonged or repeated high-dose corticosteroids
- Disease-Modifying Antirheumatic Drugs (DMARDs)
- IVIG - may need many rounds or ongoing

Life-Threatening / Extremely Debilitating / Chronic
- IVIG - may need many rounds or ongoing
- High-dose corticosteroids or IV Steroids, methylprednisolone
- DMARDs
- Plasmapheresis (TPE)
- Rituximab or other immune modulators

Psycho-Therapeutic Treatment

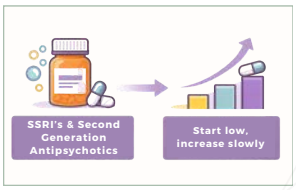


Overview of Treatment of PANS-3CAP Vol27, 2017
Swedo, MD, Frankovich, MD, MS, Murphy, MD, MS

- The goal is to decrease suffering and adherence to treatment.
- Will not treat the underlying neuroimmune condition
- Not needed for every patient
- If needed, duration varies

Psychiatric Medications Require Modifications

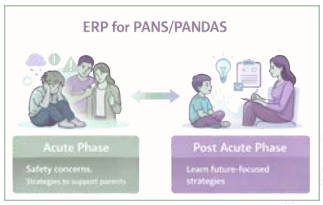
- Most often antimicrobials and anti-inflammatories are employed first
- Patients are more likely to experience side effects from SSRIs & second-generation antipsychotics (Thienemann Met al J Psych Res 2021)



- Lower doses of medications typically provide relief from anxiety, OCD, agitation and aggression
- "Start Low and Go Slow" with subclinical doses - ¼ or less of standard
- Avoid reacting to a temporary increase in symptom severity before the benefits of medical treatments can work.

Psycho-Therapeutic Treatment

Various therapies utilized for PANS PANDAS symptoms
- Therapies can include : Feeding, Occupational, Speech, other Psychological Therapies - ERP, EMDR, DBT, etcERP
- Exposure Response Prevention Therapy - Gold standard therapy for OCD.
  - A behavioral therapy gradually exposes patients to situations designed to provoke their obsessions in a safe environment
- Considerations of current medical status must be taken and adaptations made



Acute Phase
- Safety is the top priority
- Patients may be unable to fully participate in therapy
- Parents focus on recognizing OCD & management strategies to avoid reinforcing OCD

Post Acute Phase
- Patients can engage in therapy for skill-building
- Focus on strategies to manage symptoms during relapse
- Therapy is adapted to current medical status and symptom level.

PANS and PANDAS Symptoms in Depth

Obsessions & Compulsions -OCD – 100%

Developmental Differences:
- In younger children:
  - OCD may not be readily apparent,
    - Presents- rage, anxiety, shut down
  - Often don't have words to describe
  - Separation anxiety is notable
- In adolescence:
  - Unlikely to share intrusive thoughts
  - Separation anxiety looks more quiet - remain in house near mom but not so overtly obvious

Obsessions - Intrusive thoughts, images, impulses
- Occur repeatedly
- Don't feel controllable
- Often attached to feelings - fear, aversion, apprehension, doubt, need for "just right"
- Not based on rational thought - Afraid not doing/thinking something in a certain way will cause harm
- Time-consuming, interferes with activities the person values and wants

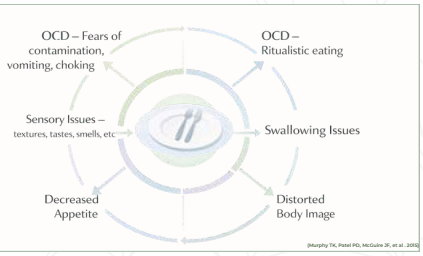
Compulsions - repetitive physical or mental actions with the intent to neutralize, counteract, negate obsessions
- Time-consuming & interferes with activities
- Pure O - Compulsions are often mental compulsions not just physical
- Therapy doesn't don't get rid of intrusive thought

Common Obsessions
- Intrusive Thoughts, Rigid Thinking
- Perfectionism
- Contamination Fears
- Fear of bad things happening
- Fear of doing something wrong
- Needing things to be "just right"
- Unwanted thoughts of hurting others
- Unwanted sexual thoughts

