# Rural Health's Role in Recognizing and Treating PANDAS/PANS

NWPPN

nwppn.org

# Presenters

- Sarah Lemley, MPA; HA
  - Co-founder and Executive Director of Northwest PANDAS/PANS Network (NWPPN)
- Industry Background:
  - Healthcare Administrator for over a decade (OHSU, BMC, Concentra
  - Medical Social Worker (Legacy)
  - Rape/Domestic Violence Victim Advocate
- Personal Background
  - Child with PANDAS
  - Onset at 9 with acute onset (overnight) of Severe Anxiety including Separation Anxiety, OCD, Tics, Eating Restrictions, Agoraphobia, Rage, Age Regression, Handwriting Changes, Sensory Sensitivities

# Presenters

- Kym McCornack
  - Head of Family Support for Northwest PANDAS/PANS Network (NWPPN) and founding Board Member
- Industry Background
  - Professional Photographer
- Personal Background
  - Child with PANDAS
  - Sudden onset of ADHD and Tics with additional symptom presentation to include food restrictions, insomnia, anxiety, hallucinations, tics, rage, urinary issues, regression in drawing and writing

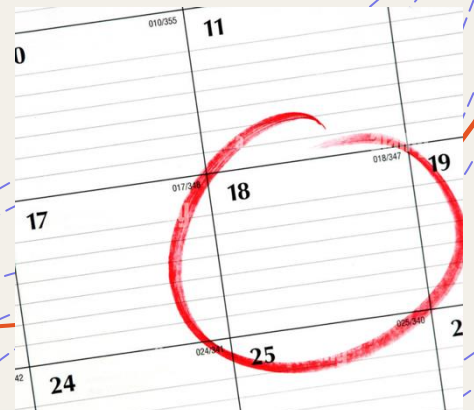
# Learning Objectives

- This session will enable the learner to **understand the basic biological processes** involved in post-infectious neuroinflammatory disorders such as PANDAS and PANS.
- Participants will be able to **RECOGNIZE key symptoms** which indicate the need for the medical/behavioral health provider and/or staff to advocate for thorough and appropriate medical evaluation.
- Participants will demonstrate competency of where to seek out **established diagnostic and treatment guidelines** specific to clinicians.
- This session will enable the learner to **understand barriers to care** while introducing **local resources** that can support both the patient and family.

KM

# What happened to my child?

- Thousands of children in our state and others are having psychiatric and neurological manifestations post infection.
- Most of these children are being misdiagnosed as psychiatric or behavioral cases or overlooked altogether
- Families are left to wonder, ‘What happened to my child?’




NWPPN

nwppn.org


Before PANDAS

*"Imagine a previously healthy and happy school-age child **suddenly** screaming in terror, displaying repetitive rituals and compulsions, and clinging to a parent; this is the clinical presentation of PANDAS/PANS."*

- Bagian & Hartung, 2014

# History of PANDAS

- Susan Swedo, MD was a researcher in the field of pediatrics and neuropsychiatry, and since 1998 served as the Chief of the Pediatrics & Developmental Neuroscience Branch at the US National Institute of Mental Health.
- She was studying OCD in children when she discovered a correlation with abrupt onset of OCD and Tics related to Group A Strep Infection
- In 1998, Swedo was lead author on a paper describing Pediatric Autoimmune Neuropsychiatric Disorders Associated with Streptococcal infections (PANDAS), proposing a link between Group A streptococcal infection in children and some rapid-onset cases of obsessive-compulsive disorder (OCD) or tic disorders such as Tourette syndrome.

Susan Swedo, M.D.

NWPPN

nwppn.org

HTTPS://AJP.PSYCHIATRYONLINE.ORG/DOI/10.1176/AJP.155.2.264


SL

NWPPN

nwppn.org

# Infection-Triggered Autoimmune Neuropsychiatric Disorders are not "New"


CHOREA

## Rheumatic Fever triggered by Strep Infection (Group A Streptococcus)

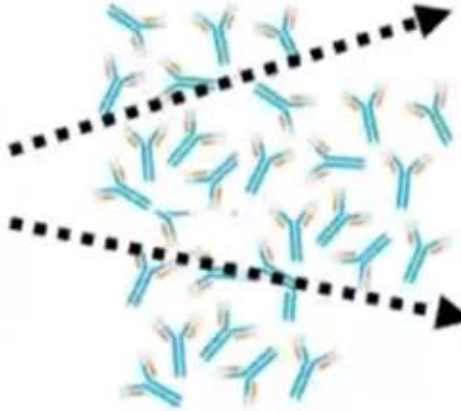
1894: Sir William Osler described ***"bizarre"*** and ***"perseverative behaviors"*** of children with ***"chorea minor,"*** obsessive-compulsive (OCD) symptoms and Sydenham's chorea (SC)

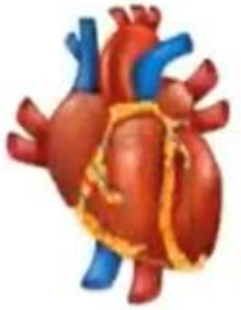
**Also known as "St. Vitus' dance"**

- **abnormal movements**
- **Loss of fine-motor control**
- **Loss of emotional control**

**Sydenham Chorea**

**Group A Strep**





**Acute Rheumatic Fever (ARF)**

**Sydenham Chorea**

# Can Infections Really Trigger Neuropsychiatric Disorders?

***A large portion of neuropsychiatric disorders are caused by an infection-triggered autoimmune dysfunction***


Kohler-Forsberg, O., et al. (2019)
*JAMA Psychiatry, 76*(3), 271-279

March 2019

***JAMA Psychiatry: "Harbingers of Mental Disease***

***Infections Associated With an Increased Risk for Neuropsychiatric Illness in Children"***


Danish study of ***1,098,930 individuals birth to 18 years old:***

If ***hospitalized for a severe infection***, the risk of developing mental disorders ***increased by more than 80%*** for diagnosis of:

- ***Schizophrenia, autism spectrum disorder, obsessive compulsive disorders, ADD/ADHD, personality and behavior disorders, ODD/OD and tic disorders***

"How could exposure to infections affect the brain mechanistically to give rise to mental disorders? ***Circulating autoantibodies that enter the brain*** via a compromised blood-brain barrier and ***bind to neurotransmitter receptors*** is a potential explanation, and this mechanism has been proposed in ***PANDAS and other mental disorders***."

