



Understanding and Supporting PANS/PANDAS

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Why I do this work



Image is of children holding the word hope at sunset

Because PANS/PANDAS offers hope:

To save lives

To provide healing for those suffering

To alter the trajectory of multiple crisis

What Do PANS & PANDAS Stand For?

PANS

Pediatric **A**cute **N**europsychiatric **S**yndrome

PANDAS

Pediatric **A**cute **N**europsychiatric **D**isorder **A**ssociated with **S**trep

Diagnostic Criteria of PANS

A: Sudden onset or sudden worsening of:

Obsessive Compulsive Disorder

Intrusive thoughts, rigid rules, repetitive behaviors

and/or

Severely Restricted Food and/or Fluid Intake

Limited food choices, fear of choking, refusal to eat, will not swallow/spit

Diagnostic Criteria of PANS (cont.)

B: And symptoms from two of the following seven categories....

1. Anxiety & Separation Anxiety
2. Aggression, Oppositional Defiance, Rage
3. Emotional Lability & Depression
4. Sensory Amplification & Motor Abnormalities (including tics)
5. Behavioral (Developmental) Regression
6. Deterioration in School Performance
7. Somatic Complaints including: urinary issues and sleep disturbances

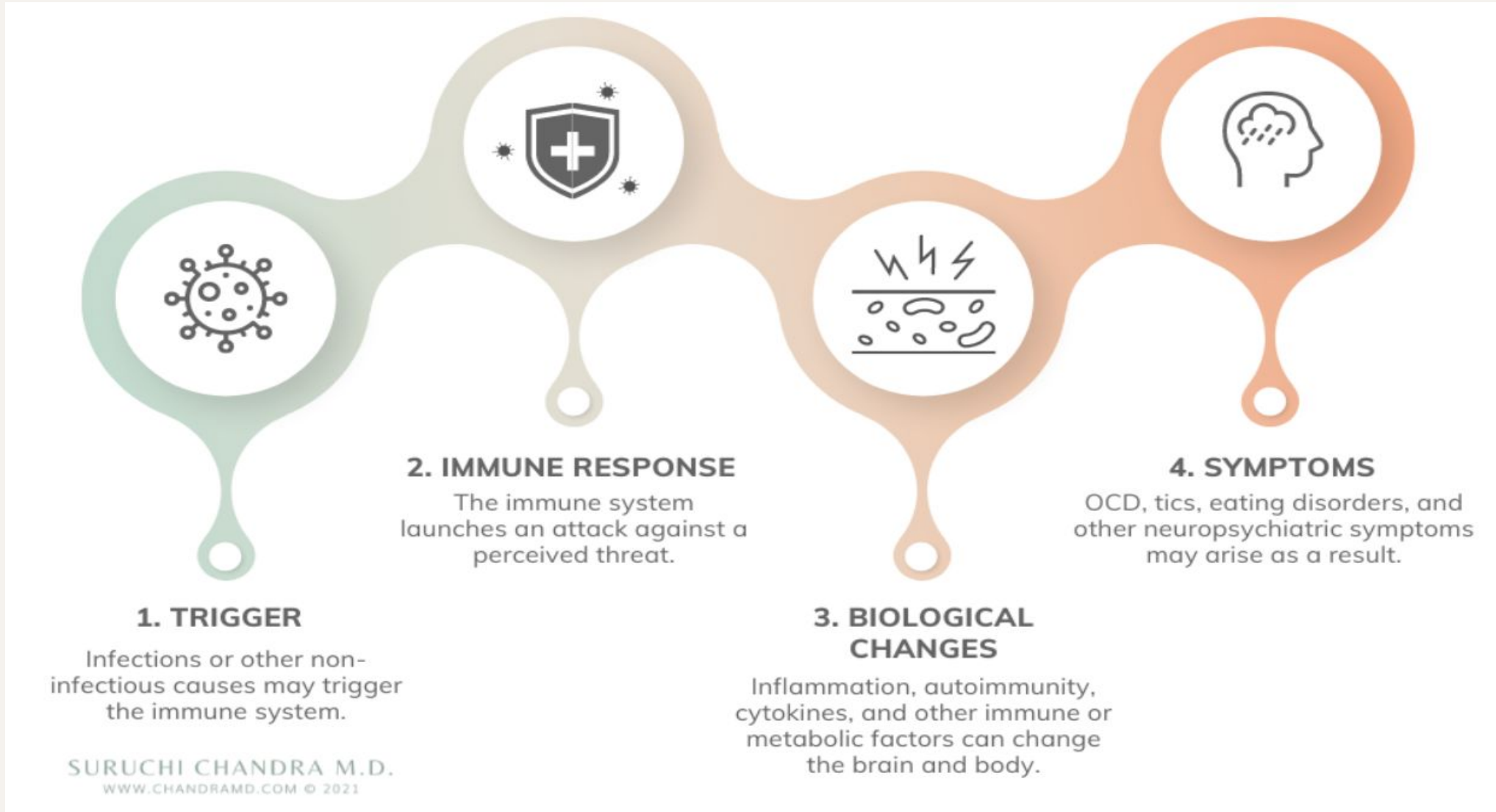
C: Diagnosis of Exclusion

D: No Age Requirement

What Are PANS/PANDAS?

- PANS and PANDAS are conditions in which a subset of children and adolescents experience an encephalitic like (inflammation of the brain) onset of neuropsychiatric symptoms
 - The symptoms occur following exposure to an immune trigger (infection) such as Group A Streptococcus, Mycoplasma Pneumonia (walking pneumonia), Lyme and viruses (eg, Mononucleosis, Herpes, Flu, COVID)
 - PANS does not require a known trigger but it is typically infectious
 - PANDAS requires a temporal relationship to Group A Streptococcus.
 - PANDAS is a subset of PANS.
-

Immune Reaction



The Science behind PANS/PANDAS

Antibodies created to fight these infections become misdirected and attack the brain, especially the basal ganglia.

This autoimmune reaction results in the acute onset of neuropsychiatric symptoms.

Both PANS and PANDAS are clinical diagnoses.