Common Compulsions
- Checking/re-checking/repeating
- Constant washing or cleaning
- Ordering or arranging items
- Mental compulsions, praying, reviewing
- Frequent confessing or apologizing
- Saying lucky words or numbers
- Excessive reassurance seeking
- Hoarding various items

PANS and PANDAS Symptoms in Depth

Food Restrictions – 50% (non-life threatening issues) & 17% (>10-15% of body mass)



PANS PANDAS: Restricted Eating - Overview & Studies

https://aspire.care/clinicians/pans-eating-disorder-food-restrictions

PANS and PANDAS Symptoms in Depth

Anxiety - 100%
- Link to OCD issues
- Generalized Anxiety which can be constant
- Separation Anxiety is a hallmark of this disorder:
  - Not age appropriate
  - Leads to attendance issues
  - Won't sleep alone
  - If under 12, can't leave mom, if over 12, can't leave the house

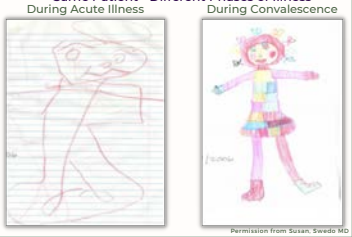
Aggression, Defiance, Rages – 62%
- Rages are often not remembered
- Antecedent not always identified – out of the blue
- Patient often remorseful but not always sure for what

PANS and PANDAS Symptoms in Depth

Behavioral Regression – 100%

Examples:
- Tantrums
- "Baby Talk"
- Sucking Thumb
- Refusal/Avoidance of doing age-appropriate tasks
- Separation anxiety
- Not acting their age
- Difficulty interacting with peers

Same Patient - Different Phases of Illness



Permission from Susan, Swedo MD

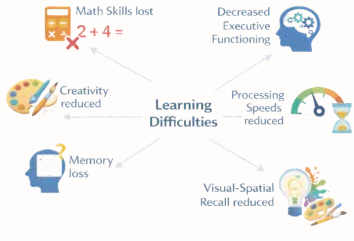
PANS and PANDAS Symptoms in Depth

Poor Concentration – 90%

Impulsivity– 70%

Short Term Memory – 62%

Learning Difficulties – 62%
- Math Skills lost
- Decreased Executive Functioning
- Processing Speeds reduced
- Memory loss
- Visual-Spatial Recall reduced
- Creativity reduced

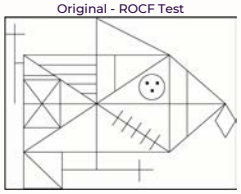


Visual-Spatial Recall Reduced

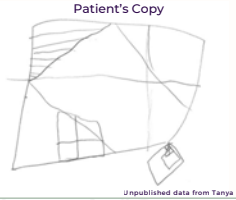
Rey-Osterrieth Complex Figure Test

Copy Task
- Most scored below the 1st percentile

Original - ROCF Test



Patient's Copy



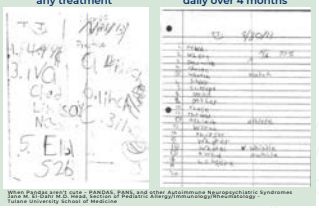
Unpublished data from Tanya Murphy, MD

PANS and PANDAS Symptoms in Depth

Fine Motor Skill Deterioration – 89%
- Dysgraphia - Handwriting Skills

Age 10- 6 months after symptom onset, prior to any treatment

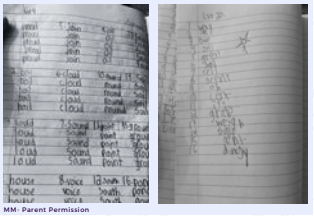
On prednose, weaned from 40 mg -> 20 mg daily over 4 months



When Pandas aren't cute – PANDAS, PANS, and other Autoimmune Neuropsychiatric Syndromes
Jane M. St. Clair M.D. Head, Section of Pediatric Allergy/Immunology/Rheumatology
Tulane University School of Medicine