KM

# What is PANDAS?

**P**ediatric

**A**utoimmune

**N**europsychiatric

**D**isorder

**A**ssociated with

**S**treptococcal infections

NWPPN

nwppn.org

# What is PANS?

**P**ediatric

**A**cute onset

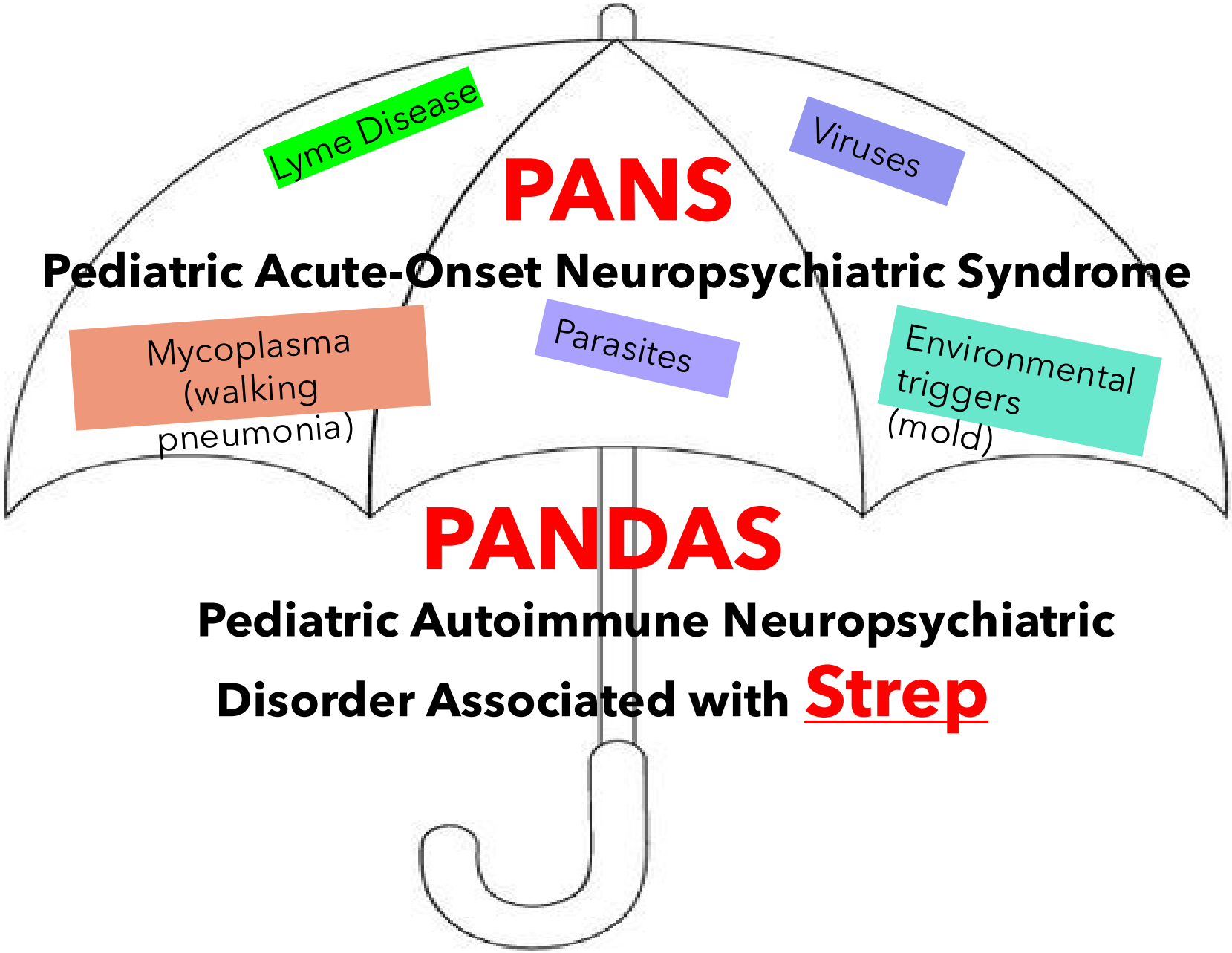
**N**europsychiatric

**S**yndrome

NWPPN

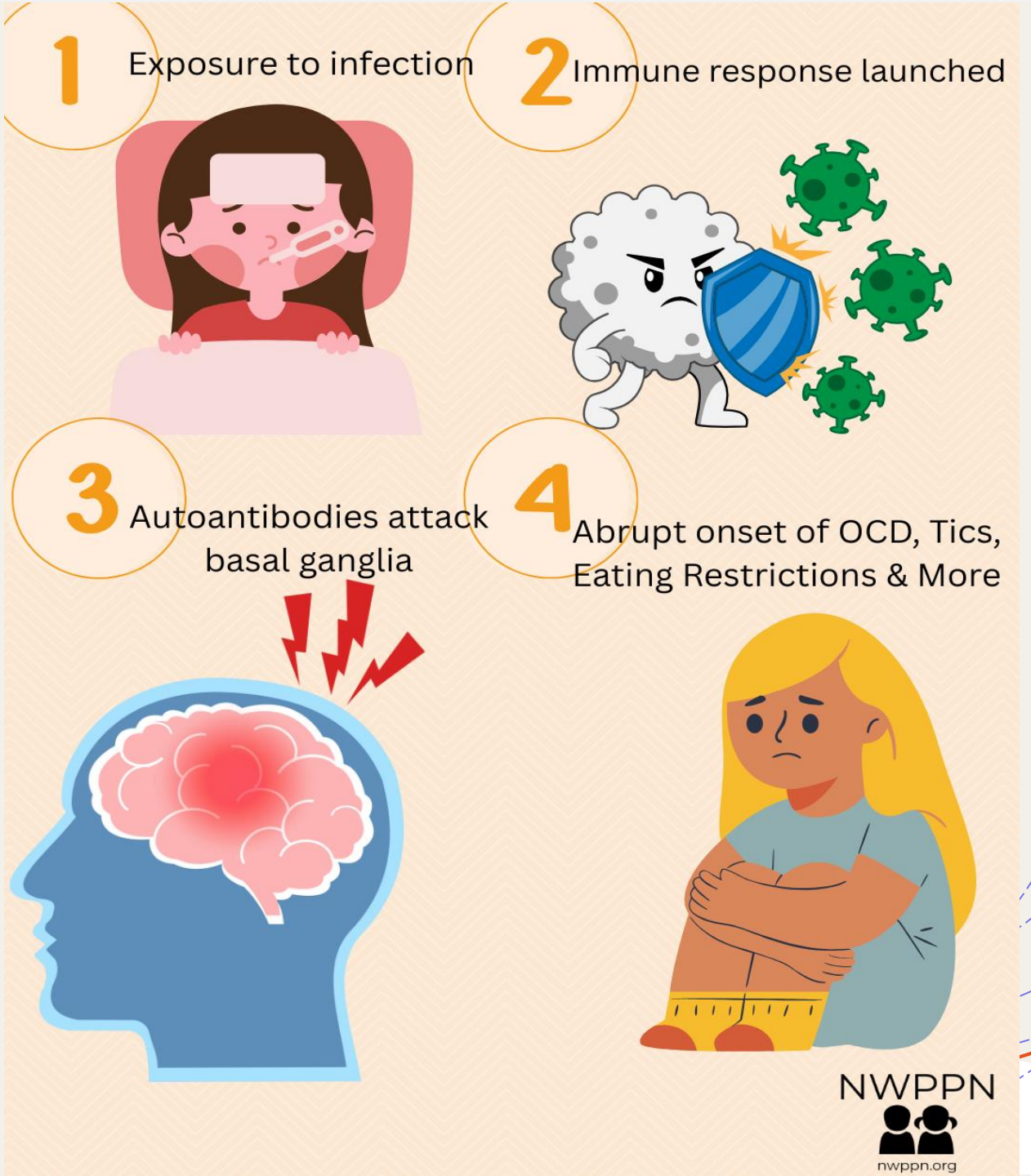
nwppn.org

KM


Lyme Disease
Viruses
PANS
Pediatric Acute-Onset Neuropsychiatric Syndrome
Mycoplasma (walking pneumonia)
Parasites
Environmental triggers (mold)
PANDAS
Pediatric Autoimmune Neuropsychiatric Disorder Associated with Strep

KM

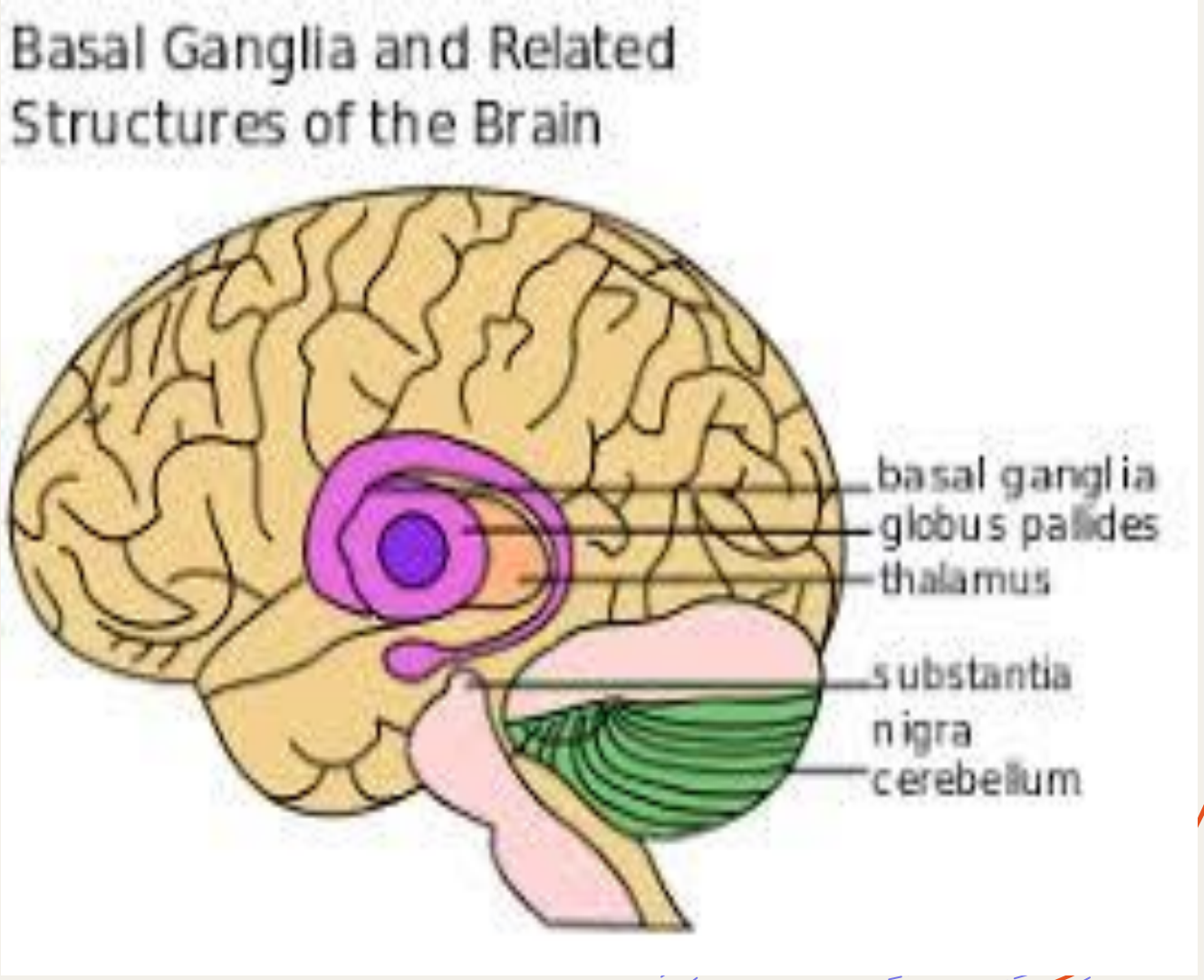
# Basic Biological Process




NWPPN
nwppn.org

# Basal Ganglia is responsible for:

Emotions
Mood
Anxiety
Movement
Balance
Cognition
Executive function
Memory
Procedural learning
Habit formation



# Infections, Inflammation & Autoimmune Disorders

- Rheumatoid Arthritis-Ebstein Barr Virus (EBV)
- Lupus-EBV
- Multiple Sclerosis-Epstein Barr Virus
  - Measles
- Type 1 Diabetes-Coxsackie Virus & Cytomegalovirus
- Hashimoto's Thyroiditis-Coxsackie
- Myocarditis-COVID
- Rheumatic Fever-Streptoccocal



https://www.ncbi.nlm.nih.gov/books/NBK605875/

# 2013 PANS Consortium

2013 PANS Research Consortium

# DIAGNOSTIC (2015) GUIDELINES AND THE PANS CONSORTIUM

SL

## Institutions Represented

+ **National Institute of Health**
+ **Stanford University**
+ **Harvard University**
+ **Yale University**
+ **Georgetown University**
+ **Columbia University**
+ Stonybrook University
+ University of Oklahoma
+ University of Minnesota
+ University of Delaware
+ University of South Florida
+ University of Texas
+ Wayne State

## Specialties Represented

+ Pediatrics
+ Pediatric Neurology
+ Neurology & PET imaging
+ Pediatric Rheumatology
+ Allergy & Immunology
+ Microbiology
+ Pediatric Cardiology
+ Otolaryngology (ENT)
+ NeuroAnatomy
+ Psychiatry
+ Genetics & OCD

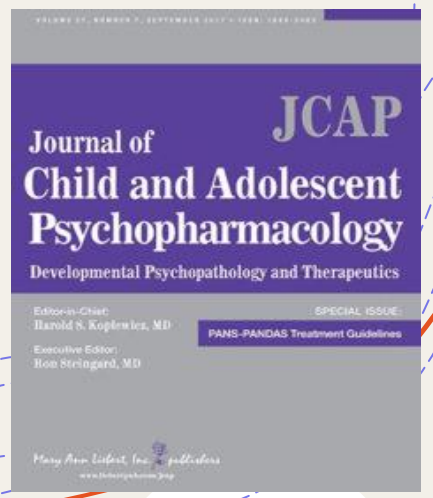

NWPPN
nwppn.org

# PANDAS Diagnostic Criteria

Pediatric Autoimmune Neuropsychiatric Disorder Associated with Streptococcal Infections

**Guidelines for diagnosing PANDAS include:**

1. Presence of OCD **and/or** tics, particularly multiple, complex or unusual tics
2. Age Requirement (Symptoms of the disorder first become evident between 3 years of age and puberty)
3. Acute onset and episodic (relapsing-remitting) course
4. Association with Group A Streptococcal (GAS) infection
5. Association with Neurological Abnormalities




NWPPN

nwppn.org

There are three severity levels for PANDAS/PANS: Mild, Moderate and Severe.