PANDAS is a subset of PANS

Early Recognition and Treatment of Neuroimmune Psychiatric Conditions: A Paradigm Shift in Neuropsychiatry



PRESENTED BY

Juliette C. Madan, MD, MS



www.pandasppn.org

CME Course

The body and brain communicate with one another

- Inflammation in the body causes an inflammatory response in the brain
 - The brain is not immune privileged and when the body is inflamed, the brain activates the immune cells called microglia to send out inflammatory markers to protect it
 - Triggers: Strep, mycoplasma, flu, mono, lyme, COVID, environmental triggers
- Trauma/Stress/Anxiety create an inflammatory response in the body
 - The research on this is overwhelming
 - Stress hormones prepare the body to run/fight/freeze for it's life, activating the immune system and sending out inflammatory cytokines to protect the body

- The basal ganglia is in the forebrain and is strongly interconnected with most of the brain.
- Behaviors disorders noted in this region include movement (e.g., tics/Tourette's), OCD, learning problems, addictions (the reward center)

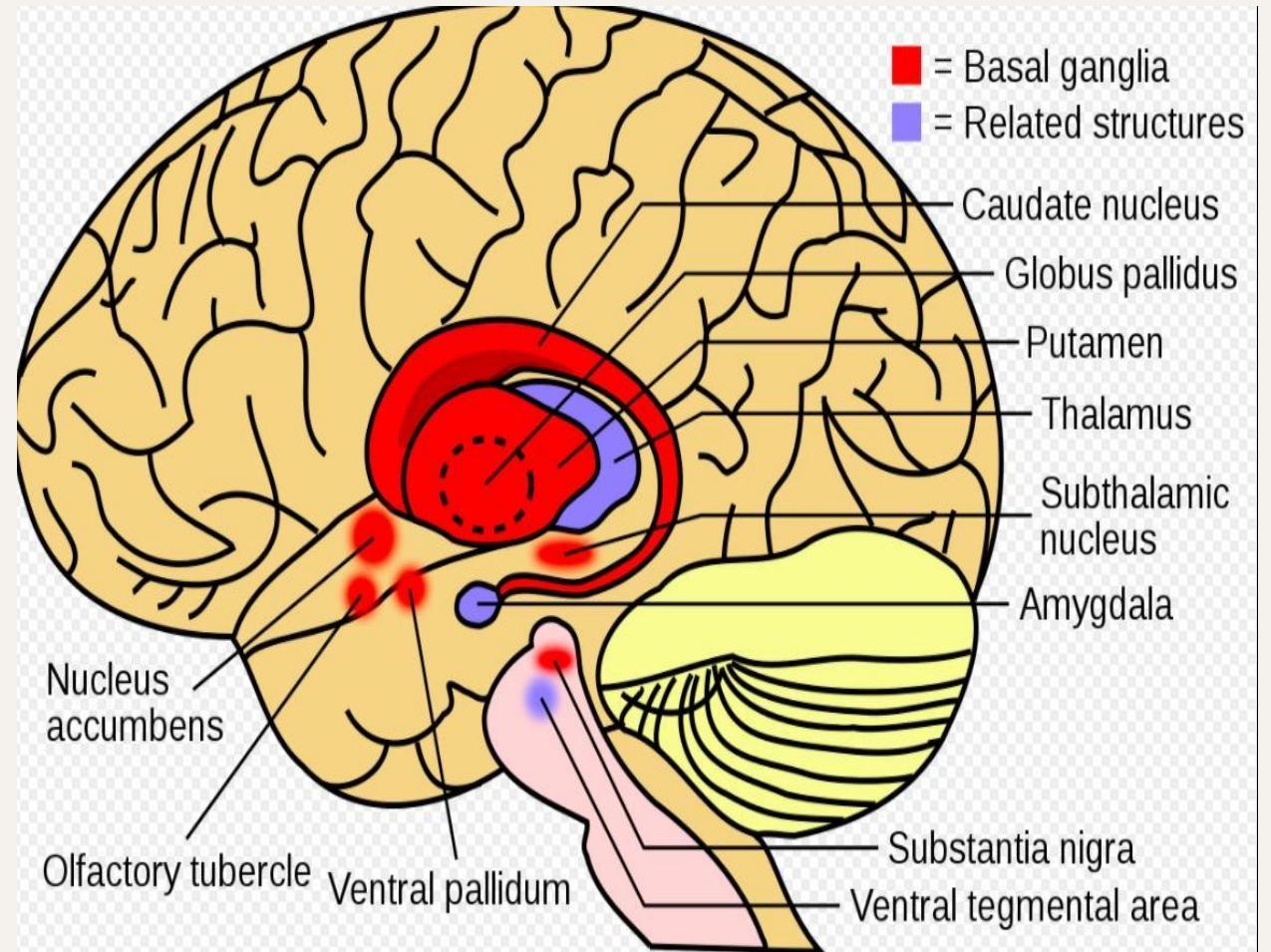


image is of brain and part of brain

Overview

Average Age of Diagnosis:

1-3 yrs: **11%**, 4-9 yrs: **69%**, 10-13 yrs: **19%**, 14+ **1%**

Numbers are likely under reported

A Spectrum Disorder:

- Initial and Subsequent triggers vary from child to child
- Symptoms mix and how they present vary from child to child
- Symptom severity varies from child to child

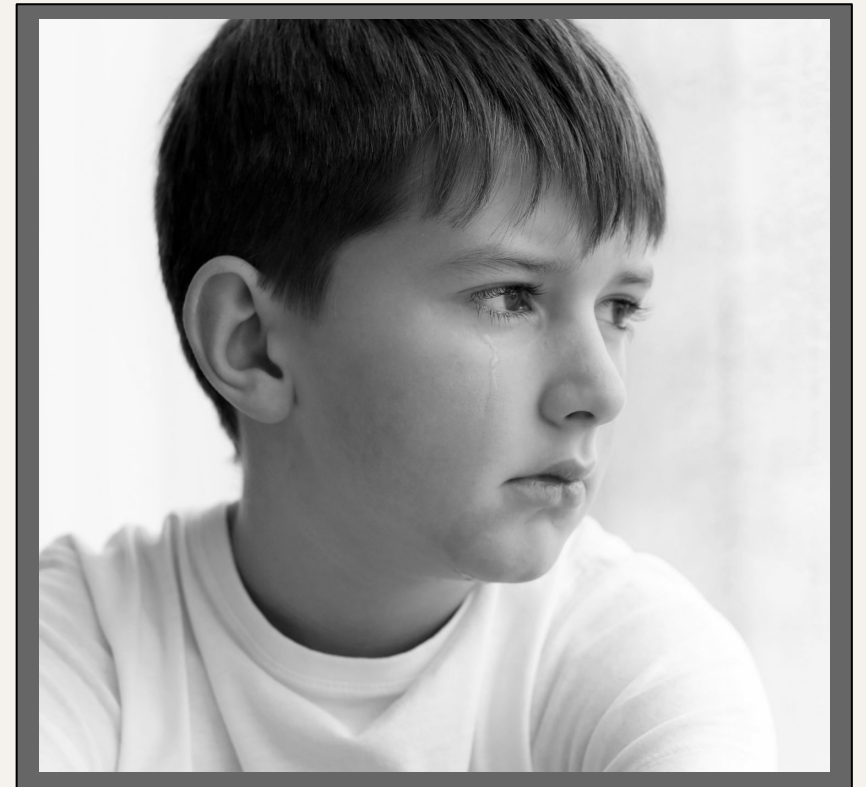


image is of young person looking away

Overview

Immune based conditions:

- Found in 71% of patient's families

Can adults have PANS? :

- Yes. PANS has no age restriction.
- Studies not done for adult onset - but 26 year old brain being studied at Georgetown medical - preliminary findings are damage to basal ganglia.



