

## PANS / PANDAS Symptoms & Solutions in the School Setting

School Nurse In-Service

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Related Encephalopathies  
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## We aspire to improve lives.

**Our Mission:** To improve the lives of children and adults affected by PANS, PANDAS, and related encephalopathies.

**Our Vision:** We aspire to create a world where children and adults affected by PANS, PANDAS and related encephalopathies obtain a timely diagnosis from informed providers and receive effective, proven, and affordable treatments and support in all areas of daily living, without discrimination.


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## ASPIRE School In-Service Lectures

ASPIRE has provided 100 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. There is no cost to schools this year. After, we provide toolkits and lecture slides. We remain available for questions all year long. We typically schedule 2 hours (the lecture is 1.5 hours plus questions and answers). We can accommodate shorter schedules.


Contact ASPIRE to schedule a virtual in-service on PANS PANDAS

More info: <https://aspire.care/treating-pans/pans-at-school>

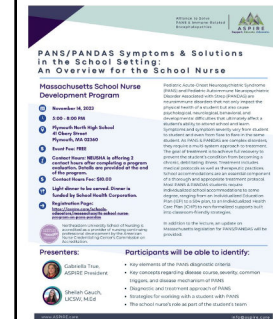
Email: [gabriella@aspire.care](mailto:gabriella@aspire.care)

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## Participants will be able to identify:



- Key elements of the PANS diagnostic criteria
- Key concepts regarding disease course, severity, common triggers, and disease mechanism of PANDAS
- Diagnostic and treatment approach of PANS
- Strategies for working with a student with PANS
- The school nurse's role as part of the student's team

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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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**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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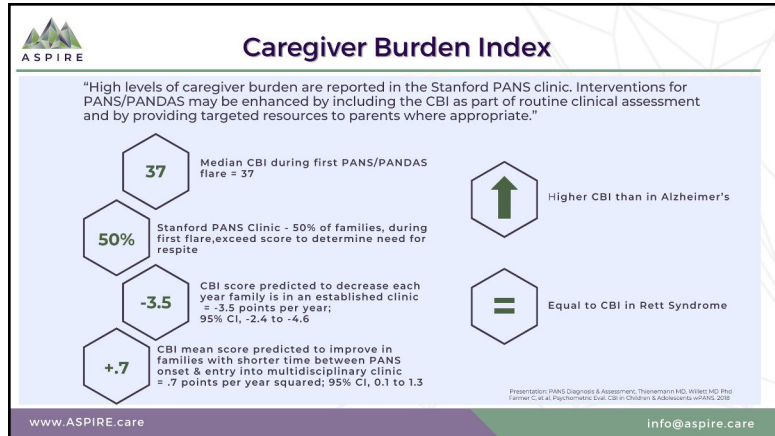
**What is Happening with These Families?**

"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!"

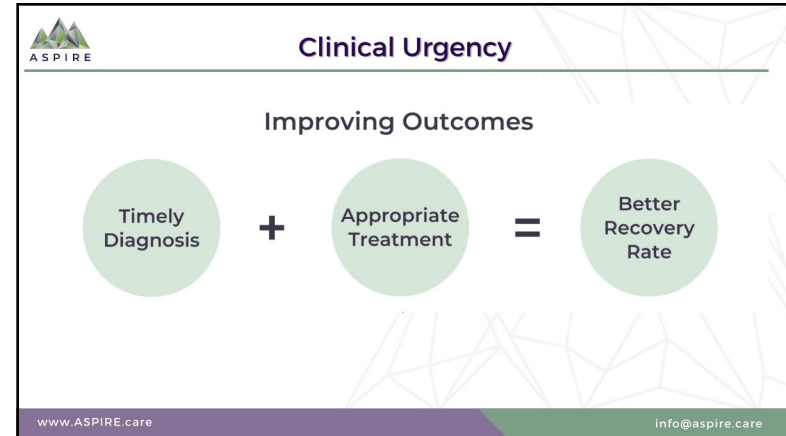
Understanding the Impact of Symptoms, A Psychologists View - Dr. Lisa Scholder, LP