KM

# Complexity of Strep

- More than half of all strep infections are missed in young children
- GAS cultures can be difficult to obtain, and one must adequately swab the affected areas.
- GAS may reside in tonsillar crypts and may not be detected using routine throat swab.
- Rapid strep tests miss 15%-20% of infections, so overnight (or 48-hour) cultures must be done.
- According to the Hysmith et al (2017) study, 65% of new strep infections by group A strep caused no symptoms yet were immunologically significant. Because of this, **it is vital to do perform a 48 hour culture**.
- However, normal titers do not always mean strep is not present!
  - According to the Shet et al (2003) study
    - Only 54% of children with strep showed a significant increase in ASO
    - Only 45% showed an increase in anti-DNASE B
    - Only 63% showed an increase in either ASO and/or anti-DNASE B
    - **Not all people who have strep will have a rise in titers**
- Strep can occur in the sinuses, the ears, the gut, on the skin and in the vagina and peri-anal areas. **A throat swab and/or culture will not give you a positive result for strep that is occurring somewhere else in the body.**

NWPPN

nwppn.org

# Known Strep Complications

- Rheumatic Fever
  - A serious **inflammatory** condition that can affect the heart, joints, nervous system and skin
  - Sydenham chorea, or St. Vitus dance occurs in up to 40% of those with RF
- Scarlet Fever
  - Bacterial illness that develops in some people who have strep throat
- Poststreptococcal reactive arthritis
  - Inflammation of the joints
- Glomerulonephritis
  - Inflammation of your kidneys
- Otitis media(spread of infection to the middle ear)
- Meningitis(spread of infection to the lining of brain and spinal canal)
- Pneumonia(lung infection)
- Toxic shock syndrome(a rare but severe complication of strep pharyngitis, causing severe widespread infection and organ failure); and/or
- Abscess formation around the tonsils and behind the throat (peri-tonsillar abscess and retro-pharyngeal abscess)
- Sepsis

# PANS Diagnostic Criteria

KM

Pediatric Autoimmune Neuropsychiatric Syndrome


**Guidelines for diagnosing PANS include:**

1. An **abrupt, acute, dramatic onset** of obsessive-compulsive disorder **or** severely restricted food intake
2. Concurrent presence of additional neuropsychiatric symptoms with similarly severe and acute onset from at least 2 of the following categories:
   · Anxiety
   · Emotional Lability and/or Depression
   · Irritability, Aggression, and/or Severe Oppositional Behaviors
   · Behavioral (Developmental) Regression
   · Sudden Deterioration in School Performance
   · Motor or Sensory Abnormalities
   · Somatic Signs and Symptoms, including Sleep Disturbances, Enuresis, or Urinary Frequency
3. Symptoms are not better explained by a known neurologic or medical disorder
4. Age requirement – None

NWPPN

nwppn.org

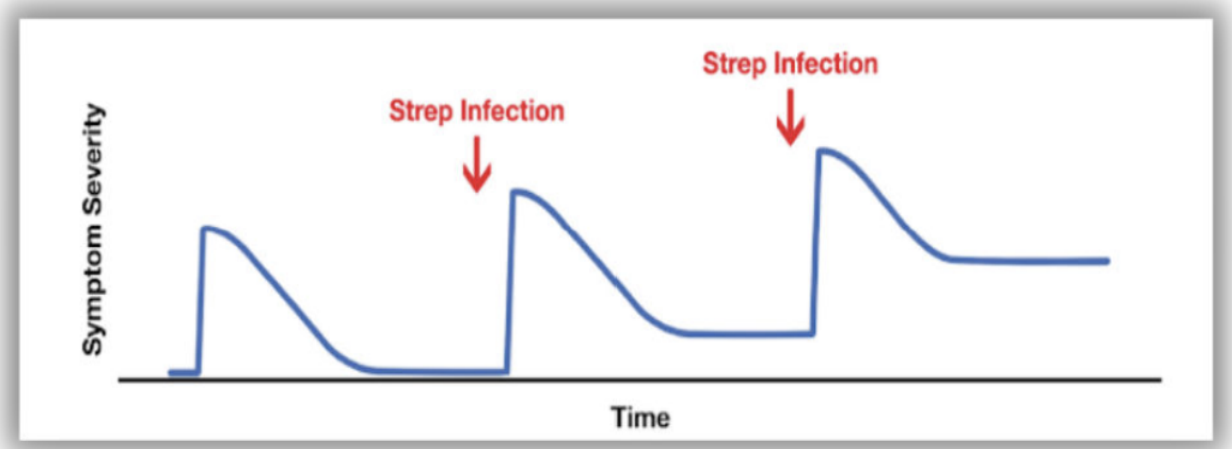
# Non-Strep Infectious Triggers

- **Mycoplasma Pneumoniae:** Mycoplasma pneumoniae is also known as walking pneumonia.
- **Staph Infections**: Staph can occur in multiple places in the body: On the skin, in the nose, and it has even been found in the biopsy results on tonsils post-tonsillectomy.
- **Tick Borne Infections:** Lyme, Bartonella, Babesia
- **Influenza**.
- **Herpes Virus:**
  - HSV 1 & 2
  - EBV
  - Coxsackie HHV6
- **COVID**

# FLARES
## RELAPSING AND REMITTING SYMPTOMS

## UNDERSTANDING **SYMPTOM PATTERNS**

### Repeated Flares & Symptom Baseline




Source: NIMH Information About PANS/PANDAS
https://www.nimh.nih.gov/research/research-conducted-at-nimh/research-areas/clinics-and-abs/sbp/information-about-pans-pandas.shtml

PANS symptoms can relapse and remit. Some symptoms do not return to baseline between flares, while others are only reduced. In some cases, subsequent flares can be more severe with a longer duration and become chronically debilitating. PANS symptoms can remit completely, especially if treated quickly and thoroughly. Treatment plans should clear the current flare but also address ongoing symptoms. The goal is to relieve symptoms and prevent them from becoming chronic.

*Credit: ASPIRE-Alliance to Solve PANS & Immune-Related Encephalopathies*

KM

# SYMPTOMS

## MAJOR CRITERIA

### + OBSESSIVE COMPULSIVE DISORDER (OCD)

5 types

- Organization-things being in precisely the right place or symmetrical
- Contamination- The first is the thought that people can spread non-viral illnesses through touch or proximity. The second is that everyday things, thoughts, and words can "contaminate" a person, making them feel unclean
- Intrusive Thoughts-hurting a loved one, causing harm to a stranger, or even the idea that simply thinking about something can make it more likely to occur. To quiet these obsessions, a person might have to perform an action, such as saying something aloud or repeating something mentally.
- Ruminations-ideas that get stuck in the head, might be philosophical, religious, or metaphysical conundrums
- Checking-a person is concerned about causing damage or harm by being careless. Their compulsions might include checking doors to make sure they're locked, stoves to make sure the burners are off,

IOCDF 'What is OCD'

### + RESTRICTIVE EATING

This includes selective eating and food refusal. There can a variety of reasons why the child experiences this, including contamination fears, sensory sensitivities, trouble swallowing, fear of vomiting or weight gain, and more.

### + TICS

Tics are repetitive movements or sounds that can be difficult for a child to control.

- Motor tics can include eye-blinking, head-jerking, shoulder shrugging, nose-twitching, and facial grimacing. Some motor tics are a series of movements, performed in the same order.
- Vocal tics can include grunting, humming, throat clearing, coughing, repeating words or phrases. Some children are able to suppress tics temporarily, but doing so can cause extreme discomfort. Relief comes through performing the tic.

KM

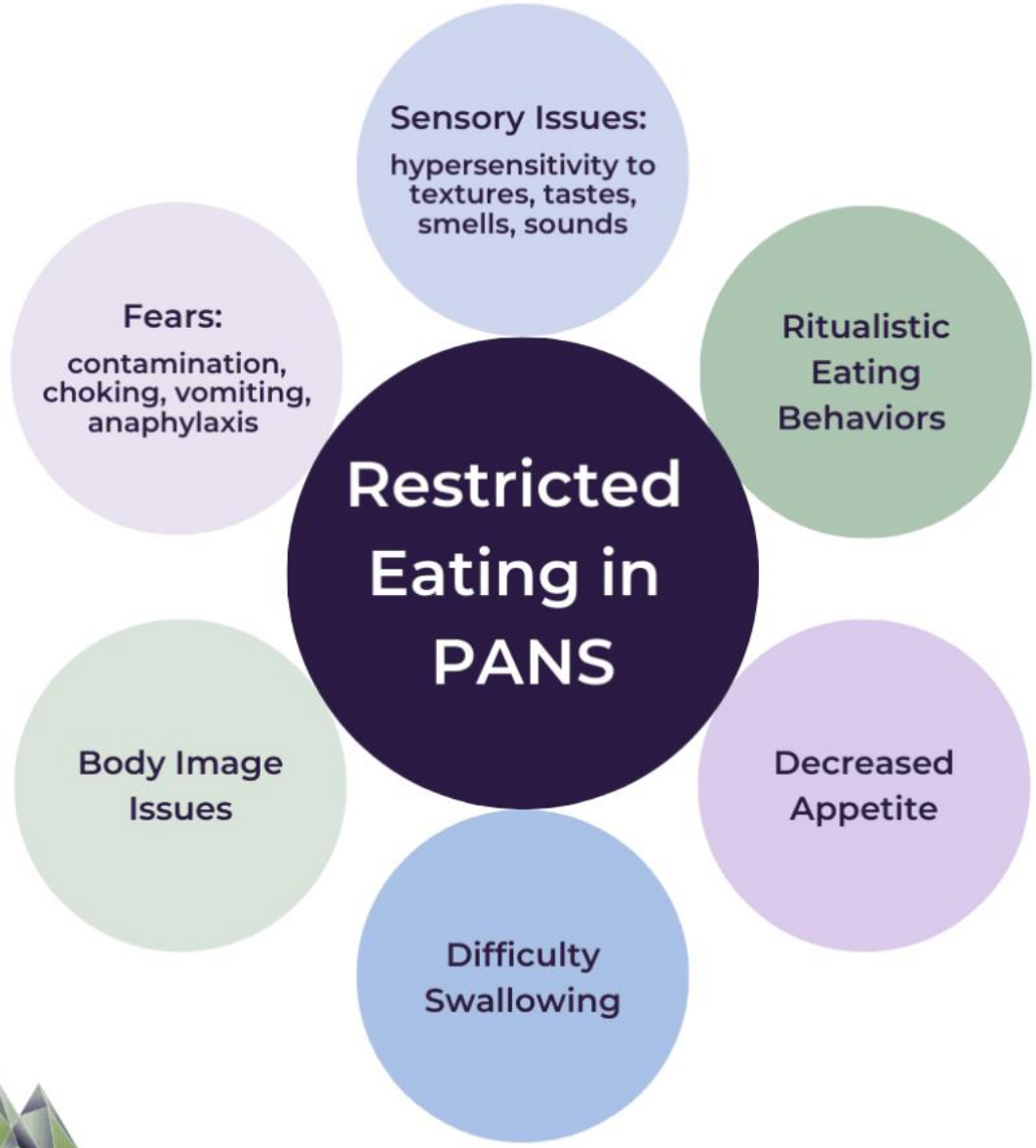
# OCD Symptoms

- Contamination obsessions
- Sexual or religious obsessions
- Aggressive obsessions of harm to oneself or others
- Repeating compulsions
- Symmetry and exactness obsessions
- Ordering / arranging compulsions
- Counting compulsions
- Checking compulsions and requests for reassurance
- Need to touch, tap, or rub
- Intrusive images, words, music or nonsense sounds
- Need to tell, ask, or
- Colors, numbers, or words with special significance
- Ritualized eating behaviors
- Hoarding behaviors