PANS Remission

PANS Exacerbation



MM- Parent Permission

PANS and PANDAS Symptoms in Depth

Tics/Adventitious Movements – 79%
- Tics:
  - May meet criteria for Tourette Syndrome
- Choreiform movements
  - Piano fingers
- Movement changes
  - Decline in fine motor skills
  - Increased clumsiness
  - Gait issues
  - Balance issues
  - Akathisia - inability to sit still
- Hyperactivity

Simple Tics		Complex Tics	
Brief movements or sounds involving a small number of muscles.		Coordinated patterns involving **multiple muscle groups** or more structured vocalizations.	
Simple Motor	Simple Verbal	Complex Motor	Complex Verbal
Squinting eyes	Bark	Hopping	Repeating one's own words or phrases
Sniffing	Throat clearing	Jumping	Repeating others' words or phrases
Head jerk	Squeal	Spinning	Obscene words or phrases
Nose twitch	Cough	Twisting or bending	Mimicking sounds
		Gestures	
		Smelling or touching objects	

PANS and PANDAS Symptoms in Depth

Sensory Integration – 39%
- Hyper/Hypo-sensitivities to light, sound, textures, touch
- Dexterity issues
- Food restrictions
- Hallucinations - visual and/or auditory

Sleep Problems – 84%
- OCD Related Long bedtime ritual – Trouble falling asleep
- Night terrors, night waking
- Decreased REM Sleep is seen in many patients
- Difficulty sleeping alone - separation anxiety
- Fatigue - non-restorative sleep

Urinary Symptoms – 88%
- Polyuria - Frequent Urination – 3x an hour & increased urge
- Secondary Enuresis
- Urinalysis is typically normal

PANS and PANDAS Symptoms in Depth

General Hypotonia – Majority of Patients
- Intermittent Dystonia – 3%

"Hyper Alert"/ "Puppet Like" Facial Expression - 80%
- Autonomic dysfunction – dilated pupils
- Panic Stricken look
- Hyperarousal & hypervigilance – "fight or flight"

Persistent, non-specific Abdominal Complaints – 79%
- No infection/abnormality. Negative findings on 120 scoped kids
- Strep & Lyme can cause stomach pain

Hallucinations – 9%

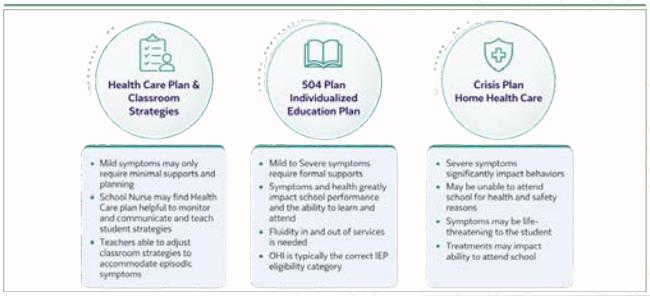
Selective Mutism – 7%

Impact on Functioning

Behavior/Symptoms directly connect to
- emotional functioning
- social functioning
- psychological functioning

Affects Multiple Learning Domains
- Social/Behavioral
- Cognitive/Academic
- Physical
- Sensory
- Executive Function

Continuum of Care



Prioritize Health

Health takes priority, especially in acute exacerbation
- All symptoms can impact ability to attend and learn
- Academics and other demands may be temporarily secondary
- Functioning can change rapidly
  - Both entering and coming out of an exacerbation
  - Ensure flexible entry and exit from supports and services

Changes in symptoms/behavior may be due to:
- Treatment effects
- Exposure to triggers

Next steps:
- Collaborate with the student's home team (medical providers, behavioral health providers, parents)
- Determine when to pause or defer behavioral/therapeutic interventions until symptoms are medically stabilized

Not in a Flare ≠ Back to Baseline

Not in a Flare ≠ Back to Baseline:
Support Requires a Phased Approach

Healing takes time
- Inflammation and brain function do not normalize immediately
- Regulation, flexibility & impulse control may take months to years to learn or regain

Residual symptoms still impact behavior
- OCD, anxiety, sensory sensitivity, misophonia, rigidity

Exaggerated threat perception

What we may miss
- Internal distress is often invisible
- Symptomatic Episode Triggers may include:
  - Noise, movement, peer behavior
  - Transitions, social interactions
  - Day to day stress

