

# PANS / PANDAS


## Symptoms & Solutions

School Nurse In-Service

Gabriella True  
ASPIRE - President  
The Alliance to Solve PANS and Immune-Related Encephalopathies  
gabriella@aspire.care

www.ASPIRE.care info@aspire.care

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## Disclosure Statement

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

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## 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.

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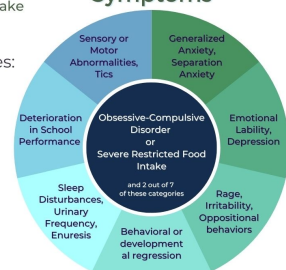
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## PANS Diagnostic Criteria

1. Abrupt, acute onset or 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. Symptoms are not better explained by a known neurologic or medical disorder
4. Age requirement – None

**Symptoms**




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

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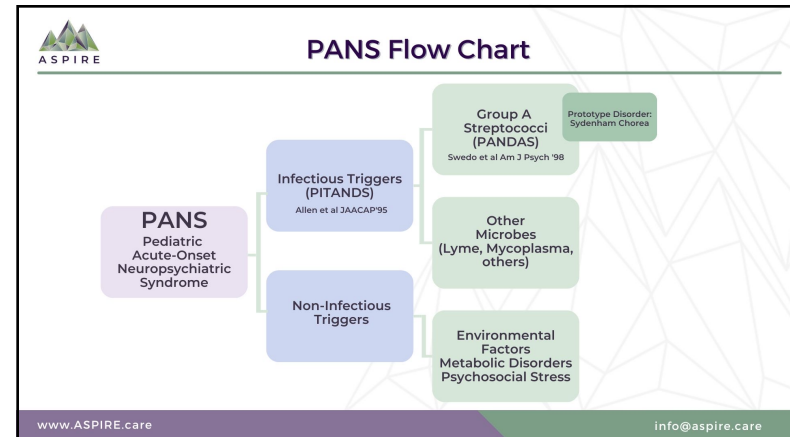
**Who Gets PANS/PANDAS?**

- How Many Have PANS? Estimated at 1 in 200
- Average Age of Diagnosis: 3-13 years old
- Peak Age of Onset: 4-9yrs (69%)
- Below Age 8: 4.67 Boys: 1 Girl
- Above Age 8: 2.6 Boys: 1 Girl
- **No Age Requirement:** Symptoms can continue into adulthood & adult-onset can happen
- **Family History:** 70% of PANDAS families have history of autoimmune or strep related illness



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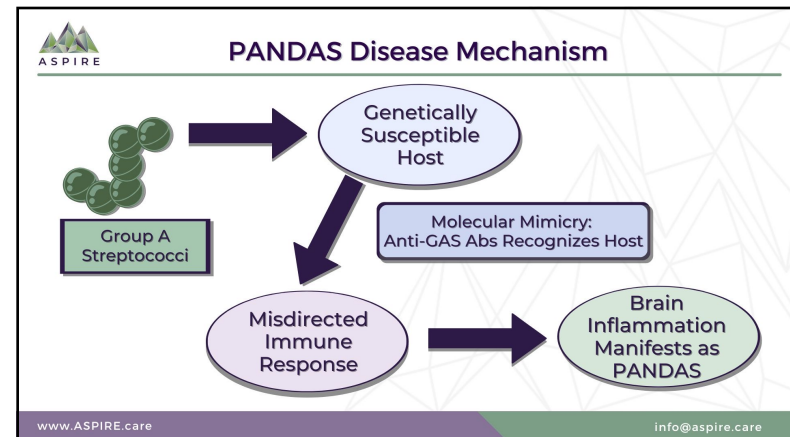
**PANS Triggers**

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.

<b>Infectious Triggers</b>	<ul style="list-style-type: none"> <li>• Strep – (PANDAS)</li> <li>• Mycoplasma Pneumonia</li> <li>• Tick-borne illness (Lyme, B. miyamotoi, Bartonella, etc)</li> <li>• Coxsackie virus</li> <li>• Upper respiratory infections</li> <li>• Epstein Barr virus</li> <li>• Sinus infections</li> <li>• COVID-19</li> <li>• Influenza</li> <li>• Other infections</li> </ul>
<b>Non-Infectious Triggers</b>	<ul style="list-style-type: none"> <li>• Mold</li> <li>• Environmental toxins</li> <li>• Metabolic imbalances</li> <li>• Endocrine imbalances</li> <li>• Psycho-Social stress</li> </ul>

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**Blood-Brain Barrier**

**1 Closing the Trap Door**  
Vascular biologist Dritan Agalliu has discovered that Th17 immune cells damage the blood-brain barrier, the trap door that keeps the brain safe from invaders. Understanding how this happens could lead to better therapies.