NWPPN

nwppn.org

# Restricted Eating in PANS PANDAS




ASPIRE

www.aspire.care

NWPPN

nwppn.org

# SYMPTOMS

## MINOR CRITERIA

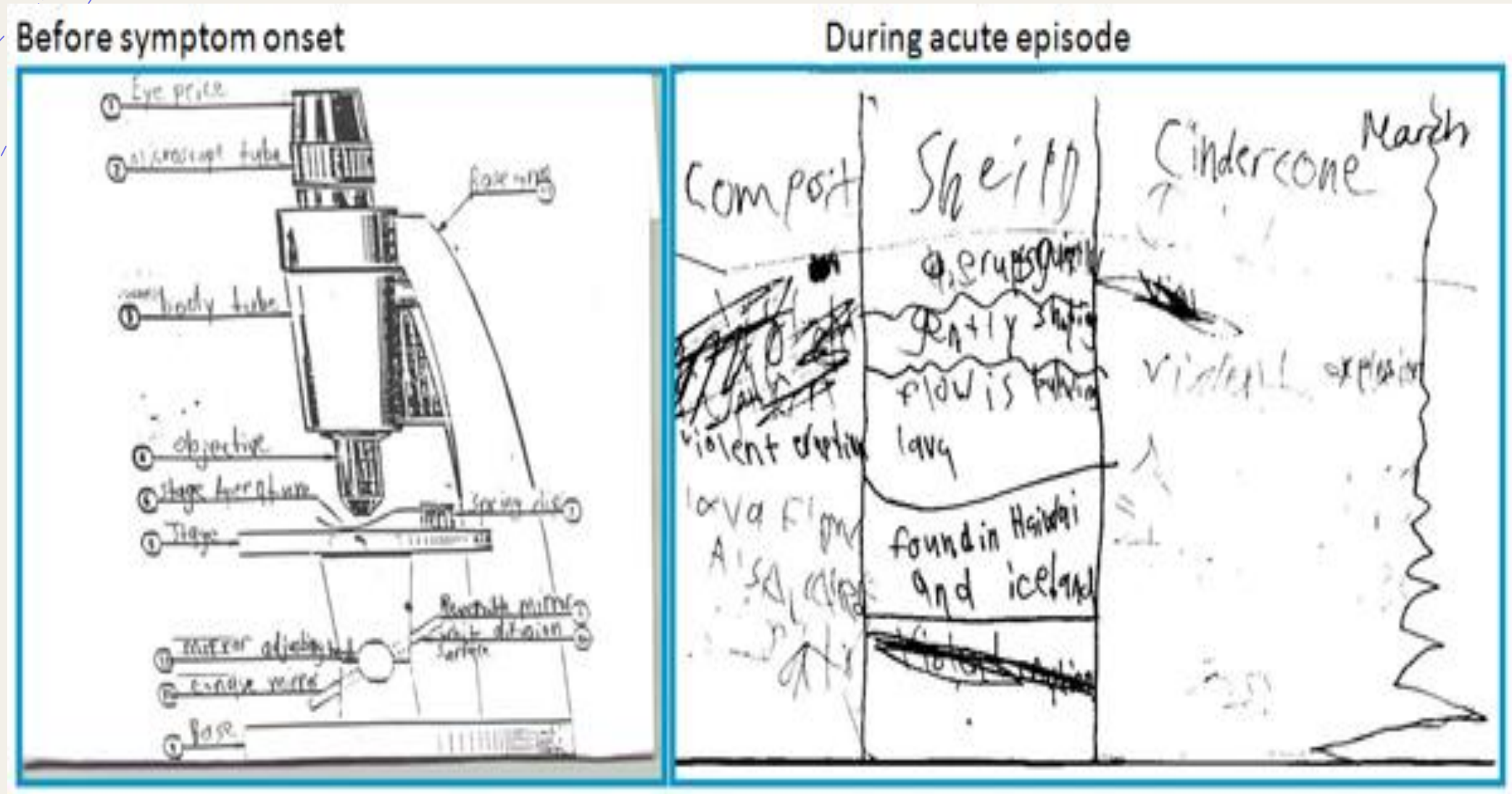
+ **ANXIETY/SEVERE SEPARATION ANXIETY**
  Separation anxiety in an older child will present differently. For example, a child may be unwilling to leave the house or their bedroom
+ **EMOTIONAL LABILITY**
  Emotional lability includes not being able to control one's emotional response such as uncontrollable crying or laughing. This is a neurological symptom.
+ **DEPRESSION**
+ **RAGE-IRRITABILITY AND AGGRESSION**
+ **IMPULSIVITY-** Jumping out of 2nd story windows, moving cars, etc.
+ **BEHAVIORAL REGRESSION**
  This includes baby talk.
+ **DEVELOPMENTAL REGRESSION**
+ **DETERIORATION IN SCHOOL PERFORMANCE**
  This includes deterioration in math skills, inability to concentrate, difficulty retaining information, and school refusal. School performance can also be a result of another contributing symptom, such as OCD or severe separation anxiety.

# SYMPTOMS

## MINOR CRITERIA

+ **CHANGES IN HANDWRITING**
  This includes margin drifts and legibility.
+ **SENSORY SENSITIVITIES**
  This can include being sensitive to touch, sounds, and noise. Simple touches may feel like they are hurting. For example: being unable to tolerate the way socks feel or the texture or temperature of certain foods. Sensory processing problems can also cause difficulty in finding an item when it is among a vast selection of items. For example, a child may have a hard time finding a shirt in a full dresser or finding words in a word search.
+ **SLEEP DIFFICULTIES-85%**
  Early, middle or terminal insomnia. Refusal to sleep alone or restless sleep. Periodic limb movement of sleep. REM behavior disorder.
+ **URINARY SYMPTOMS-80%**
  Enuresis (bedwetting), excessive daytime urinary frequency or accidents
+ **HYPERACTIVITY**
+ **CHOREIFORM MOVEMENTS**
  Chorea refers to involuntary movements characterized by their random, brief, and non-rhythmic character. They are often described as seeming to "flow" from one body part to another unpredictably, though they can also be confined to a single area of the body (such as the mouth area or hands). Choreic movements can often look like restlessness or fidgeting to those not familiar with them.
+ **HALLUCINATIONS**
  This includes both visual and auditory hallucinations.
+ **FIGHT OR FLIGHT RESPONSE**
+ **DILATED PUPILS**
+ **RHEUMATIC PAIN OF JOINTS**
  Is often described.

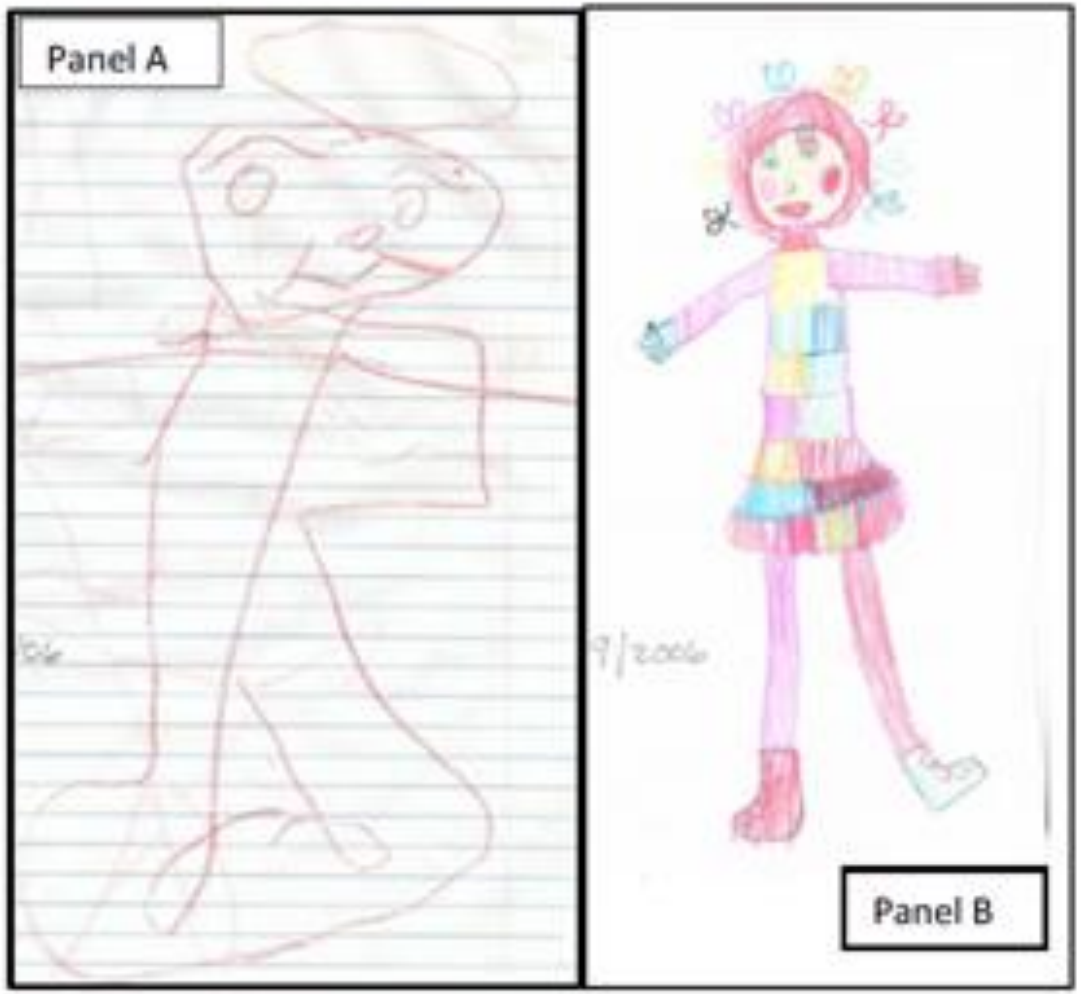
# Deterioration in Fine Motor Skills




NWPPN

nwppn.org

HTTPS://WWW.LONGDOM.ORG/OPEN-ACCESS/FROM-RESEARCH-SUBGROUP-TO-CLINICAL-SYNDROME-MODIFYING-THE-PANDAS-CRITERIA-TO-DESCRIBE-PANS-PEDIATRIC-ACUTE-ONSET-NEUROPSYCHIATR.PDF




Panel A– Drawing produced during an acute exacerbation of OCD and other symptoms of PANDAS which appears quite messy and immature.