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### Clinical Urgency

- PANS/PANDAS is treatable. Early identification and appropriate treatment improve the odds of a successful outcome. Research suggests that early and aggressive treatment of the inciting infection with antibiotics decreases the likelihood of residual symptoms and recurrence.
- Parents currently see an average of 8 doctors and spend three years seeking a correct diagnosis due to a lack of awareness and education.
- If left untreated, possible permanent neurological damage, years of developmental disruption, life-long struggle to the patient, and devastation to their families cannot be ignored. Thus, early identification is paramount.
- Missed PANS/PANDAS diagnoses have resulted in patients being placed on unnecessary psychiatric medications or in more restrictive costly psychiatric facilities, causing more harm than healing. According to the NIMH, a timely diagnosis and appropriate treatment may prevent as much as 25% of all pediatric mental illnesses.
- Multiple deaths of PANS/PANDAS patients have resulted in death by suicide, for a treatable illness to accelerate to this tragic outcome is alarming.

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### Roadblocks to Diagnosis & Treatment

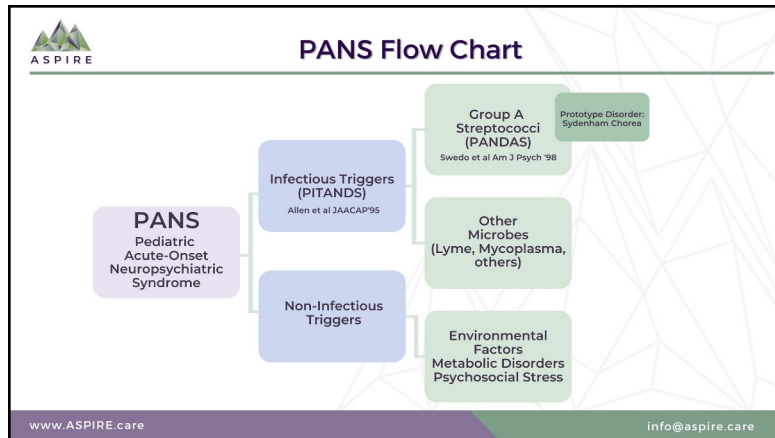
There are many roadblocks to a PANS PANDAS diagnosis and treatment. The list below includes some of the most common roadblocks but are not all-encompassing.

- 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 be seen as a "blip"
- Not all comorbid health conditions may be identified
- Not all triggers may be identified

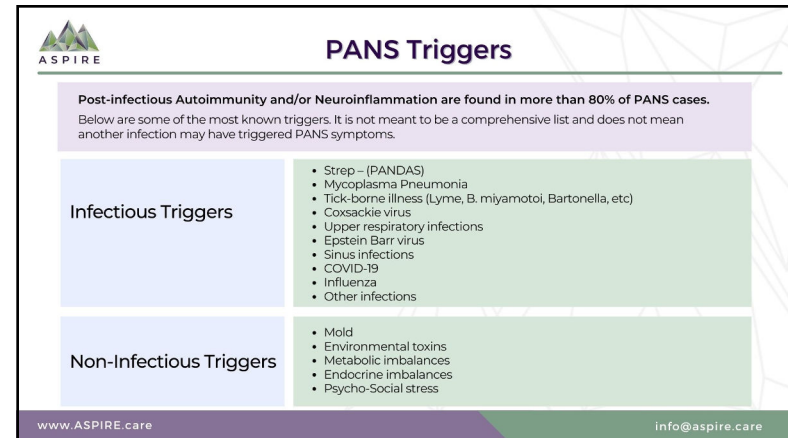
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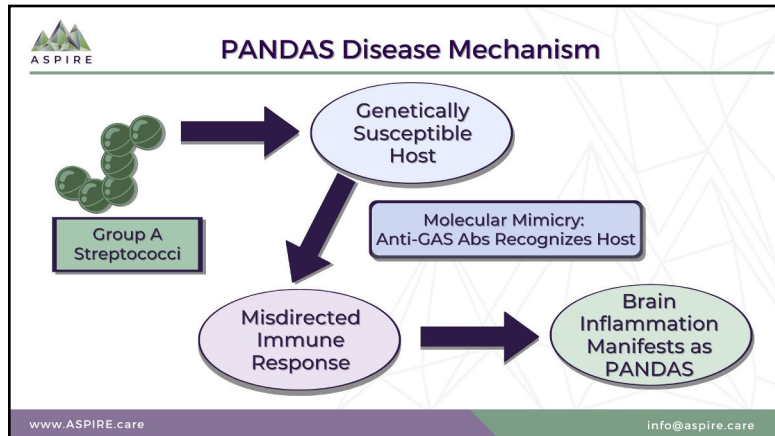