Strep bacteria  
Bacteria enter through nose  
Immune response triggered inside nasal cavity

**THE BLOOD-BRAIN BARRIER**  
The brain takes extra measures to keep out enemies.

Open pore  
Tight junction  
Neuron "seal" make an additional wall

Normal blood vessel  
Brain blood vessel

**HOW TH17 CELLS SNEAK IN THROUGH THE OLFACTORY AREA**  
Since strep invades via the nose, Th17 cells gather near the olfactory bulb and mistakenly attack the blood-brain barrier, thinking it's strep.

Blood vessel  
Olfactory bulb  
Olfactory nerves  
Thin layer of spongy bone  
Epithelial cells  
Nasal cavity  
Antibodies  
Th17 cells

Once Th17 pokes holes in the blood-brain barrier, antibodies it would normally keep at bay flood the brain and cause it to turn on itself. Researchers think these attacks break down vital cellular structures and disrupt brain function, leading to the psychiatric symptoms seen in patients with PANDAS.

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**Effects of Basal Ganglia Inflammation**

Basal Ganglia is a relay station through which run neurons that control:

Basal Ganglia Function	Inflammation in the Basal Ganglia may cause:
Mood & Emotion	<ul style="list-style-type: none"> <li>OCD</li> <li>Mood Lability</li> <li>Anxiety</li> </ul>
Cognition	<ul style="list-style-type: none"> <li>Slow Processing Speed</li> <li>Memory Issues</li> <li>Learning Deficits eg Math</li> </ul>
Sensory	<ul style="list-style-type: none"> <li>Sensitivity to:               <ul style="list-style-type: none"> <li>Light, Sounds, Smells, Textures, Tastes</li> </ul> </li> </ul>
Motor Movements	<ul style="list-style-type: none"> <li>Tics</li> <li>Choreiform Movements</li> </ul>
Procedural Learning	<ul style="list-style-type: none"> <li>Handwriting Changes</li> <li>Clumsiness</li> </ul>
Behavior	<ul style="list-style-type: none"> <li>OCD</li> <li>Rage</li> <li>Developmental Regression</li> </ul>

PANDAS PPN - Seeing Your First Child with PANDAS

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**Neurological Symptoms vs. Behaviors**

**Challenging behaviors may actually be PANS/PANDAS symptoms**

- Symptoms aren't the same as behavior, even if they look like it
- Not all behavior is choice-based due to neuroinflammation in basal ganglia
- Some behaviors are involuntary
- PANS symptoms/Neurologically based behaviors are not always responsive to traditional behavior modification methods

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**Symptom Course**

**Single Episode**  
Trigger

**Relapsing/Remitting Course**  
Trigger

**Chronic/Static Course**  
Trigger

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

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**Symptom Severity**


Mild	Moderate	Severe
 <ul style="list-style-type: none"> <li>Symptoms interfere with daily life but not in all settings</li> <li>Able to attend school but with separation anxiety</li> <li>OCD occupies 1-2 hours a day without escalating to obsessional fears</li> <li>Other symptoms vary from patient to patient and from flare to flare but are not incapacitating</li> <li>Symptoms require some school accommodations</li> </ul>	 <ul style="list-style-type: none"> <li>OCD occupies 50%-70% of the waking day. Impacts daily activities severely but not fully disabling</li> <li>Other symptoms are also moderate; impact daily life but not incapacitating</li> <li>School attendance may be affected, but the patient may be able to engage in other activities</li> <li>Symptoms require increased school accommodations and supports</li> </ul>	 <ul style="list-style-type: none"> <li>Neuropsychiatric symptoms can result in life-threatening situations               <ul style="list-style-type: none"> <li>Hazardous impulsivity and/or regression</li> <li>Weight loss (&gt;10%-15% of body mass) due to obsessional food restrictions</li> </ul> </li> <li>OCD, anxiety, and fears occupy 80%-100% of waking day</li> <li>Unable to attend school due to OCD and separation anxiety</li> <li>Irritability, depression, aggression, and other symptoms can be equally present</li> </ul>

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**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
  - Rheumatology - 80% have arthralgias, myalgias, and other evidence of inflamed joints and muscles
  - Neurology – evaluate for SC - Choreiform Movements vs Piano Fingers
  - Eyes - dilated or constricted (deer in the headlight), vision issues including distortions, hallucinations of bugs, colors, people
  - 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.