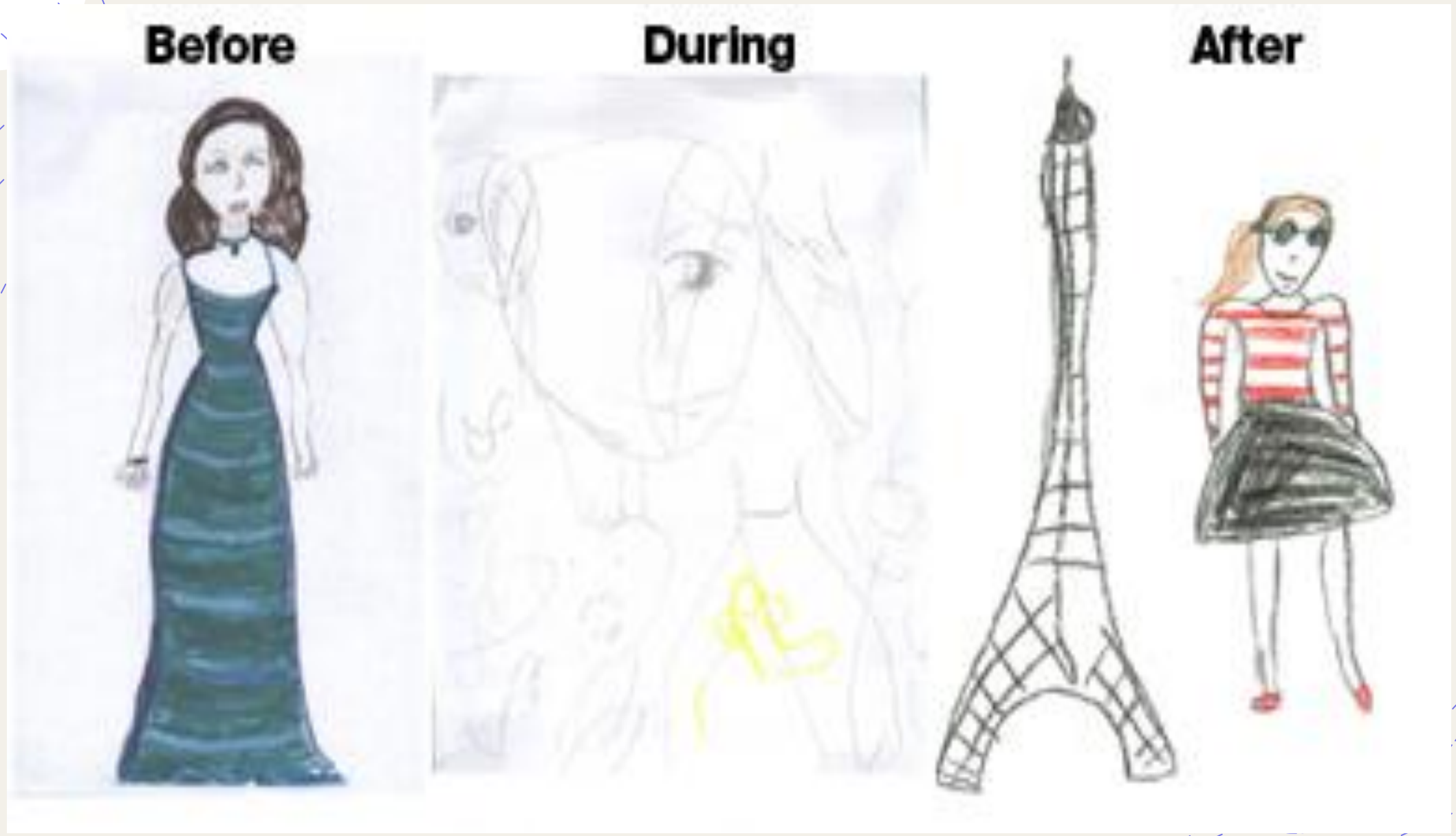
Panel B – Age-appropriate picture drawn after treatment with IVIG and symptomatic improvement.

NWPPN

nwppn.org

HTTPS://WWW.LONGDOM.ORG/OPEN-ACCESS/FROM-RESEARCH-SUBGROUP-TO-CLINICAL-SYNDROME-MODIFYING-THE-PANDAS-CRITERIA-TO-DESCRIBE-PANS-PEDIATRIC-ACUTE-ONSET-NEUROPSYCHIATR.PDF