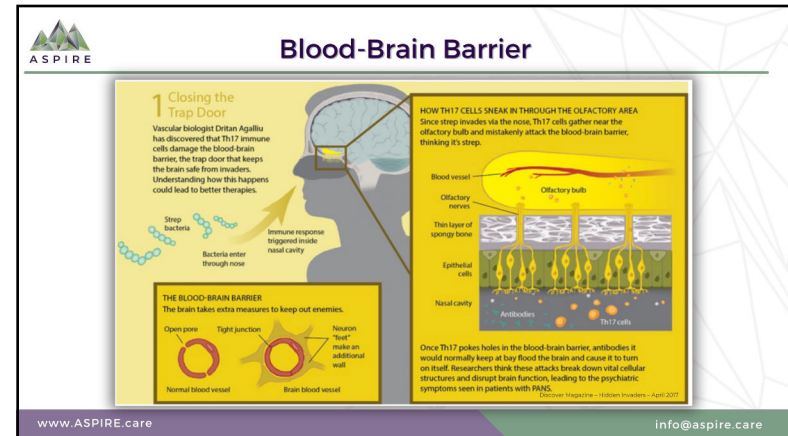
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**Effects of Basal Ganglia Inflammation**

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

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**

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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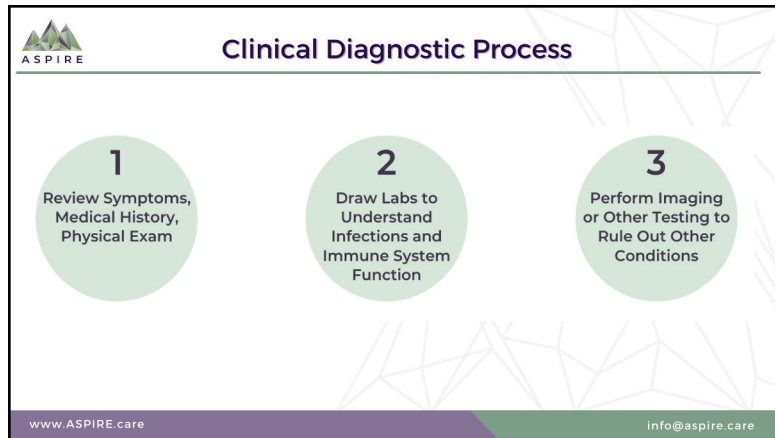
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**Symptom Severity**

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/Molecular - 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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**Clinical Diagnosis**

**Diagnosis of Exclusion**

**Differential Diagnosis**

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

Rule out psychosocial trauma

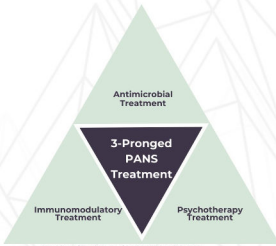
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**Three-Pronged Treatment Guidelines**

**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-ICAP V6Z7, 2017  
Seeds, MD, Frankovich, MD, MS, Murphy, MD, MS

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**School Nurses & Infection Control**

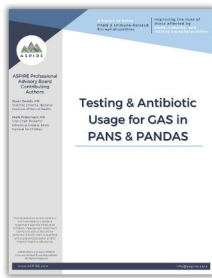


- **Provide ideas for reducing infection spread in the classroom**
  - Must be Consistent & Classroom Wide
  - Follow prevention for comorbid health conditions
  - No sharing supplies, Proper station/desk cleaning, Repeated Handwashing
- **Communicate with family and school community about strep and 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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**Individualized Treatment Plans**