What looks like "defiance" may be overload or internal distress

Neuroinflammation→Chronic Threat Response

Basal Ganglia Inflammation:
When the Brain Holds Onto Fear to Stay Safe

- In PANS/PANDAS, neuroinflammation can keep the brain in a **constant fight–flight–freeze state**, even without a real external threat
  - These students are in a stress response 24/7
- **Symptoms** like OCD, anxiety, sensory overload, act as internal triggers, **keeping the nervous system on high alert**
- As a result, behaviors are driven by a **dysregulated nervous system**—**not willful choice**
- These patterns are frequently **misunderstood as behavioral,** oppositional, or defiant, when they are **actually survival responses**

Fight - Flight - Freeze

Fight

Fight (anger / rage response):
Frequently misunderstood as behavioral, oppositional, or defiant

- OCD rage; explosive anger, irritability, aggression
- Verbal outbursts, hitting, throwing, or "losing control"
- Intense frustration when routines are interrupted or things don't feel "right"
- Episodes of dysregulation that escalate quickly
- Pervasive Demand Avoidance
- May appear "willful," especially in school refusal
- Often no prior history of true oppositional behavior *(e.g., behaviors that would have warranted suspension)*

Flight

Flight (escape / avoidance response):
Driven by the need to escape perceived danger; often mistaken for refusal or noncompliance

- Avoiding people, places, school, or specific triggers
- Panic or urgent need to leave situations
- Refusal behaviors that can look oppositional but are fear-based
- Constant need for reassurance or safety behaviors
- Use of "anytime pass" to go to the nurse or a designated safe space
- Repeated calls/texts to caregivers for reassurance or to be picked up
- Elopement from the classroom or building

Freeze

Freeze (shutdown / immobility response):
Often mistaken for noncompliance, lack of motivation, or school refusal

- Emotional shutdown, withdrawal, or going quiet
- "Stuck" behaviors—unable to move, decide, or respond
- Brain fog, dissociation, appearing disconnected
- OCD - Perfectionism
- Task avoidance—not refusal, but inability to initiate or complete work
- Pervasive Demand Avoidance
- Attendance issues; refusal to leave home
- Gets to school (or parking lot) but cannot enter and needs to go home

Cognitive Load

Brain & Physical Fatigue = increased symptomatic episodes ie "behaviors"
When cognitive load is high → capacity is low → behavior changes/symptom increase

What's happening in the brain
- Brain is under significant cognitive load
- Inflammation + disrupted neurotransmitters = reduced efficiency & functioning
- Managing symptoms uses constant mental energy
- Multiple symptoms compound and intensify

What this looks like
- Fatigue → increased dysregulation ("behaviors")
- Difficulty with tasks that appear "simple":
  - Following routines
  - Transitions
  - Social interaction
- Brain becomes overloaded more quickly

What students need
- Reduce cognitive load (brain is on empty)
- Rest and reset time is critical
- Accommodations & supports are essential
- Lower demands during high-symptom periods

Important reminder
- Distinguish choice-based vs. non-choice-based responses
- Avoid blaming the student for symptoms
- Increase expectations gradually, when medically appropriate

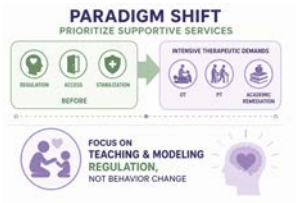
Support Requires a Phased Approach

Start here:
- First, see symptoms, not behavior
- Focus on nervous system regulation & calming the brain
- Intervene before the 0 → 60 moment
- Provide supports vs therapeutic/academic interventions at appropriate levels during exacerbation

As capacity improves:
- Gradually reduce accommodations
- Support safe, supported exposure to discomfort
  - Exposure = gently facing feared situations
  - Building the ability to function while anxious
  - Retraining the brain that the fear is not a true threat

Always consider:
- Crisis planning and safety supports as needed

Support & Behavioral Strategies



During Acute Flares
- Traditional interventions have limited effectiveness
  - Remedial approaches
  - Behavioral (ERP & incentives)
- Many behaviors or skills are not within the student's control
- Reduced capacity for:
  - Impulse control
  - Self-monitoring
  - Understanding consequences
  - Retaining old skills
  - Learning new skills