SL

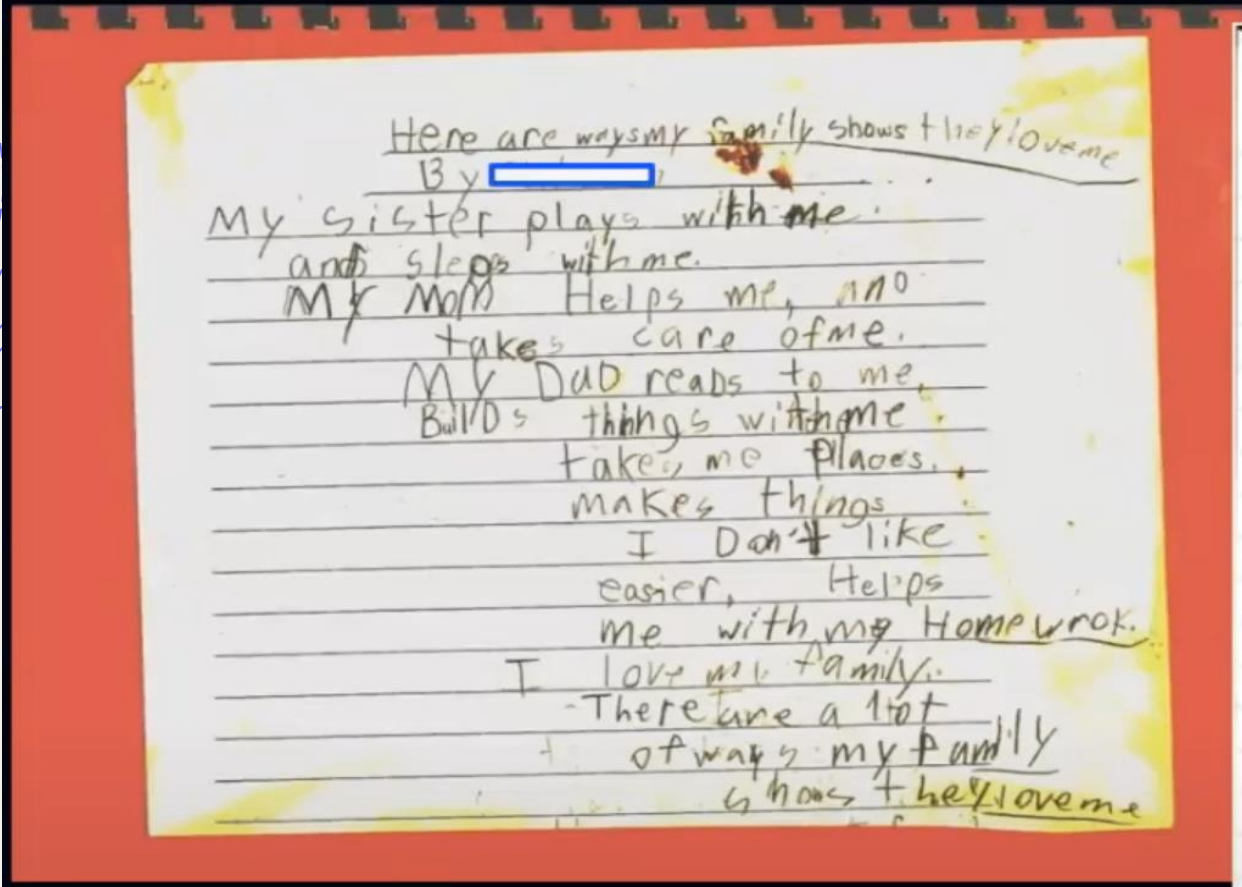


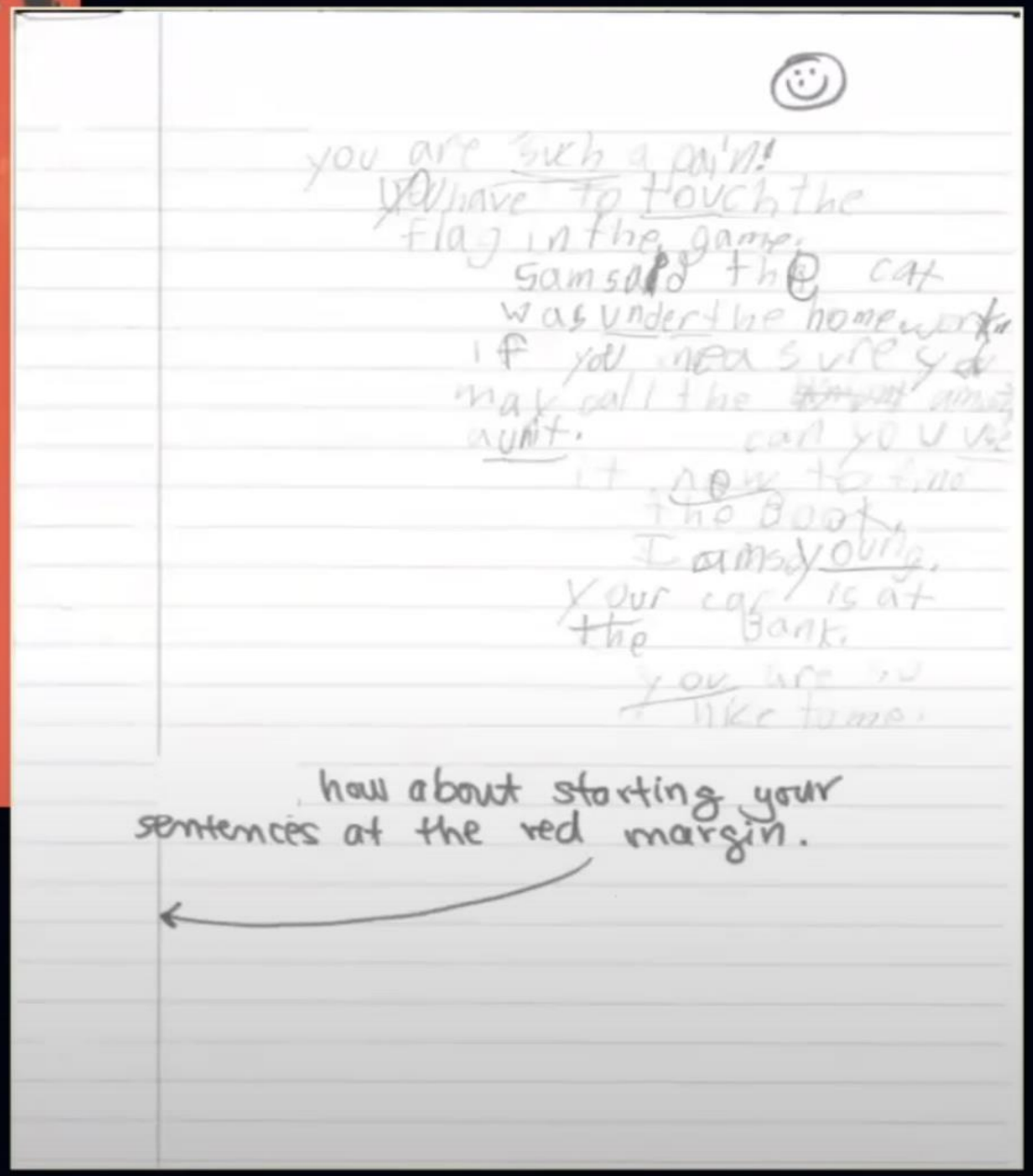

NWPPN

nwppn.org

HTTPS://WWW.LONGDOM.ORG/OPEN-ACCESS/FROM-RESEARCH-SUBGROUP-TO-CLINICAL-SYNDROME-MODIFYING-THE-PANDAS-CRITERIA-TO-DESCRIBE-PANS-PEDIATRIC-ACUTE-ONSET-NEUROPSYCHIATR.PDF

# Unusual Margin Drift




Late March 2008

# CHOREA

# PREVALENCE, ONSET AND RISK FACTORS

- PREVALENCE
  - Estimates differ with the highest thus far being **1 in 200 children** in the U.S. alone experience PANDAS/PANS. However, the true lifetime prevalence of PANDAS/PANS is not known because the disease is still misunderstood and underdiagnosed
  - Boys outnumber girls 2.6 to 1
- ONSET
  - Average age of onset is between the ages of 3 and 13, but onset can happen in children younger than three years old and older than thirteen and into adulthood.
- FAMILY HISTORY
  - 70% of PANDAS families a have a history of autoimmune or strep related illness.

# Barriers to diagnosis

+ Most medical providers are not PANDAS/PANS literate-medical education does not cover the diagnosis.
+ Medical providers misunderstanding that strep is required for a diagnosis.
+ Overall lack of awareness, **considered rare** despite prevalence being conservatively estimated at **1 in 200**, in line with juvenile diabetes and cancer.
+ Lag within the medical community about the disorder despite NIMH, NIH, CDC, World Health Organization and JCAP guidelines. AAP recognized in Dec 24.
+ Research is evolving quickly.
+ Clinical diagnosis, no clear marker (YET).
+ Symptoms can remit and relapse as exposed so clinical picture is always changing.
+ PANDAS/PANS providers are typically only private pay and do not accept insurance.
+ Misdiagnosis is common as most symptoms present as psychiatric or movement based.

NWPPN

nwppn.org

KM

# Family Burden

- Inability to find a PANDAS/PANS knowledgeable provider
- Health inequity as far a who can obtain care
- Sibling impact
- Marriage failure
- Navigate special education services
- Insurance denials and appeal process
- Financial ramifications
  - Cost to access care
  - Lost family revenue with caregiver requirement
- Child Protective Services/Justice System
- Trauma/PTSD
- Loss of community  (Including family)

NWPPN

nwppn.org

# Caregiver Burden Index

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

**37** Median CBI during first PANS/PANDAS flare = 37

**50%** Stanford PANS Clinic - 50% of families, during first flare,exceed score to determine need for respite

**-3.5** CBI score predicted to decrease each year family is in an established clinic = -3.5 points per year; 95% CI, -2.4 to -4.6

**+.7** CBI mean score predicted to improve in families with shorter time between PANS onset & entry into multidisciplinary clinic = .7 points per year squared; 95% CI, 0.1 to 1.3

Higher CBI than in Alzheimer's

Equal to CBI in Rett Syndrome

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

# Emergency Room Experiences

- "We are considering taking our son to ER for safety issues getting worse. Any recommendations in pdx. He's on Xanax and it was helping but starting to see rage again"
- "Last week I took my daughter to the ER for the third time that week. I went with multiple bags-ready to move in".
- "Been at ***** for 3 days. Mri, ekg, lumbar puncture, bloodwork. Psych just came in and said i have an hour to decide if i want them to refer to **** in oregon city. If not we go home. Its the same doc we saw in ER before who already said its just OCD".
- "We are at the ER and the triage nurse had never heard of PANDAS. Sigh…."
- "We ended up going to the ER so many times for anger/rage and he ended up going to 2 different residential treatment centers".
- "In my son's case, he was six years old and he was in the **** pediatric emergency room for 6 days and nights. They continued to say it couldn't be PANS PANDAS"
- "My 11 year old PANDA destroyed her classroom today and was violent with her teachers and to herself. She was screaming to kill her. They called an ambulance and we are now in ER".
- "My son had strep and his initial onset of PANDAS with every single symptom and severe abrupt onset OCD, out of nowhere rage/aggression and he was losing his mind...he had an active fever and my husband and I had been dx with strep two weeks prior. The *** ED doc completely failed us and called it a behavior issue and it was only weeks later when we did a blood draw and saw the sky high ASO level that we finally were suggested to meet with a PANDAS specialist".

PANS PANDAS UK

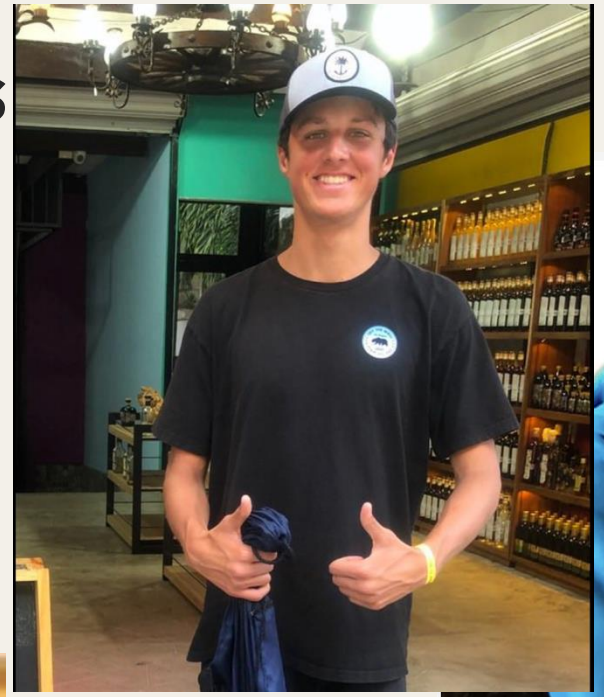
awareness support education

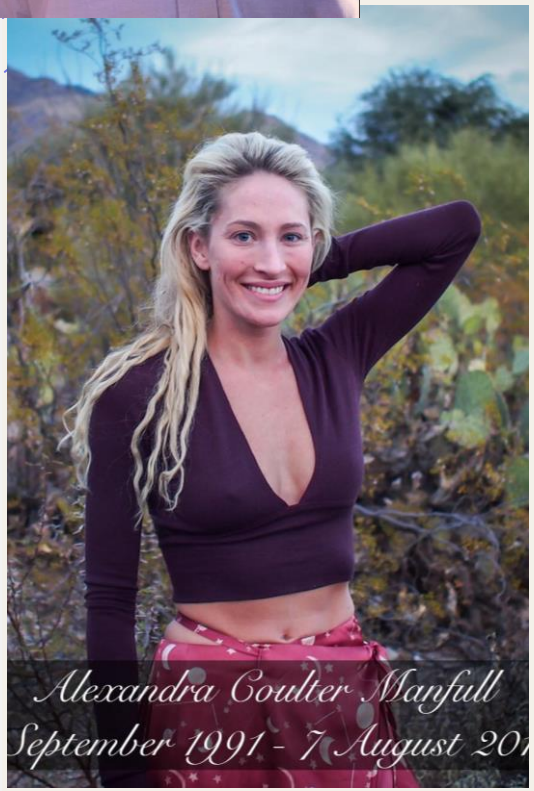
0:00 / 1:24

# Ultimate Price of Misdiagnosis

"I want everyone to know we lack providers," says Max's mom, a health care provider. "We lack AWARENESS, and we lack COOPERATION from our pediatricians.

I want families to know we can no longer take 'no' for an answer from our doctors."