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**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.
- MRI (rule out ADEM), EEG, Lumbar Puncture (To look for AE in CNS on very sick patients, Swallowing Study, Sleep Study)

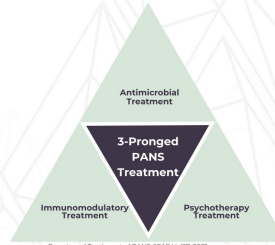
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**Three-Pronged Treatment Guidelines**

**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.



Overview of Treatment of PANS, JCAP Vol27, 2007  
Sweeds, MD, Frankovich, MD, MS, Murphy, MD, MS


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## School Nurses & Infection Control



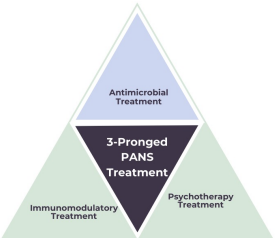
- **Provide ideas for reducing infection spread in the classroom**
  - Must be Consistent & Classroom Wide
  - Follow prevention for comorbid health conditions
  - No sharing supplies, Proper station/desk cleaning, Repeated Handwashing
- **Communicate with family and school community about strep and other infectious illness (mycoplasma pneumonia, Coxsackie, impetigo, etc.)**
  - 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.

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## Monitoring & Treating Infections



Overview of Treatment of PANS-3CAP Vol27, 2017  
Sewds, 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
- 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 for Rheumatic Fever - Prevent neural injury
- Lasting remission can happen from antibiotics alone in some cases.

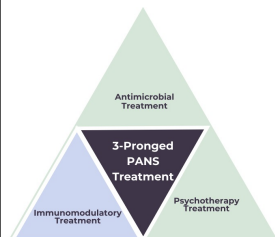
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## Immuno-Modulatory/Anti-Inflammatory Therapy

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



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

**Mild Severity**

- For a first mild flare - Antibiotics, "tincture of time" and therapy may suffice.
- Persistent symptoms may require non-steroidal anti-inflammatory drugs and/or short oral corticosteroid burst.
- Intravenous immunoglobulin (IVIg) may be indicated
- NSAIDs for 6 weeks may be effective

**Moderate to Severe Severity**


- Prolonged corticosteroids or repeated high-dose corticosteroids may be indicated. Improvement from Corticosteroids is not long lasting and prolonged use has permanent side effects.
- IVIg is typically warranted. Number of IVIg doses varies.

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## Immuno-Modulatory/Anti-Inflammatory Therapy



**Life Threatening / Extremely Debilitating**

- Plasmapheresis/Therapeutic Plasma Exchange
  - First-line therapy either alone or with IVIg, high-dose corticosteroids and/or rituximab.
- Rituximab or other immune mediators are indicated with evidence of neuroinflammation or auto-immunity.

**Chronic**

Temporary post-infectious pathological immune response evolved into a chronic autoimmune condition

- May need more frequent aggressive immunomodulatory therapies
- Repeated high-dose methylprednisolone or corticosteroids
- Rituximab or other immunosuppressants

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**Psycho-Therapeutic Treatment**

**Psychoactive Medication Dosing**

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

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**Psycho-Therapeutic Treatment**

**Exposure Response Prevention Therapy**

- Behavioral therapy gradually exposes patients to situations designed to provoke their obsessions in a safe environment
- Gold standard therapy for OCD.
- However, for PANS/PANDAS, considerations of current medical status must be taken and adaptations made

**Acute Phase**

- Patient may not be able to participate. Parents learn Parent Management Techniques strategies to not “feed the ocd”. Keeping child safe is always paramount.