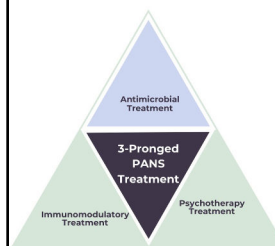


- Individualized per patient, per flare, per symptom course – Not one size fits all
- Evaluate treatment efficacy at frequent intervals
- Modify as needed - depending on symptom worsening/improvement
- Taper or stop treatments as symptoms resolve
- Reintroduce treatments as needed in relapses

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**Monitoring & Treating Infections**



- 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.

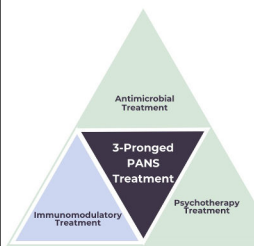
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**ASPIRE Immuno-Modulatory/Anti-Inflammatory Therapy**

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



Overview of Treatment of PANS/SCAP 10/27/2017  
Savits, 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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**ASPIRE 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**

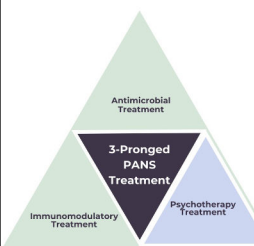
Temporary post-infectious pathological immune response evolved into a chronic autoimmune condition

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

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**ASPIRE Psycho-Therapeutic Treatment**



Overview of Treatment of PANS/SCAP 10/27/2017  
Savits, MD, Frankovich, MD, MS, Murphy, MD, MS


**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 - 1/4 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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**ASPIRE 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

**OCD Cycle**

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**PANS and PANDAS Symptoms in Depth**

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

**Restricted Eating in PANS**

- Sensory Issues: hypersensitivity to textures, tastes, smells, sounds
- Ritualistic Eating Behaviors
- Decreased Appetite
- Difficulty Swallowing
- Body Image Issues
- Fears: contamination, choking, vomiting, anaphylaxis

- 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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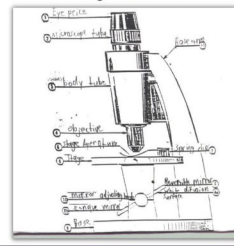
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**PANS and PANDAS Symptoms in Depth**

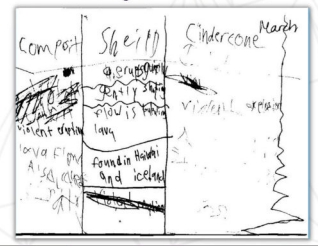
**Fine Motor Skill Deterioration – 89%**

- Dysgraphia - Handwriting Skills

**During Acute Illness**



**During Convalescence**



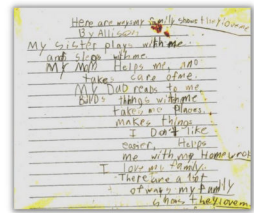
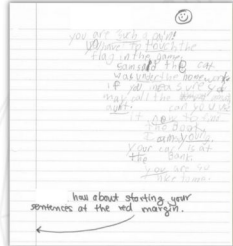
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**PANS and PANDAS Symptoms in Depth**

**Unusual Margin Drift**

- As seen in other autoimmune encephalopathies

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**PANS and PANDAS Symptoms in Depth**

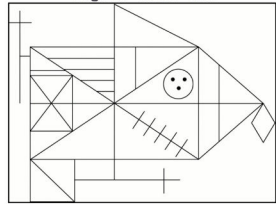
**Visual-Spatial Recall Reduced**

**Rey-Osterrieth Complex Figure Test**

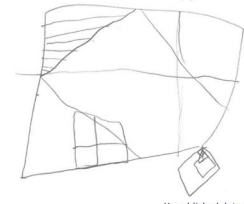
Copy Task

- 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

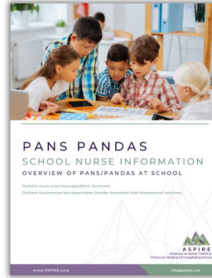
**Hallucinations – 9%**

**Selective Mutism – 7%**

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 **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)

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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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## 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

**Individual Health Care Plan excerpts from several IHPs.**

**Not meant to be all-inclusive.**

**Assessments:**

- Infection: The 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 the inability to predict or control symptoms.
- Increased susceptibility from contact with any contagious disease. PANS manifests in OCD, ADHD, ODD behaviors, motor/vocal tics, depression, etc.