**“The findings suggest that the function of CD3+**
**astrogliosis (**Astorcytes are glial cells and cont

**is critical in understanding the pathogenesis/p**
**therapeutic treatments in autoimmune disorder**

# Rural Health Providers can Diagnose and Treat PANDAS/PANS


NWPPN
nwppn.org

KM

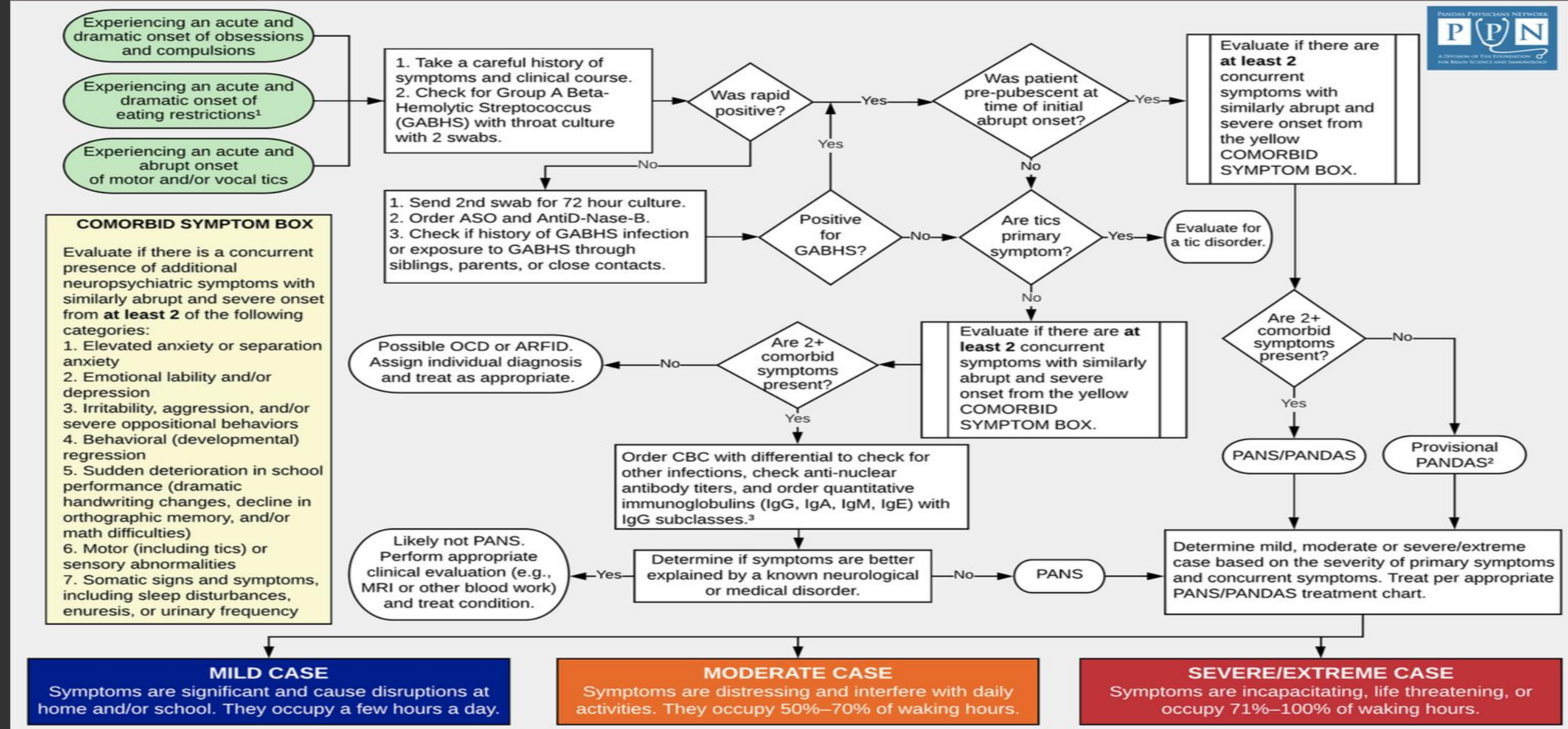
# Published Treatment Guidelines (2017, 2020) Based on Severity


- ANTIBIOTICS
- ANTIVIRALS
- ANTIINFLAMMATORIES
- STEROIDS
- TONSILLECTOMY
- IVIG - High Dose Intravenous Immune Globulin infusion (10-20%)
- PLASMAPHERESIS - filtering out the bad plasma and replacing with new plasma, full of new antibodies to stop the misdirected immune response.
- RITUXAN
- In conjunction with above treatments:
  - COGNITIVE BEHAVIORAL THERAPY-if severity allows for behavioral intervention
  - SSRIs- **low dose and slow titration,** 1/4th or less of that used for a typical child

NWPPN
nwppn.org

# PANS/PANDAS Diagnostic Flowchart

SL




¹ If your patient is experiencing severe restrictive eating and/or ARFID (Avoidant/Restrictive Food Intake Disorder), determine if hospitalization is needed due to dramatic weight loss or if intravenous hydration is required.
² An official diagnosis of PANDAS includes an episodic course; however delaying treatment until a second onset is not recommended.
³ PANS does not exclude the possibility that the patient has or had strep. Approximately 35% of pediatric patients will not generate ASO or Anti-DnaseB titers and therefore can be a false negative for strep (Chet 2003). Throat cultures are only reliable to the extent of the rigor and approach of the practitioner and both vary greatly.



Published 15 Dec 2020 | Version 1

# MILD CASE


Treatment Guidelines for Mild Cases

Children with mild symptoms have obvious impairments as a result of their PANS/PANDAS symptomatology, but these are limited to certain situations or settings. For example, the child might need a parent to stay while falling asleep, but able to attend school or go to a friend's house (perhaps with frequent phone calls for reassurance). The symptoms may occupy a few hours a day and may cause minor disruptions at home and in school, but these are manageable with reasonable accommodations. Overall symptom severity is in the "troubled but tolerable" range.

Treatment of mild illness may include: antibiotics, corticosteroids, anti-inflammatories, and CBT/ERP.

An initial 2 week course of treatment dose of antibiotics should be prescribed while waiting for lab results. If the patient has 2+ recurrences, prophylactic antibiotics may be considered.

Anti-inflammatories may be beneficial. Oral nonsteroidal anti-inflammatory drugs (NSAIDs) such as ibuprofen or naproxen may be considered. A 5 day oral corticosteroid bursts may hasten recovery and minimize residual symptoms.

IVIG and plasmapheresis are not deemed appropriate treatments for children with mild symptoms. Both IVIG and plasmapheresis are "invasive" procedures which carry a number of associated risks. (Please see PPN Treatment Options: IVIG).

Visit the PANS/PANDAS Treatment Guidelines for Mild Cases for a more detailed review.

# MODERATE CASE


## Treatment Guidelines for Moderate Cases

Children with moderate symptoms of PANS/PANDAS have symptoms that are distressing and interfere with daily activities. They occupy 50%–70% of waking hours. The rituals or separation anxiety may prevent the child from attending school, but would be able to go to visit grandparents (if parent is along) or have friends come over for brief periods. The ancillary symptoms are similarly impairing, but do not incapacitate the child.

Clinicians should consider an initial 3-4 week course of antibiotics. Depending on the course of the illness, a treatment dose of antibiotics may be extended to 6 weeks.

Corticosteroids and NSAIDs may be beneficial, especially when implemented in the earlier stages of symptom onset. A positive response to steroids is a good indication that IVIG therapy will be helpful; however, a tepid response is not a predictor of IVIG failure. Depending on the course of the illness, moderate cases may benefit from 30 days of prednisone with taper.

Immunomodulatory therapy is justified in moderate cases to relieve suffering and hasten recovery. Intravenous immunoglobulin (IVIG) is likely to be the preferred therapy for moderate cases.

Prophylactic antibiotics are often useful in the management of PANS/PANDAS, as they help to prevent strep-triggered exacerbations.

Cognitive behavior therapy should be started as soon as the child can tolerate it. In the interim, the child and parent should receive supportive therapy, including education

# SEVERE CASE


## Treatment Guidelines for Severe Cases

Extremely severe cases are defined as those in which the symptoms are incapacitating, life threatening, or occupy 71%–100% of waking hours. For example, children with significant weight loss (>10-15% of body mass) due to anorexia or obsessional food/eating restrictions related to fear of contamination, fear of choking or vomiting and others; children with extreme impulsivity (and behavioral regression), such as the child who attempts to jump off a roof because they think they can fly; or children with suicidal ideation or self-injurious behavior, e.g., trying to jump from a moving car or threatening self or others with knives or fire. In these cases, the child's health and well-being is threatened by the PANS/PANDAS symptoms and aggressive treatment is warranted.

Children with severe symptoms of PANS/PANDAS are suffering from extreme anxiety (separation or generalized) and obsessional fears. The OCD symptoms prevent the child from attending school, playing with friends/alone, and accomplishing tasks, such as showering or toileting. Because of the separation anxiety, the child is reluctant to leave the house and sticks closely to parents – following them into the bathroom and insisting on sleeping in the parents' bed (or having the parent sleep in his). In addition to the OCD and anxiety symptoms, the child may have extreme irritability, increased aggression and emotional lability, and a dramatic personality change.

The treatment options listed for moderate illness may be considered for patients experiencing a severe/extreme form of PANDAS/PANS. Treatment for severe/extreme cases may be addressed more aggressively due to severity of symptoms. In addition, plasmapheresis might be the first-line treatment for severe illness because it has been shown to produce the greatest degree of symptom improvement over the shortest

# PANS/PANDAS Treatment Guidelines: Severe/Extreme Case

**Severe/Extreme: Symptoms are incapacitating, life threatening, or occupy 71%–100% of waking hours.**

## Initial evaluation and treatment

1. Perform comprehensive laboratory and clinical evaluation.
   a. Look for infections (Throat swab/culture child and family members for strep, check for exposure to Group A Streptococcus through close contacts, inquire about perianal redness or itching which may indicate perianal strep, and check for mycoplasma or other infections, e.g., yeast).
   b. Order additional laboratory testing to rule out other conditions and guide treatment.
   c. For patients experiencing ARFID (Avoidant/Restrictive Food Intake Disorder), evaluate to determine if hospitalization is needed due to dramatic weight loss or if intravenous hydration is required.
2. Prescribe a prednisone burst[3] or a 5-7 day course of NSAIDs at immunomodulatory dose.[2] (see resource page)
3. Begin scheduling for IVIG (1.5-2g/kg over 2 days).
4. Prescribe antibiotics (Penicillin/amoxicillin,[1] azithromycin, cefdinir, Augmentin, or others). Consider an initial 3-4 week course.
5. Consider a referral with a psychiatrist to help with symptom management.
6. Schedule telephone check-in and schedule a follow-up visit.

## Phone check-in

**Monitor progress approximately 5 days after initial evaluation via a phone check-in.**

**If significant improvement:**
1. Ensure the family has access to CBT/ERP. If the child is not able to engage in CBT/ERP due to the severity of symptoms, learning parent management techniques may be beneficial for the family.
2. Confirm a follow-up visit is scheduled.