Image is of young person

How does PANS/PANDAS present?

If you have seen one child with PANS/PANDAS - you have seen one child.

Every child presents differently - brain inflammation causes different impact in each individual.

Treatment and healing is different for everyone - if you have seen one treatment path, it is only one path.



image is of child holding ears



Image is of adult holding stomach in pain



Image is of child looking sad

Diagnostic Symptoms - How PANS/PANDAS may present

- Obsessive-Compulsive Disorder
- Obsessive Thinking (Inappropriate Thoughts/Rigid Thinking/Perfectionism)
- Compulsions (Unable to stop disruptive behaviors, reassurance seeking behavior, checking behavior)
- Eating Issues (Limited Menu/Fear of Choking/Anorexia)
- Anxiety (Separation Anxiety/School Avoidance)
- Aggression (Oppositional Defiance/Rages - for our students reported at home)
- Age Regression/Immaturity (Tantrums/"Baby Talk")
- ADHD (Fidgeting/Outbursts/Poor Impulse Control)
- Sensory Issues
- Developmental regression

Please note: you can have Autism Spectrum Disorder AND PANS/PANDAS

Physical Symptoms that are connected to PANS/PANDAS

- Stomach pain
 - Fatigue and looking tired
 - Hallucinations
 - Frequently sick
 - Low tone
 - Chapped Hands or Lips/Mouth
 - Sleep disturbances, won't sleep alone, talk and movement in sleep
 - Restricted food intake: fear of contamination, choking, sensory
 - Tics: Vocal and/or motor
 - Movement issues (feeling like they are stuck, or doing repetitive patterns)
 - Urinary frequency and involuntary urination
 - Unusual gait
 - Balance issues
 - Hair pulling and skin picking
 - Dilated pupils
-

Sensory Issues

Sensitivity to light

Misophonia (sensitive to sound)

Sensory seeking (roughhousing, craving input)

Sensory avoidance

Food restrictions due to texture/taste

The nervous system is not well regulated and leads to an increase in sensory issues.

Occupational Therapy can be supportive!

Academic & Cognitive Issues

- Loss of math skills
 - Decline in handwriting skills (dysgraphia), Margin Drift
 - Inability to perform fine motor tasks
 - Reduced concentration
 - Perfectionism (Erasing through paper, Needing to start over)
 - Poor Short-Term Memory
 - Reduced memory: working memory and holding information
 - Avoidance of High Sensory Environments (Art, Music, Cafeteria, Physical Ed, etc...)
 - Decline in creativity
 - Difficulty with decision making
 - Time management problems
 - Difficulty in planning & prioritizing
 - Visual and spatial processing difficulties
 - Processing delays
 - Selective mutism, loss of speech/communication issues
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Attendance issues

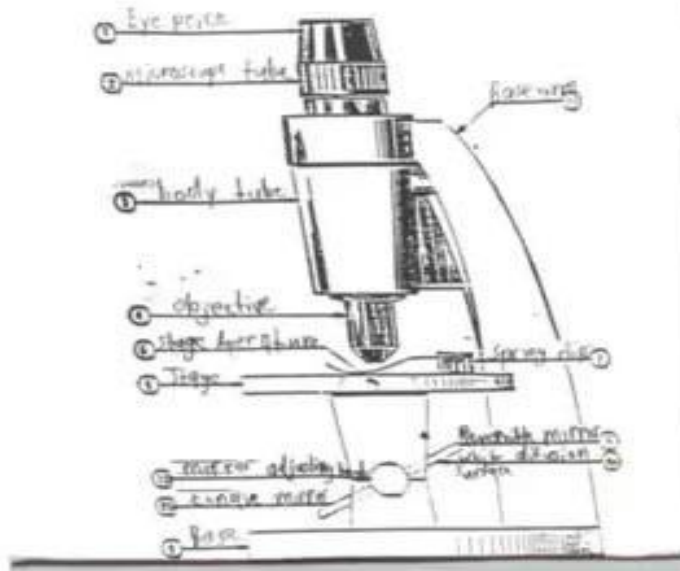
- School avoidance is often seen in PANS students due to separation anxiety and OCD.
 - In a qualitative study, half of the PANS students were placed in home-hospital services or were homeschooled.
 - 50% of children spend time on home instruction or are removed to homeschool or home/hospital temporarily or permanently
 - Students can feel sick after treatment - sometimes need more time to heal as they get better
 - 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
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Before and After PANS/PANDAS:

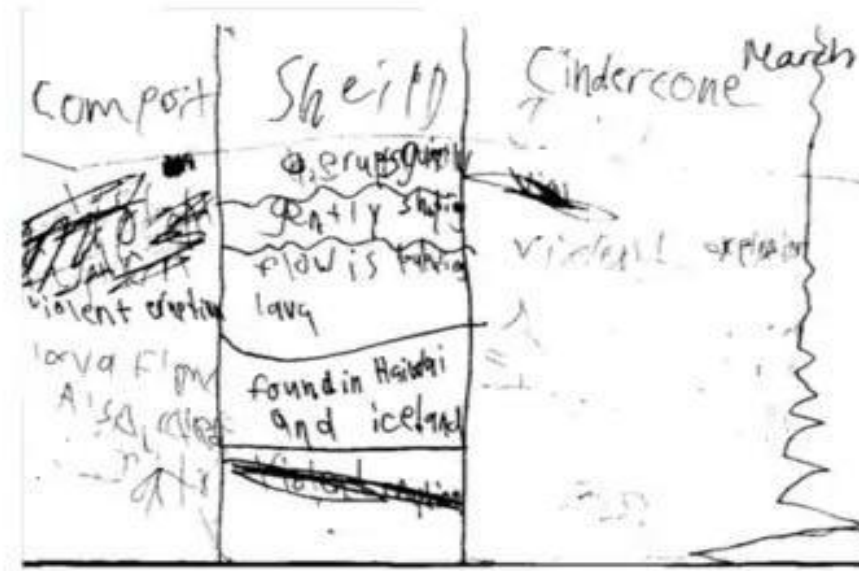
Handwriting & Fine Motor Skill Deterioration



Before Onset



After Onset



Smith, M.D. Pediatric & Developmental Neuroscience Branch NIMH, NIH Intramural Program.