**Post Acute Phase**

- Patient may not need therapy for current situation but can learn strategies to mitigate symptoms during a relapse

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**PANS and PANDAS Symptoms in Depth**

**Obsessions & Compulsions -OCD – 100%**

**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

**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

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**PANS and PANDAS Symptoms in Depth**

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

- OCD - fear of contamination, vomiting, choking, ritualistic eating
- Sensory issues - textures, tastes, smells, etc
- Swallowing issues
- Decreased appetite
- Distorted Body Image – if the situation persists and is not treated, older patients
- Can have a diagnosis of ARFID or Anorexia Nervosa

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**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

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**PANS and PANDAS Symptoms in Depth**


**Behavioral Regression – 100%**

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

During Acute Illness



During Convalescence



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**PANS and PANDAS Symptoms in Depth**

**Learning Difficulties – 62%**

- Math Skills lost
- Decreased Executive Functioning
- Processing Speeds reduced
- Memory loss
- Visual-Spatial Recall reduced
- Creativity reduced

**Poor Concentration – 90%**

**Impulsivity– 70%**

**Short Term Memory Issues – 62%**

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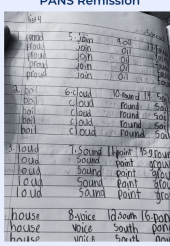
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**PANS and PANDAS Symptoms in Depth**

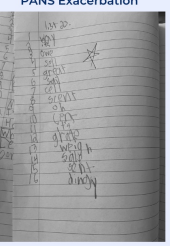
**Fine Motor Skill Deterioration – 89%**

- Dysgraphia - Handwriting Skills

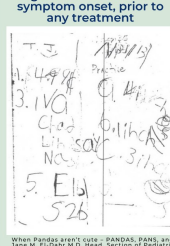
**PANS Remission**



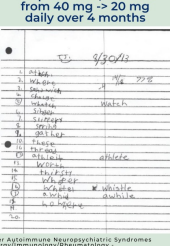
**PANS Exacerbation**



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



**On prednisone, weaned from 40 mg > 20 mg daily over 4 months**



When PANDAS aren't cured - PANDAS, PANS, and other Autoimmune Neuropsychiatric Syndromes  
 June 9, Dr. Gary R. Geff, Section of Pediatric Allergy/Immunology/Rheumatology,  
 Tulane University School of Medicine

MM- Parent Permission

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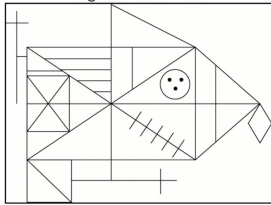
## Visual-Spatial Recall Reduced

### Rey-Osterrieth Complex Figure Test

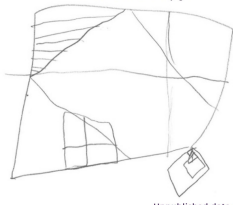
Copy Task

- Most scored below the 1st percentile

Original - ROCF Test



Patient's Copy



Unpublished data from Tanya Murphy, MD

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## PANS and PANDAS Symptoms in Depth

### Tics/Adventitious Movements – 79%

- Simple Tics: Quick, less repetitive movements - fewer muscles or muscle groups or making a single sound.
  - Simple Motor – squinting eyes, sniffing, head jerk, nose twitch,
  - Simple Verbal – bark, throat clearing, squeal, cough, grunt
- Complex Tics: Moving different parts of a body using several muscle groups, often with a pattern.
  - Complex Motor – hopping, jumping, spinning, twisting or bending, gestures, smelling or touching objects.
  - Complex Verbal – repeating your own or someone else's words for phrases, obscene words or phrases, mimicking sounds.
- Can have a Tourette Syndrome diagnosis
- Choreiform movements -Piano fingers
- Decline in fine motor skills
- Increased clumsiness - gait issues, balance issues
- Clumsiness
- Akathisia - Inability to sit still
- Hyperactivity

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## 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%

- Long bedtime ritual – Trouble falling asleep
- Night terrors, night waking
- Decreased REM Sleep is seen in many patients
- Difficulty sleeping alone - separation anxiety

### Urinary Symptoms – 88%

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

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## 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