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## Individual Health Care Plans

**Goals:**

- Student will identify sources of anxiety and fear.
- Student will identify and utilize support systems at school.
- School Nurse will inform parents of any communicable illness in classrooms.
- School Staff and School Nurse will recognize signs of a PANS flare.
- School Staff to encourage infection control measures in the classroom.
- School Staff will implement an anytime pass in order to rest or work quietly. Track the number of times anytime pass is utilized.
- Parents will inform school nurse of any health changes.
- Parents will inform school nurse of any planned IVIGs.
- School Staff will understand that student might require snacks between meals in order to sustain energy.

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## Individual Health Care Plans

Nurses Diagnosis	Student Goal	Intervention	Who/When	Why
PANS symptoms relapse 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 IVIGs 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 Nurse/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	Nurse/As Needed	See Above
See Above	NA	School Staff and School Nurse will recognize signs of PANS episode	School Staff & Nurse	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	Nurse/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.	Nurse/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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## 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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## Continuum of Care

**1**

Health Care Plan & Classroom Strategies

- Mild symptoms may only require minimal supports and planning
- School Nurse may find Health Care plan helpful to monitor and communicate and teach student strategies
- Teachers able to adjust classroom strategies to accommodate episodic symptoms

**2**

504 Plan Individualized Education Plan

- Mild to Severe symptoms require formal supports
- Symptoms and health greatly impact school performance and the ability to learn and attend
- Fluidity in and out of services is needed
- OHI is typically the correct IEP eligibility category

**3**

Crisis Plan Home Health Care

- Severe symptoms significantly impact behaviors
- May be unable to attend school for health and safety reasons
- Symptoms may be life-threatening to the student
- Treatments may impact ability to attend school

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## OHI - Other Health Impairments

OHI (Other Health Impairments) is typically the most appropriate category for eligibility determination. Students may be eligible for an IEP under different categories as well, depending on that student's symptoms, such as specific learning disability (SLD), autism spectrum disorder (ASD), or emotional and behavioral disorder (EBD). However, caution must be taken not to mislabel a student; SLD or EBD may not encompass all of the student's issues by focusing too much on a small portion of symptoms.


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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 in 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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## 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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**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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**Positive Strategies**

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

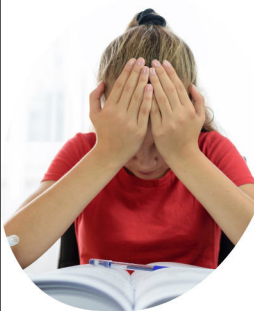


- Pause to differentiate between "choice-based" behaviors and neurological symptoms
  - Think: Would you respond in this way to a student with a seizure in your classroom?
- Praise and affirmation work best
- Reinforce productive behaviors
  - Don't place incentives on behaviors that are not in their 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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**Self-Advocacy**




- Anytime Pass
  - Need to learn when and how to use it. Not all students know when their symptoms are intensifying and need a safe space.
- Accessing Help
  - Need to learn when and who to ask for more academic help
- Learning to Describe Condition in a Developmentally Appropriate Way
  - How to explain how symptoms are impacting their functioning across all domains
  - How to explain their condition to peers without feeling shame or other negative emotions associated with being ill
- Learning to ask for help if bullied for their symptoms
  - Unfortunately, children with PANS/PANDAS are often bullied by their peers. They need support from the school and should not be expected to handle this situation by themselves. They need to trust the school will help 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

### Reasons for Absences or Modified Schedule

- Nature of Illness
  - Separation Anxiety and OCD are both major criteria for PANS. All symptoms can impact attendance and schedule
  - Some are quite ill and impacted both physically and mentally
  - Some are immunocompromised -may need to be out of school to avoid exposure
  - Fatigue and stamina also significantly impact attendance.
  - Sleep disturbances due to OCD, anxiety, and REM sleep abnormalities are seen in almost all PANS patients
- Doctor Appointments
  - Some PANS students have a large clinical team requiring many appointments
  - Some treatments require students to miss several days of school.