Before & After PANS

Visual Motor/Writing Changes

Acute Illness

Convalescence

Demonstrates
Behavioral
Regressive
Self-Portrait.



Demonstrates
Age Appropriate
Self-Portrait.



Developmental Differences

In younger children:

- OCD may not be readily apparent, may show up as tantruming, raging
- Often don't have words for what is happening
- Separation anxiety is notable

In adolescence:

- Unlikely to share intrusive thoughts
 - They don't share the separation anxiety, they just quietly refuse to leave mom and remain in the house
-

Symptom Severity

Mild



- 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

Moderate



- 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

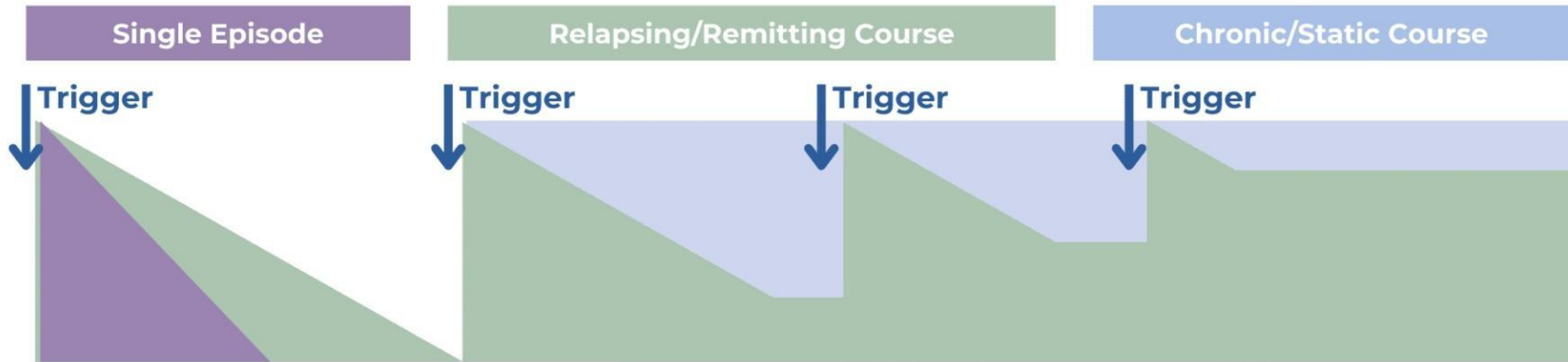
Severe



- 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

How does the illness progress/resolve

Symptom Course



Timely Diagnosis + Appropriate Treatment = Better Recovery

This is a treatable diagnosis

Parents report seeing an average of 8 doctors and spend 3 years seeking a correct diagnosis

If not caught early, may become chronic and harder to treat

Multiple deaths from suicide have been reported



Image is of Lulu Johnson



Image is of Alex Manfull

Barriers to Diagnosis

- Awareness
- Illness bridges multiple specialties
 - Mental health
 - Medical
 - (GI, immunology, rheumatology, allergy, neurology)
- Has been controversial
 - This is waning with increase in science and research
 - COVID has helped this immensely
- Semmelweis Reflex
- Paradigm shift

Responding to PANS Skepticism



1 2 3 4 5 6

Acknowledge Concerns

- It takes roughly 17 years for research to trickle into clinical practice, so an educational gap exists for many clinicians who haven't yet been apprised of advances in the field.
- Be kind and collaborative rather than argumentative.
- Acknowledge that there is a substantial need for more research to better understand PANS. Give to support research if you're able to.

Visit the [Responding to PANS Skepticism](https://neuroimmune.org/pans-skepticism) web page for the full guideline and 20+ links to supportive resources: neuroimmune.org/pans-skepticism

Legislative Action



Mass Coalition for PANS/PANDAS Legislation

DPH Permanent Advisory Council



National Alliance for PANS/PANDAS Action (NAPPA)

If you suspect PANS/PANDAS - What next?

Direct the family to wonder with their pediatrician about the illness

Educate the family - also connect with the provider to share information:

- [How to see your first PANS patient](#) - PANS/PANDAS Physician Network
- [Look. Foundation](#)

If you miss the medical underpinnings - you will see the child struggle with your interventions

Remember: this is a clinical diagnosis - you do not need lab work (it helps but the experts say to truly know - you treat to see if there is a change)

Consider using empirically backed screeners

When we suspect PANS/PANDAS as mental health providers - we have tools that are evidence based to help us understand if we may be on the right path.

C-YBOCS

- OCD is widely misunderstood and underdiagnosed - learn about the subtypes at [IOCDF](#)

PANS Screener

Horowitz - Lyme Scale

How do you treat PANS/PANDAS?



Image is a child hugging their mother

PANS/PANDAS Physician Network

Treatment Guidelines

How to Treat Your First PANS Patient

Research



Where is this being treated/researched?