Support & Behavioral Strategies

After Treatment / As Stability Improves
- Some behaviors become more choice-based
  - Ability to learn improves
  - Ability to regulate inproves
- Gradually introduce:
  - New educational concepts
  - Relearning educational concepts
  - Skill-building (CBT/ERP when appropriate)
  - Behavior supports - focused on nervous system regulation & understanding fight, flight, freeze

Teach & Practice Regulation Skills

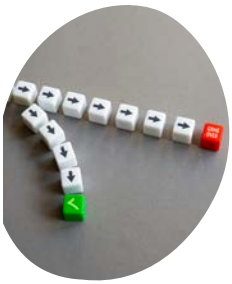
- Teach/Model & practice skills when student is calm—not in crisis
- As always, must align with medical status, level of inflammation, and capacity for choice-based control.
- Build internal regulation gradually.
- Focus on helping students reconnect to their body.
  - They don't recognize rising anxiety & physical cues - Not aware of internal state
- Skills must be realistic, classroom-appropriate & age-appropriate
  - Scheduled rest - brain breaks
  - Brief movement or reset (water, walk)
  - Brain activity (coloring, puzzle, journaling)
  - Sensory tools (fidgets, ice, sour candy)
  - Grounding techniques
  - Somatic strategies - tapping, box breathing
- Practice - skills become automatic & generalized across settings
  - Goal = student can access skills independently
- Avoid over-reliance on external supports (constant exit, calling home)
  - Build internal regulation gradually
  - Signaling systems that don't match age (colored feelings cards for older students)

Understanding and Supporting PANS/PANDAS - Sheilah Gauch, LICSW, M.Ed

Regulation = Skill Set

Understanding and Supporting PANS/PANDAS - Sheilah Gauch, LICSW, M.Ed

Recognizing Early Warning Signs



Intervene before the 0 → 60 moment

Early signs of dysregulation may include:
- Pacing or restlessness
- Increased reassurance seeking
- Irritability or low frustration tolerance
- Withdrawal or shutdown
- Increased rigidity or difficulty with transitions
- Changes in engagement or focus

These are early indicators of overload—not defiance

If symptomatic episodes are recurring:
- Intervention is likely happening too late or not sufficiently
- The student may need:
  - More proactive supports and breaks
  - Earlier intervention
  - Greater focus on regulation skills

Repeated escalation is a signal to adjust supports—not increase consequences

Managing Antecedants

Positive Strategies

Positive strategies & approaches are far more successful

A student who feels safe at school, is better able to regulate. Students do well if they can! This is NOT a skill or a will issue.

- Pause to differentiate between "choice-based" behaviors and neurological symptoms
  - Think: Would you respond in this way to a student with a seizure in your classroom?
- Praise and affirmation work best
  - Be willing and ready to shift your expectations
- Work on Relationship-Building - Be the safe space
  - Especially in times without conflict. Remember, PANS is traumatizing to the patient
  - The time you take now helps down the line

Trauma Informed Classrooms

Offer students some agency and ownership over choices
- Give two options - they can be two non-preferred choices

Stay out of shame
- Shame triggers a stress response and is therefore inflammatory

Reinforce productive behaviors
- Do not used incentive based plans -
  - Placing incentives on behaviors that are not in their control is not effective
  - The root of the behavior is brain inflammation and will create shame

Avoid Shame. Support Regulation.

Language Matters: Avoid Shame →

Prevent More Stress Responses
- The brain is already in a threat state—language can either calm it or escalate it
- Shame-based or minimizing statements can trigger another fight-flight-freeze response

Avoid saying:
- "There isn't anything to be scared of."
- "Cheer up—you have so much going for you."
- "You can go to one class, you should be able to do two."
- "You just need to try harder."

Why this matters:
- These statements can feel invalidating or overwhelming
- They increase pressure, not capacity
- They can worsen anxiety, shutdown, or rage

Instead, aim for:
- Validation ("I can see this is really hard right now.")
- Safety ("You're safe—we'll figure this out together.")
- Flexibility ("Let's take this one step at a time.")