### Hallucinations – 9%

### Selective Mutism – 7%

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**Impact on Functioning**

Behavior/Symptoms directly connect to

- emotional functioning
- social functioning
- psychological functioning

Affects Multiple Learning Domains

- Social/Behavioral
- Cognitive/Academic
- Sensory/Motor
- Executive Function

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**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 Baglan, 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 and IEP plans
- **Educate the school community on PANS/PANDAS.**
  - Share information via newsletter, website, meetings, staff meetings, etc.
  - Refer students to their primary care provider if you suspect PANS/PANDAS
- **Provide emotional support to parents and students.**

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**Collaborate with Providers**

- Trusting relationship is key
- Often complex cases involving multiple medical or therapeutic providers.
- Provider input and access, when facilitated by parents/ families, can be quite helpful
- May be useful for providers to review behavior plans to ensure symptoms (tics, etc.) have not been mischaracterized. Or to help plan for side effects from med changes.

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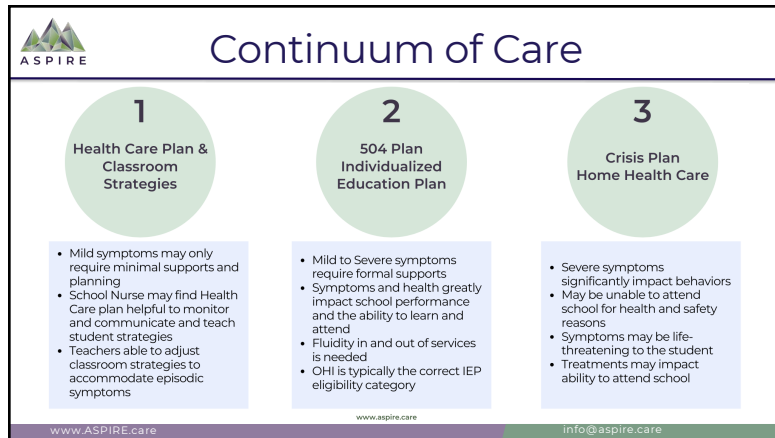
**Communication is Key**

**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

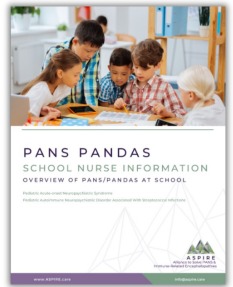
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## Individual Health Care Plans




Nurses Diagnosis	Student Goal	Intervention	Who/When	Why
PANS symptoms release and remit. Medical needs may vary during school year.	NA	<ul style="list-style-type: none"> <li>Parents to review and update the health history assessment each school year or more frequently if changes occur</li> <li>Parents will inform school nurse of any planned IVs/other medically necessary interventions requiring days off from school.</li> <li>Medications at School: Obtain health care provider authorization. Obtain Medical Supply. Maintain medication administration record.</li> </ul>	Parent & School Nurses/As Needed	<ul style="list-style-type: none"> <li>To promote health and well-being.</li> <li>Not all symptoms are seen at school as not all are seen at home; open communication is critical to addressing flares early and consistently</li> </ul>
See Above	NA	Notify parent of any changes in student's condition of PANS episode.	Nurses/As Needed School Staff & Nurse	See Above
See Above	NA	School Staff and School Nurse will recognize signs of PANS episode.	Nurses/As Needed	See Above
Biodefense related to increased susceptibility of PANS flare from contact with any infectious disease	NA	Share/exchange health information with parent with regard to communicable diseases in classroom	Nurses/As Needed	To promote health and well-being. Potential for flare related to compromised immune system. Decrease chance of cross contamination
See Above	Student will learn hand washing & hygiene.	School Staff to provide education on proper hand washing and basic hygiene to prevent spread of infections.	Nurses/As Needed	See Above
Separation Anxiety & Fear - Related to OCD and inability to predict or control symptoms.	Student will attempt to identify and utilize calming techniques	<ul style="list-style-type: none"> <li>Work with counselor on techniques while not anxious to build toolbox.</li> <li>Provide anytime pass to Safe Place.</li> <li>Track times used</li> <li>If symptoms are not resolving, not able to work to school expectations, notify parents ASAP</li> <li>Refrain from criticism, shaming</li> </ul>	School Counselor/Weekly Sessions	To create a bank of calming techniques so symptoms do not escalate.