Stanford University

The University of Arizona

Dartmouth Medical

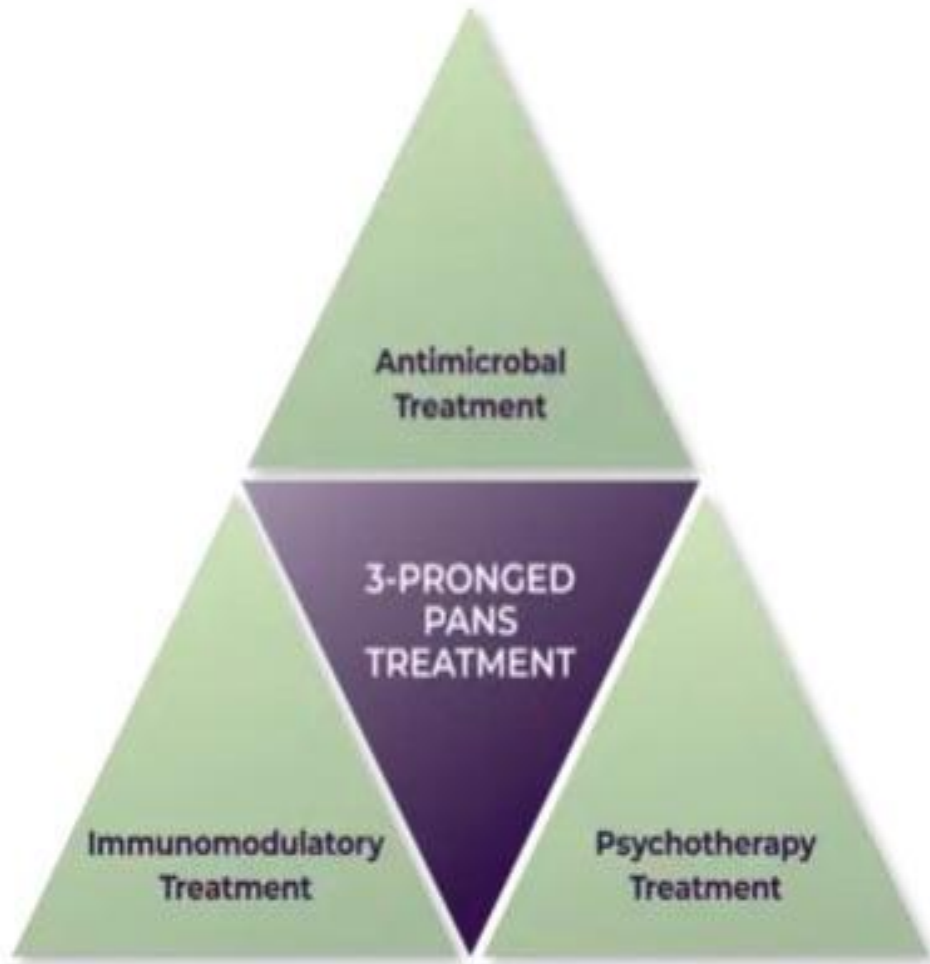
MGH

Columbia University Irving Medical

- Precision Psychiatry
- Lyme Clinic

Johns Hopkins

Georgetown Medical - POND Brain Bank



(Overview of Treatment of PANS, Swedo, MD et al, JCAP-Vol27, #7, 2017)

Treating of PANS PANDAS involves a three-pronged approach that utilizes psychiatric medications when appropriate to provide symptomatic relief, antimicrobial treatments to eliminate the source of neuroinflammation, and anti-inflammatory and immune-modulating therapies to treat disturbances of the immune system."

- **Treat Symptoms:** psychoactive medications, psychoactive therapies, and supportive therapies
- **Remove Inflammatory Source:** antimicrobial treatments
- **Treat Immune System Dysregulation:** anti-inflammatory and/or immunomodulating medications

Treatment Basics



Symptomatic Relief

Psycho-Therapeutic

Therapy

- Cognitive Behavior (CBT)
- Parent Management Techniques (PMT)
- School-Based

Psychotropic Medications

- "Start Low & Go Slow" approach
- Symptom specific



Inflammatory Source

Anti-Microbial

Antibiotics

- Therapeutic or prophylactic

Other Anti-Microbials

- Anti-virals or
- Anti-fungals
- if the trigger is not a bacterial infection



Immune Dysregulation

Immunomodulation

Anti-Inflammatories

- NSAIDs
- Steroids

Immunomodulatory Agents

- IVIG
- Plasmapheresis
- Rituximab
- Cellcept



Other Considerations

Supportive

- Tonsillectomy & Adenoidectomy
- Antihistamines (H1 & H2 Blockers)
- Vitamin D3, Omegas
- Dietary Changes

What kind of treatments are typical?

Antibiotics and anti inflammatories are common first line treatments

Steroids

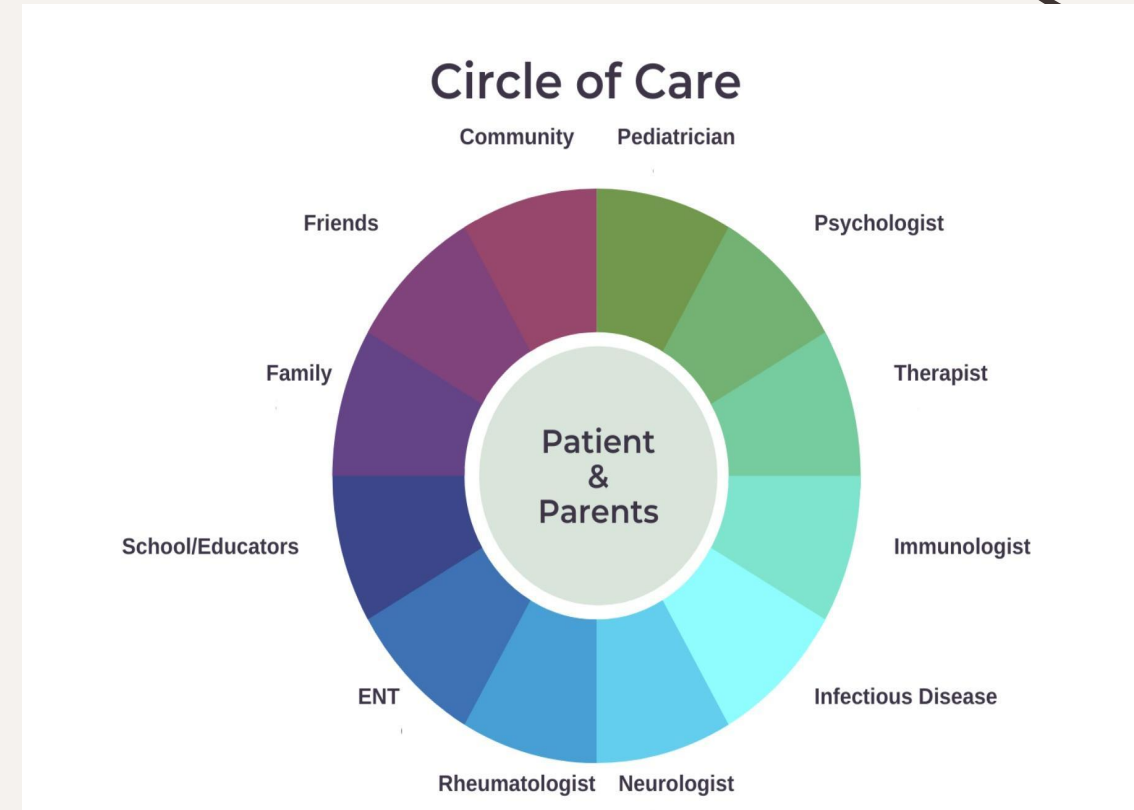
IVIG

Psychotropic medications - those impacted by PANS/PANDAS often react very differently - they are far more sensitive to medications

ERP/CBT therapy

The Importance of Teaming

- Children with PANS/PANDAS require communication with caregivers and other team members regularly
 - To ensure you understand what is happening at home, medication changes, or any illness they have had
 - Reports on how things are at home are essential for providers to know how to support student
- Providers may be the first to see a shift in presentation (writing, OCD, sensory issues)