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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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## Flexible Schedule


### Flexibility is Needed

- The goal is to keep students in school as much as possible but flexibility is needed due to the relapsing-remitting nature of the disease.
- Recognize students may need homebound or hybrid instruction
- Plan for frequent absences or shortened days including late arrival, early dismissal, and additional breaks during the day.
- Facilitate access to tutoring for any child with a medical condition as part of general education and also in connection to IEP or 504 where appropriate.
- Explore flexible, hybrid supports: partial school day schedules, online learning, and in-home tutoring during times of acute flare up.

Educators should first and foremost be aware that PANDAS/PANS may have significant impact on a student's attendance... Planning for possible attendance issues should be an essential element of school discussions.

PANDAS and PANS in School Settings: A Handbook for Educators, Edited Patricia Rice Doran, 2017


#PANSatSchool



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## Re-entry Strategies Often Needed


- Provide gradual re-entry strategies where necessary. May not be back to baseline. Pushing too hard may result in a backslide.
- Flexibility in scheduling: may start with preferred classes (art, gym, etc.) and/or classes that are best from a health/ exposure management standpoint
- Positive reinforcement and encouragement rather than punishing or shaming for missing school
- Reward approximate behavior (get through 5 mins of math, 10 mins of math, etc.)
- Consistent, welcoming, low-anxiety routines around the beginning and end of day
- Emphasis on self-advocacy and socio-emotional adjustment at first, not necessarily academics (for example, it may take all a student's energy to focus on following behavioral norms)
- Be mindful of trauma/ past experience for re-entering students
- If students don't feel they can access school at re-entry, delivering the rest of the curriculum is not likely to be successful.

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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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## Educational Supports

<b>General</b> <ul style="list-style-type: none"> <li>• Reduce stress</li> <li>• Provide homework accommodations</li> <li>• Plan for acute flares</li> <li>• Plan for periods of remittance</li> <li>• Plan for frequent absences and tardiness.</li> <li>• Encourage student to avoid germs, clean tables, wash hands, etc</li> </ul>	<b>Communication</b> Students benefit from strong and proactive school communication <ul style="list-style-type: none"> <li>• Report abrupt changes: behavior, eating habits, or school performance</li> <li>• Inform family of any communicable illness in classrooms</li> <li>• Parents will inform school nurse of any health changes.</li> </ul>
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PANDAS: A New Frontier for Occupational Therapy/Intervention Tonia Posner info@aspire.care

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## Educational Supports

<b>OCD</b> <b>Obsessions:</b> <ul style="list-style-type: none"> <li>• Special words/prompts to interrupt obsessive thoughts</li> <li>• Allow spell check at times</li> <li>• Interruptive actions</li> </ul> <b>Compulsions:</b> <ul style="list-style-type: none"> <li>• Alter work sequence</li> <li>• Identify &amp; substitute less disruptive behavior</li> <li>• Timer for transitions</li> <li>• Computer for erasing issues</li> <li>• Space to release compulsions</li> </ul>	<b>Perfectionism</b> <ul style="list-style-type: none"> <li>• Understand school is trigger for perfectionism</li> <li>• De-emphasize scoring, grading, checklists approaches</li> <li>• Offer opportunities to redo, correct, adjust (seek input from provider)</li> </ul> <p><b>Note:</b> May need to consult with student's provider &amp; family on timing of accommodating compulsions and using strategies to reduce them. Typically, with PANS OCD, CBT/ERP is not initiated during active flares</p>
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## Educational Supports