Supportive language helps regulate the nervous system—not escalate it

Accountability: Repair vs Punishment

Punishment alone does not lead to lasting change
- Reward-and-punishment systems (giving rewards for "good" behavior or consequences for "bad" behavior) do not build long-term skills
- These approaches can increase shame, anxiety, and escalation, especially in dysregulated students

Accountability still matters—but looks different
- Focus on repair, not blame
- Repair happens when the student is regulated—not in crisis

What accountability looks like:
- Supported restorative conversation
- Developmentally appropriate "make it right" plan
- Structured re-entry to rebuild safety
- Practicing what to do next time

Restorative practices teach real-world skills
- Understanding impact
- Taking responsibility
- Rebuilding relationship

Consequences

Not all behaviors can be productively targeted as choice-based behaviors
- Limits & consequences may be appropriate but should be applied with this understanding that symptoms/ behaviors are a manifestation of the disorder

Focus on encouraging students to put structures and routines in place to help themselves self-regulate
- Create goals for creating routines and adhering to them

Involve parents & providers & full school team
- Beneficial to incorporate their participation and feedback

Flexible Curriculum & Scheduling

Flexible Curriculum & Scheduling Are Essential
Flexibility is not lowering expectations—it's meeting students where they are so they can stay engaged

- Functioning can change rapidly—students may go from high-performing to struggling with daily tasks in a short time
- Schools need the ability to respond quickly and adjust supports as symptoms fluctuate

The goal is to keep students connected to school, but flexibility is critical due to the relapsing-remitting nature of PANS/PANDAS
What this looks like:

- Adjust placement and setting as needed
- Plan for frequent absences or shortened days (late arrival, early dismissal, breaks)
- Offer homebound or hybrid instruction when necessary
- Provide access to tutoring and academic support (general education, IEP, or 504)
- Use flexible learning options: partial days, virtual learning, in-home support during flares

Attendance

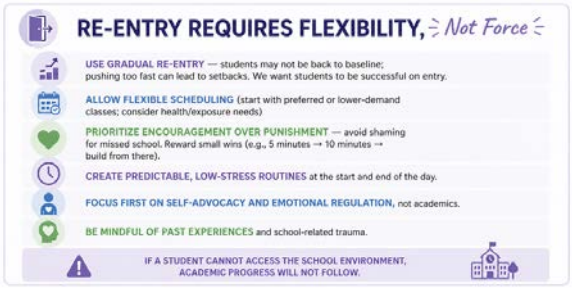
- 90-100% of PANS students experience attendance issues
- 50% of children with PANDAS/PANS spent time on home instruction or moved to homeschool/homebound instruction temporarily or permanently

- Not typical "School Refusal"
  - Attendance issues are a function of symptom severity and disease course.
    - School phobia, associated with separation anxiety and/or OCD, is extremely common.
  - Students can feel sick after treatment - May need time to heal as they get better
  - Unlikely to be productive to address this by simply saying "You have to go to school". At a certain point during recovery that may be a part of the treatment plan.

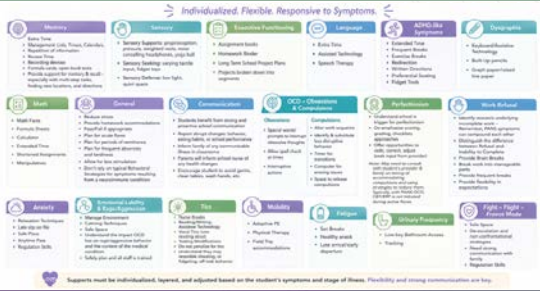
- Penalties for missed classes or days are counterproductive

- When medically appropriate, continuing to expose students to school when we can is essential to lessen their stress response (which in turn impacts their immune system) and retrain their brain school is safe

Re-entry Strategies Often Needed



Educational Supports



Communication is Key

If you see something, say something

- Inform the family of communicable illnesses in the classroom

- Inform the family of other non-infectious triggers the student may be exposed to

- Inform the family of new or worsening symptoms
  - Work with family to create a list of early signs & symptoms

Consider PANS PANDAS

If a Student Has a New Onset or Worsening of OCD and/or Food Restriction along with Multiple Neuropsychiatric Symptoms, Consider PANS/PANDAS