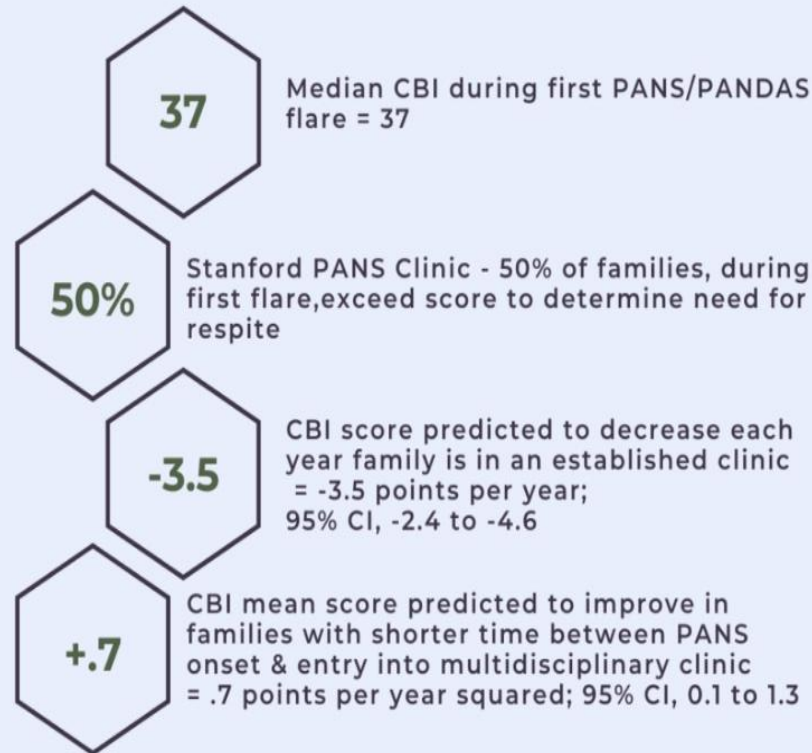


The Stress of Caring for a Child with PANS/PANDAS

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.”



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 wPANS, 2018

Supporting caregivers is essential

- They are the case managers of their child's care
- Give them techniques to regulate their nervous system
- They may present in acute fight/flight/freeze
- Providers may be supporting/meeting with caregivers as much as children
- They need reminders to care for themselves
- They will need repeated psychoeducation about illness
- Need to connect them into supports and resources

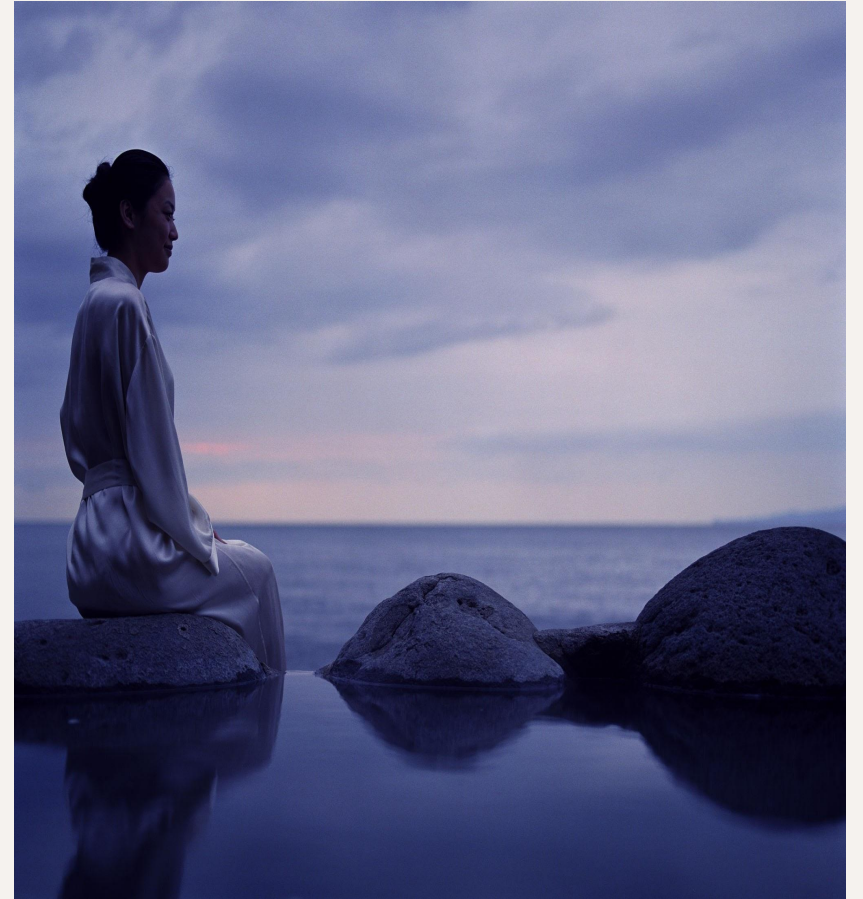
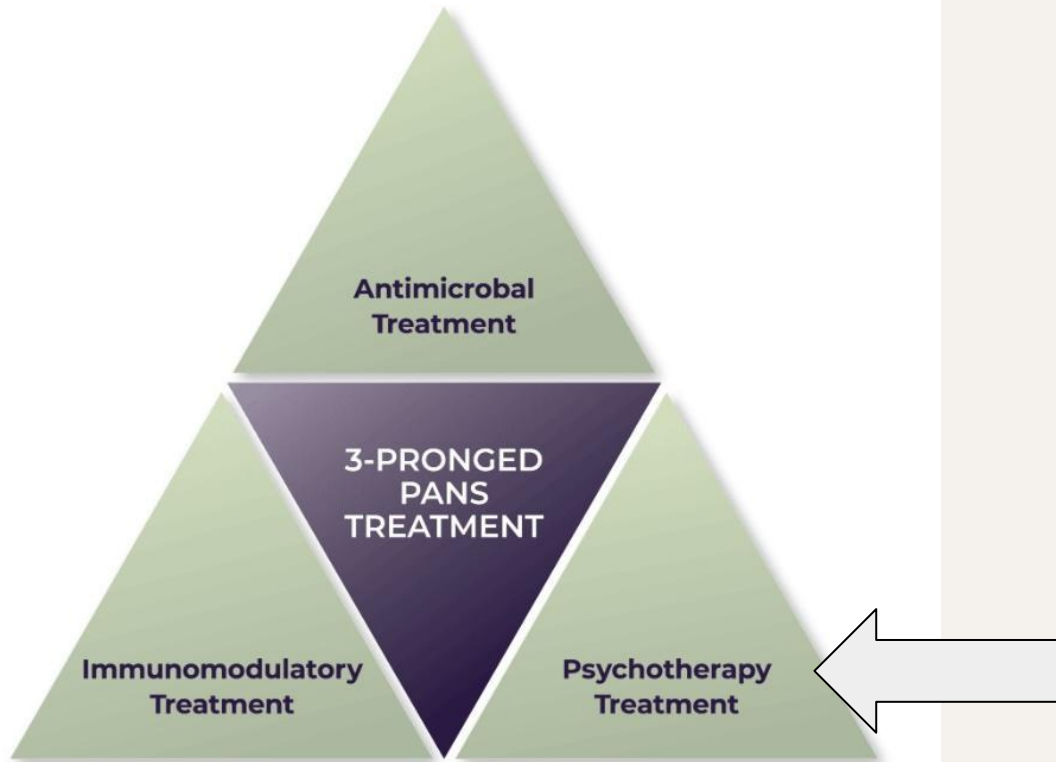