<b>Work Refusal:</b> <ul style="list-style-type: none"> <li>•Identify reason/s underlying incomplete work – Remember, PANS symptoms can compound each other</li> <li>•Distinguish the difference between Refusal and Inability to Complete</li> <li>•Break work into manageable parts</li> <li>•Provide frequent breaks</li> <li>•Provide flexibility in expectations</li> </ul>	<b>Anxiety</b> <ul style="list-style-type: none"> <li>•Relaxation Techniques</li> <li>•Late slip on file</li> <li>•Safe Place</li> <li>•Anytime Pass</li> </ul> <b>Emotional Lability &amp; Rage/Aggression</b> <ul style="list-style-type: none"> <li>•Manage Environment</li> <li>•Calming Techniques</li> <li>•Safe Space</li> <li>•Understand the impact OCD has on rage/aggressive behavior and the context of the medical condition</li> <li>•Safety plan and all staff is trained</li> </ul>
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## Educational Supports

<b>Tics</b> <ul style="list-style-type: none"> <li>•Nurse Breaks</li> <li>•Reading/Writing: Assistive Technology</li> <li>•Vocal Tics: Less reading aloud</li> <li>•Testing Modifications</li> <li>•Do not penalize for tics</li> <li>•Understand they may resemble shouting, or fidgeting, off-task behavior</li> </ul> <b>Mobility</b> <ul style="list-style-type: none"> <li>•Adaptive PE</li> <li>•Physical Therapy</li> <li>•Field Trip accommodations</li> </ul>	<b>Fatigue</b> <ul style="list-style-type: none"> <li>•Set Breaks</li> <li>•Healthy snack</li> <li>•Late arrival/early departure</li> </ul> <b>Urinary Frequency</b> <ul style="list-style-type: none"> <li>•Low-key Bathroom Access</li> <li>•Tracking</li> </ul> <b>Fight or Flight Mode</b> <ul style="list-style-type: none"> <li>•Safe Space</li> <li>•De-escalation and non-confrontational strategies</li> <li>•Need strong communication with family</li> </ul>
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## Educational Supports

<b>Memory</b> <ul style="list-style-type: none"> <li>•Extra Time</li> <li>•Management: Lists, Timers, Calendars,</li> <li>•Repetition of information</li> <li>•Review Time</li> <li>•Recording devices</li> <li>•Formula cards, open book tests</li> <li>•Provide support for memory &amp; recall – especially with multi-step tasks, finding new locations, oral directions</li> </ul>	<b>Sensory</b> <ul style="list-style-type: none"> <li>•Sensory Supports: proprioception, pressure, weighted vests, noise cancelling headphones, yoga ball</li> <li>•Sensory Seeking: varying tactile input, fidget toys</li> <li>•Sensory Defense: low light, quiet space</li> </ul> <b>Executive Functioning</b> <ul style="list-style-type: none"> <li>•Assignment books</li> <li>•Homework Binder</li> <li>•Long Term School Project Plans</li> <li>•Projects broken down into segments</li> </ul>
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## Educational Supports

<b>Language</b> <ul style="list-style-type: none"> <li>•Extra Time</li> <li>•Assisted Technology</li> <li>•Speech Therapy</li> </ul> <b>ADHD</b> <ul style="list-style-type: none"> <li>•Extended Time</li> <li>•Frequent Breaks</li> <li>•Exercise Breaks</li> <li>•Redirection</li> <li>•Written Directions</li> <li>•Preferential Seating</li> <li>•Fidget Tools</li> </ul>	<b>Dysgraphia</b> <ul style="list-style-type: none"> <li>•Keyboard/Assistive Technology</li> <li>•Built-Up pencils</li> <li>•Graph paper/raised line paper</li> </ul> <b>Math</b> <ul style="list-style-type: none"> <li>•Math Facts</li> <li>•Formula Sheets</li> <li>•Calculator</li> <li>•Extended Time, Shortened Assignments</li> <li>•Manipulatives</li> </ul>
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## CASE EXAMPLES - JOSIAH