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## Prioritize Health




**For students in acute exacerbations, other considerations, including academics, may be temporarily secondary to health.**

- Functioning can change rapidly. Must respond quickly
- Changes in symptoms/behaviors may result from.
  - Treatments
  - Exposure to incitatory trigger
- Important to work with student's home team (medical & behavioral providers, parents) to determine if typical behavioral or therapeutic interventions should be deferred until medical treatments ameliorate symptoms

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## Planning Supports



- Supports: similar to accommodations & strategies used for disparate conditions (ADHD, OCD, urinary issues, etc).
  - Teachers may need to "layer" or utilize multiple accommodations
  - Supports need to be individualized per student and flare
- OCD Accommodation:
  - Utilize provider recommendations
  - Not typically recommended for non-PANS OCD/anxiety.
  - However - may be appropriate for students with acute health as well as behavioral needs depending on stage of flare

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## Cognitive Load

**Brain & Physical Fatigue = increased “behaviors”.**

**Significant Cognitive Load due to PANS/PANDAS**


- Brain is working extra hard to get through the day
- Brain is working differently due to inflammation & neurotransmitters not functioning correctly
- Managing symptoms takes a lot of brain power and not always possible. The multiple symptoms compound their severity
- Seemingly easy cognitive tasks are difficult – remembering rules & and routines, transitioning activities, interacting with other people, etc

**Reduce Cognitive Load - Brain is on empty - Need time to reset**

- Accommodations and supports are critical
- Rest is critical
- Reducing expectations and stress is critical
- Remember the difference between choice-based and non-choice-based behaviors. Don't blame the student for their illness
- Gradually increase expectations only when medically appropriate

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## Behavioral Strategies

**During Acute Flares**


- Traditional methods of behavioral intervention, including ERP and incentive-based approaches, may have limited utility during a flare
- Behaviors may not be within the student's control
- Children may not have the executive function, understanding, long-term planning, or impulse control to adequately recall consequences, self-monitor, or engage in long-term cost-benefit analysis

**After Treatment**

- After appropriate & adequate PANS treatment
  - Some students have some learned behavior, which can be targeted through cognitive-behavioral therapy or behavior modification
  - Input from a student's medical care team is critical to help determine timing and what is and is not choice based behavior vs symptom

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## Managing Antecedents

- Manage antecedents, environments, and frustrating situations
- Consider strategies validated for TBI, concussion, and other neurological disorders
  - Break down the school day -
    - identify triggers - noise, sensory, subjects of academic decline, subjects with increased resistance or perfectionism
    - Walk through the day with student and/or parent
- Unlike other disorders - anticipating challenging situations for a PANS student is not giving in to choice-based behaviors
- Rather, challenging situations cause challenging behaviors bc of the neurological response in the inflamed brain
- Provide Anytime Pass - allow for a way out before situations escalate
- Intervene before behaviors/symptoms become unmanageable due to neurological limitations
- Note: not all symptoms/behaviors can be anticipated


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## Positive Strategies

**Positive strategies and approaches are far more successful**




- 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
- Reinforce productive behaviors
  - Don't place incentives on behaviors that are not in their control
- Work on Relationship-Building - especially in times without conflict. Remember, PANS is traumatizing to the patient


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## Consequences




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


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## Flexible Curriculum




### Functioning may change rapidly

- It's a hallmark of PANS/PANDAS to go from honor roll to multiple daily living challenges in just days or hours. Schools must move quickly.
- Give school teams the authority to rapidly intensify supports when sudden medical changes intensify symptoms.
- Appropriate placement and setting may need to be modified

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## Attendance


**Attendance Can Be Greatly Impacted by PANS PANDAS**

- 90-100% of PANS students experience attendance issues
- As per one qualitative study, 50% of children with PANDAS/PANS spent time on home instruction or moved to homeschool/ homebound instruction permanently
- Not typical "School Refusal"
  - Typically attendance issues in PANS PANDAS are a function of symptom severity and disease course. School phobia, associated with separation anxiety and/or OCD, is extremely common.
  - It is 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

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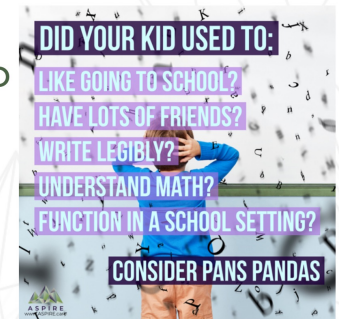
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## Consider PANS PANDAS

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



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