Image is of a person looking at the ocean

PANS/PANDAS: Both Medical AND Mental Health



- A medical illness that presents as mental health.
- A mental illness that has medical roots.

Mental health providers are critically important in supporting healing.

(Overview of Treatment of PANS, Swedo, MD et al, JCAP-Vol27, #7, 2017)

School Based Accommodations/Level of Support

- Level of support is contingent upon the severity of symptoms
- Supports may be based on those commonly utilized for students with that specific symptoms:
 - Math Regression
 - Dyslexia
 - Dysgraphia
 - Language Issues
 - Executive Functioning
- Plan for the worst symptoms and hope for the best; in preparation for a flare, including all appropriate accommodations so school staff can react and implement quickly
- Supports should be individualized.

Reimagining behavior

- These are NOT behaviors - they are symptoms of illness
- Brain Inflammation is driving the symptoms
- The anxiety you see is neuroinflammatory
- If you see an increase in anxiety - wonder if this is a flare
- If symptoms are persisting - wonder what might have been missed

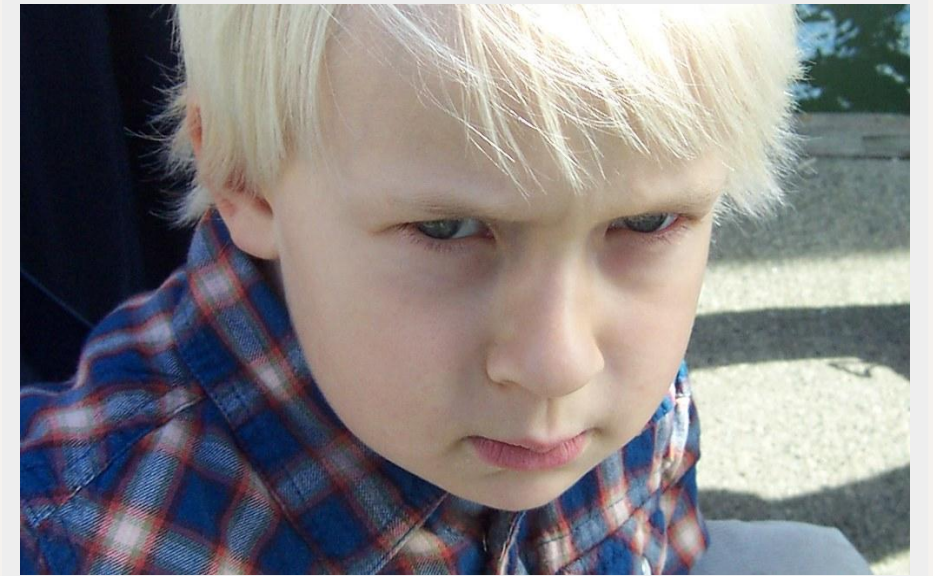
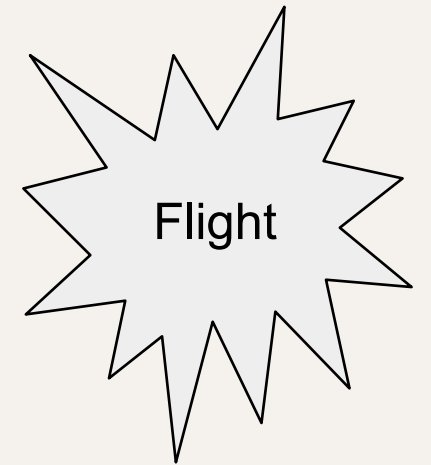


Image is of a young child looking angry

Their brain believes they are being chased by a lion



Image is of an animal chasing another animal



Separation Anxiety, OCD, Panic Disorder, Intrusive Thinking, Irrational Phobias, Social Anxiety, School Avoidance

To support children:

Offer 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

Do not use incentive based plans

- The root of the behavior is brain inflammation and will create shame

Remember: Kids do well if they can! This is NOT a skill or a will issue.

Be willing to and ready to shift your expectations/practice

This is supportive care first.

In a flare, or if not yet well managed, you will be holding space for healing.

The area of the brain that is impacted is causing near constant anxiety and fear.

Giving psychoeducation about how PANS/PANDAS works, and why they feels so badly is key.

You are likely going to be doing a lot of safety/crisis planning.

Anxiety Demands TWO Things:

Certainty: “I have to know what’s going to happen next...and I want to control it!”

Comfort: “I want to feel safe and comfortable...or else I want out!”

First: Help Regulate the Nervous System

Consider somatic techniques:

- Breathing
- Tapping
- Grounding techniques
- Exercise
- Meditation
- Journaling
- Consider a “Care-Flare Plan”

(Credit: Melissa Glynn-Hyman, LICSW)



Image is of the ocean

When medically stable

Support with:

CBT - Cognitive Behavioral Therapy

ERP - Exposure Response Prevention Therapy

ACT - Acceptance Commitment Therapy

Evidence based practices helps everyone feel grounded with a plan to face the anxiety.

You will have to adjust this to accomodate an inflamed brain.

Helps retrain the brian that they are safe - and therefore stops stress hormones from reactivating the immune system,

PANS/PANDAS Mental Health Myths

“They had PANS/PANDAS, but it resolved. Now they have (insert DSM-5-TR disorder).”

“All patients with PANS/PANDAS need psychotropic medication”

“They had a rule out and the labs were normal”

“They got worse with treatment so it can’t be PANS”

“It can’t be PANS because it rare”

“They had a week of antibiotics so they were treated.”