<p>Before - 10<sup>th</sup> Grade</p> <ul style="list-style-type: none"> <li>•easygoing</li> <li>•always been a good student</li> <li>•many friends</li> <li>•takes mostly honors classes</li> <li>•excellent in math</li> </ul>	<p>Following Flu suddenly developed</p> <ul style="list-style-type: none"> <li>•eye blinking tics</li> <li>•erratic behavior</li> <li>•anxious</li> <li>•argumentative</li> <li>•missed relatively easy questions on math tests</li> <li>•developed obsessions - pacing, setting the volume button on electronics to multiples of 5, and having everything "just so."</li> <li>•suicidal, resulting in hospitalization</li> </ul>
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## CASE EXAMPLES - JOSIAH

Strategies and Supports

- Math supports
- Academic accommodations: additional time, calculator, separate testing room
- Flexible attendance policy
- Counselor support and purposeful selection of peers for group work or activities
- Positive behavior, not focused on negative consequences
- Active monitoring of classroom dynamics to avoid exposure to triggering situations
- Health plan to monitor exposure to infection and adjust accordingly

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## CASE EXAMPLES - RAYMOND

<p>4 year old with attention and behavior difficulties</p> <ul style="list-style-type: none"> <li>•mild visual perceptual and fine motor issues, but no sensory processing problems.</li> <li>•began occupational therapy</li> </ul>	<p>Later</p> <ul style="list-style-type: none"> <li>•mild OCD</li> <li>•refused to don his socks and complained that the waistband of his pants hurt.</li> <li>•demonstrated regression in drawing</li> <li>•no longer able to write the letters of his name legibly.</li> </ul>
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## CASE EXAMPLES - RAYMOND

Strategies and Supports

- Strong home-school communication
- Sensory and fine motor activities
- Occupational and fine motor support and services
- Assistance with adaptive behavior tasks
- Positive behavior supports and antecedent management
- Choice-based activities
- Anticipation of high-anxiety situations and moments that may trigger challenging behavior
- Health plan to monitor exposure to infection and adjust accordingly
- Communication

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 **CASE EXAMPLES - LUCIA**

<p><b>Third Grade Girl</b></p> <ul style="list-style-type: none"> <li>•no recent trauma, supportive family</li> <li>•many friends</li> <li>•no identified social problems</li> <li>•easy going student</li> <li>•loved school</li> <li>•not overwhelmed by schoolwork</li> </ul>	<p><b>Post Strep Infection</b></p> <ul style="list-style-type: none"> <li>•acutely school phobic.</li> <li>•intensely anxious every morning</li> <li>•refused to get on the school bus, had to be driven to school. She crouched in the car, sobbing and clinging to the seat</li> <li>•urinary issues: frequent accidents at school, constant need to use bathroom</li> <li>•hard time completing schoolwork</li> </ul>
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 **CASE EXAMPLES - LUCIA**


**Strategies and Supports**

- Flexible attendance in collaboration with healthcare team
- “Flash pass” for restroom use or counselor’s office
- Attendance plan: comforting positive routines around arrival (and dismissal)
- Consider prioritizing high-interest activities or classes for attendance
- Home-school communication system
- Recognize perfection may not be accomplished; reward approximate behavior

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 **Take Home Pearls**



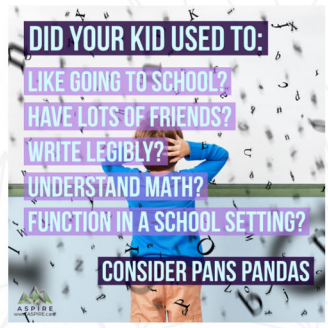
- Patients can get better
- Earlier diagnosis and treatment equals better outcomes
- It is a Clinical Diagnosis
- PANS/PANDAS is essentially a spectrum disorder
- It takes a whole team. Use a multidisciplinary team approach.
- Increase awareness; share this information with everyone!
- Symptoms are relapsing and remitting
- The three Treatment Modes must be individualized
- PANS/PANDAS is not rare; it is rarely diagnosed
- Please don't blame the patient for his/her illness
- PANS/PANDAS is Medical

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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**



**DID YOUR KID USED TO:**

- LIKE GOING TO SCHOOL?
- HAVE LOTS OF FRIENDS?
- WRITE LEGIBLY?
- UNDERSTAND MATH?
- FUNCTION IN A SCHOOL SETTING?

**CONSIDER PANS PANDAS**

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