“I understand OCD so I understand PANS/PANDAS”

Help them find connection

The Look. Foundation
www.lookfoundation.org

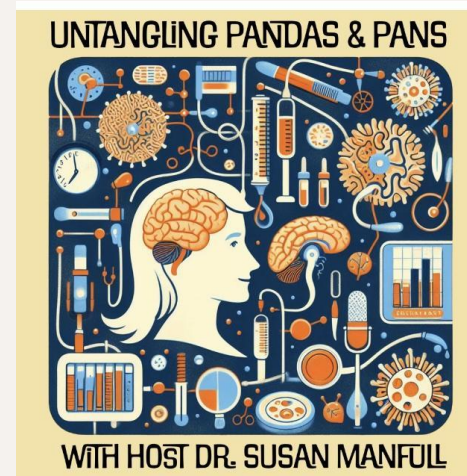
Aspire
www.aspire.care

Neuroimmune Foundation
www.neuroimmune.org

PANDAS Physician Network
www.pandasppn.org

The Alex Manfull Fund
www.thealexmanfullfund.org

Pandas Network
www.pandasnetwork.org



[Untangling PANS and PANDAS Podcast](http://www.thealexmanfullfund.org/tanf-podcast-untangling-pandas-pans/)

www.thealexmanfullfund.org/tanf-podcast-untangling-pandas-pans/

Ensuring equity for all: no one is missed



image is of a starfish leaning on a shell on the beach

Who have we missed? Understand prevalence.



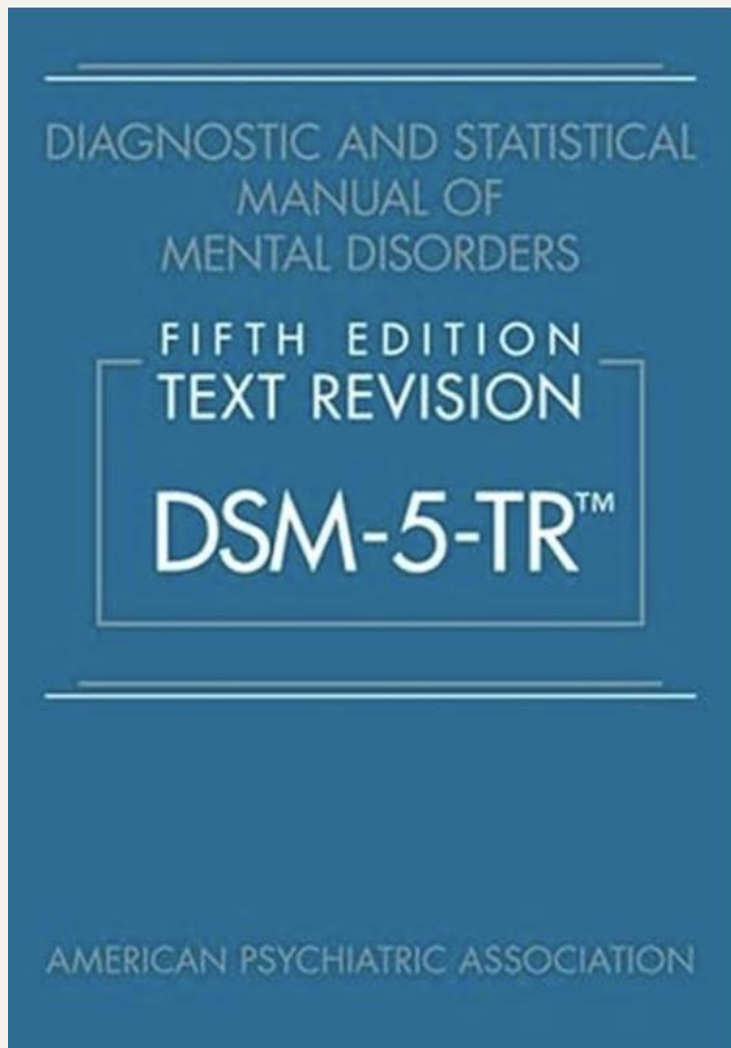
Image is of young child looking through a fence

- Leading advocacy groups hypothesis 1:200 children/young adults
- Not rare: rarely diagnosed
- Expert members of the PANDAS/PANS Collaborative Consortium estimate these disorders to affect 1% to 2% of the pediatric population

In Massachusetts that would mean as many as **30,000** children may have PANS/PANDAS

*OCD is also one of the most underdiagnosed mental health conditions - often missed as other diagnosis

We always do a medical rule out



- Prior to diagnosing a mental health condition, we know we are supposed to do a differential diagnosis and rule out “Rule Out a Disorder Due to Another Medical Condition”
- Should likely be a “medical rule in”

Dearborn Academy Mental Health Initiative

Diagnostic Consult Model

- Ensuring appropriate DSM 5 Diagnosis (through empirically backed screeners)
- Review of psychiatric, medical, educational, family history
- Student Interview
- Lab work

Caregiver Support

- 10 week Trauma Group
- Drop in support
- Psychoeducation

Research

- Two approved IRBs to collect data and share what we learn
-

Some things we have found when people have been missed:

- Many students had an acute onset of symptoms - caregiver knows the date their child changed
 - Students whose mental health symptoms were not finding relief - no matter what they tried
 - Students had a constellation of medical issues that have been missed
 - Students presented with OCD symptoms, but had never been screened
 - Students have intrusive thinking that was missed
 - “Suitcase effect” multiple DSM 5 TR Diagnosis, but none adequately describe/fit symptoms
 - When looking at past neuropsych evals, students had clear drops in functioning that are not well explained
-

Case Study: 14 year Female

History of:

- Treatment resistance
- Suicidal ideation
- Multiple suicide attempts
- Multiple psychiatric hospitalizations
- Significant school avoidance
- Had not accessed school in years
- Multiple DSM 5 diagnosis
- Appeared unable to move, “frozen”

Diagnostic Consult Model:

- OCD not previously screened - met criteria
- Met clinical diagnosis for PANS/PANDAS

Caregiver support:

- Mother accessed 10 week trauma group
-

After Seeking Treatment

- Caregiver found connection and support with other caregivers
 - Student went on to receive treatment for:
 - PANS/PANDAS
 - OCD (works with a therapist trained in OCD)
 - Student began to attend school daily
 - Received acceptances into four different colleges
 - Reports they did not expect to still be alive, and now sees a future for themselves.
-

Children are healing

They are not returning to psychiatric hospitals.

They are going to college.

Their suicidal ideation abates.

They are able to do classwork for the first time in years.

They are now our graduation speakers.

“I just wish it hadn’t taken 5 years to find help.” - Dearborn Academy Caregiver

[Look story](#)