**If no improvement at phone check-in:**
1. Consider prolonged steroids (30 days) with taper.[3] Continue antibiotics while the patient is taking steroids. (see resource page)
2. Consider switching antibiotics (to azithromycin, cefdinir, or Augmentin).
3. Refer patient to ENT for evaluation of tonsils and adenoids.
4. Consider proceeding with IVIG treatment (1.5-2g/kg over 2 days).
5. Based on the situation/safety, consider inpatient hospitalization or a center specializing in neuroimmune disorders.
6. Confirm a follow-up visit is scheduled.

## Follow-up assessment

**If significant improvement:**
1. Consider long-term prophylactic antibiotics[1]. (see resource page)
2. If NSAIDs were prescribed, continue at immunomodulatory dose for a total of 6-8 weeks.[2] (A Proton Pump Inhibitor (PPI), such as omeprazole, lansoprazole, pantoprazole, or oresomeprazole, should be considered at prescribed dosages throughout the course of NSAIDs to prevent GI complications.) (see resource page)
3. If improved, but not back to baseline, schedule IVIG (1.5-2g/kg over 2 days) and follow-up visit at 30 days. Continue a treatment dose of antibiotics until IVIG treatment is completed. Prescribe prophylactic antibiotics post IVIG treatment.[1] (see resource page)

**If no improvement:**
1. Change antibiotic (to azithromycin, cefdinir, or Augmentin). Total duration of antibiotic treatment is at least 30 days.
2. Check for sinusitis and consider a perianal strep swab.
3. Prescribe prolonged steroid (30 days) with taper.[3] Continue antibiotics while the patient is taking steroids. (see resource page)
4. Consider checking antinuclear antibody titers, cross-reactive antineuronal antibodies, and CaM Kinase II activation.[4] (see resource page)
5. Based on situation/safety refer for inpatient help or a center specializing in neuroimmune disorders.
6. Schedule IVIG (1.5-2g/kg over 2 days) and follow-up visit at 30 days. Continue a treatment dose of antibiotics until IVIG treatment is completed. Prescribe prophylactic antibiotics post IVIG treatment.[1] (see resource page)

# PANS/PANDAS Treatment Guidelines: Mild Case

**Mild: Symptoms are significant and cause disruptions at home and/or school. They occupy a few hours a day.**

## Initial evaluation and treatment

1. Perform a comprehensive laboratory and clinical evaluation.
2. Look for infections (Throat swab/culture child and family members for strep, check for exposure to Group A Streptococcus through close contacts, inquire about perianal redness or itching which may indicate perianal strep, and check for mycoplasma or other infections, e.g., yeast).
3. While waiting for lab results:
   a. Prescribe 14 days of antibiotics (Penicillin/amoxicillin,[1] azithromycin, cefdinir, Augmentin, or others).
   b. Consider a 5-7 day course of NSAIDs at immunomodulatory dose for 24 hour coverage.[2] (see resource page)
   c. Ensure the family has access to CBT/ERP (Cognitive Behavior Therapy/Exposure and Response Prevention) and parent support.
4. Schedule a follow up appointment.

## First follow-up assessment

**If significant improvement:**
1. No further intervention is needed at this time.
2. Schedule a follow-up appointment within 30 days (or earlier if symptoms return).

**If no improvement:**
1. Look again for infection (i.e., swab/culture child and family members, check for mycoplasma or other infections).
2. Check for sinusitis and consider a perianal strep swab.
3. Consider changing antibiotic (change to azithromycin, cefdinir, or Augmentin).
4. Consider a 5 day prednisone burst[3] or extend course of immunomodulatory dose of a NSAID.[2] (see resource page)
5. Ensure the family has access to CBT/ERP. If the child is not able to engage in CBT/ERP due to the severity of symptoms, learning parent management techniques may be beneficial for the family.
6. Consider a referral with a psychiatrist to help with symptom management.
7. Schedule a follow-up appointment.

## Second follow-up assessment

**If there was significant improvement between visits, but active symptoms:**
1. Recheck for active infection and exposure from siblings, parents, and close contacts.
2. Restart antibiotics for 14 days and schedule a follow up appointment.
3. If child has 2+ recurrences, consider prophylactic antibiotics.[1] (see resource page)

**If no improvement:**
1. Consider a 5 day prednisone burst[3] or extend course of immunomodulatory dose of a NSAID.[2] (see resource page)

# PANS/PANDAS Treatment Guidelines: Moderate Case

**Moderate: Symptoms are distressing and interfere with daily activities. They occupy 50%–70% of waking hours.**

## Initial evaluation and treatment

1. Perform comprehensive laboratory and clinical evaluation.
2. Look for infections (Throat swab/culture child and family members for strep, check for exposure to Group A Streptococcus through close contacts, inquire about perianal redness or itching which may indicate perianal strep, and check for mycoplasma or other infections, e.g., yeast).
3. Perform additional laboratory testing to rule out other conditions and guide treatment.
4. While waiting for lab results:
   a. Prescribe antibiotics (Penicillin/amoxicillin,[1] azithromycin, cefdinir, Augmentin, or others). Consider an initial 3-4 week course.
   b. Prescribe a prednisone burst[3] or a 5-7 day course of NSAIDs at immunomodulatory dose.[2] (see resource page)
   c. Ensure the family has access to CBT/ERP. If the child is not able to engage in CBT/ERP due to the severity of symptoms, learning parent management techniques may be beneficial for the family.
   d. Consider a referral with a psychiatrist to help with symptom management.
5. Schedule a follow-up appointment.

## First follow-up assessment

**If significant improvement:**
1. Schedule another follow-up appointment and monitor for recurrence.

**If no improvement:**
1. Prescribe alternate antibiotic (change to azithromycin, cefdinir, or Augmentin).
2. Check for sinusitis and consider a perianal strep swab.
3. If not tried, prescribe a 5 day prednisone burst[3] or 6 weeks of a NSAID at immunomodulatory dose.[2] (see resource page)
4. Consider MRI and EEG study.
5. Consider checking antinuclear antibody titers, cross-reactive antineuronal antibodies, and CaM Kinase II activation.[4] (see resource page)
6. Schedule a follow-up appointment.

## Second follow-up assessment

**If no current symptoms:**
1. Continue to monitor for subsequent exacerbations.
2. Advise parents to continue with CBT/ERP.
3. If child has 2+ recurrences, consider prophylactic antibiotics.[1] (see resource page)

**If active symptoms, but significant improvement between visits:**

# Evaluation

Thorough & Appropriate Medical Care

## Psychosocial Evaluations

### History of Present Illness

Chronology of current symptoms, then go back further.

### Past Medical History

Infections, illnesses, allergies, toxic exposures, mold exposures, tick exposures, recurrent rashes, gastrointestinal symptoms, urinary symptoms.

### Past Neuropsychiatric History

Developmental changes, behavior, learning challenges, mood disorders, ADHD.

### Family History

Autoimmune disorders, recurrent infections, adenotonsillar hypertrophy, psychiatric disorders

### Chart review

ER visits, Urgent Care, Etc.

# Evaluation

**Mental Status Examination**

Assess for suicidal/homicidal ideation

**Restricted Eating**

Checking orthostatic vital signs, EKG, and electrolytes, including phosphorus and magnesium and monitoring for refeeding syndrome.

**Additional Studies**

Imaging – head MRI, PET Scan

EEG

Lumbar puncture

# Medical Evaluation

## Laboratory evaluation

Labs are meant to:

- Rule out disorders that can similarly present with neuropsychiatric symptoms
  - ANA, TSH/FT4, Thyroid antibodies, celiac screen
- Evaluate for infectious triggers
  - Throat culture, NP culture, ASO titer, DNAse B titer, Mycoplasma IgM/IgG, C. Pneumonia IgM/IgG, Lyme western blot (and other tick-borne pathogens), Candida IgA/IgM/IgG, Sars-CoV2 IgM/IgG, EBV titers, CMV titers, Coxsackie A/B, HH-6, Mold toxins
- Evaluate for inflammation and immune dysregulation –
  - CRP, ESR, Ferritin, Immunoglobulin levels, Immunoglobulin G subclasses, Cunningham Panel
- Assess functional and nutritional status
  - CBC, CMP, Vitamin D, B12, Folate, Mg, Zinc, B6, urine organic acids, serum amino acids

# Mental Status Examination

- During acute episode, child may appear
  - Hyperalert
  - Anxious
  - "Terror-stricken look" during first days of illness
  - Memory impairment
    - Child often cannot recall details of symptoms or impact on functioning
  - Emotionally labile
  - Uncontrollable laughing or crying that is mood incongruent
  - Depression during later stages (affect is depressed or flat)
  - Temper tantrums/rage
  - Speech is "baby talk", selective mutism, new-onset stuttering
- Fearful of expressing the content of OCD thoughts (often violent or sexual in nature)



HTTPS://WWW.NCBI.NLM.NIH.GOV/PMC/ARTICLES/PMC4340805/

# Safety Assessment of the Child with PANDAS/PANS

SL

- Self-injurious thoughts and bx
  - Particularly worrisome with developmental regression and increased impulsivity
  - Children with PANS have made attempts at jumping out of a moving car or a second story window
- Particular attention should be paid to symptoms that pose a risk to the child or family
  - Impulsivity, physical violence or aggression, refusal to eat or drink, and suicidality
  - If found, they should be immediately addressed with appropriate environmental, educational, and pharmacological measures.
- Crisis management in PANS/PANDAS is similar to that of other disorders presenting risk of self-harm

NWPPN

nwppn.org

HTTPS://WWW.NCBI.NLM.NIH.GOV/PMC/ARTICLES/PMC5610394/

# What does the science tell us?

+ Repetitive Strep Infections → Blood-Brain Barrier Breakdown (Columbia)
+ Blood-Brain Breakdown → Autoantibodies attack basal ganglia & striatum (Harvard)
+ Stanford and Harvard MRI Study → Inflammation in brain
+ Basal Ganglia Controls → Speech, involuntary movement (tics) and emotion
+ Immunomodulation → Significant symptom reduction (Multiple studies)
+ Other Infections, including COVID trigger PANS (Lancet, May 2021)

NWPPN

nwppn.org

HARVARD UNIVERSITY

# MRI Research-Brain Inflammation Confirmed

- Research being led by Dr. Kyle Williams at Massachusetts General Hospital.
- Thirty PANDAS patients and healthy controls involved in a **novel MRI method** were scanned via MRI.
- Preliminary findings indicate that children with PANDAS have **larger areas of inflammation within the BASAL GANGLIA** when compared to healthy control children. These structures have been found to be abnormally large in previous studies of children and adults with OCD.
- In addition, some neuronal structural changes were discovered and thought to be due to **inflammatory processes**.
- The correlation of **inflammation appears to occur with OCD symptom severity**.

NWPPN

nwppn.org

Stanford University

# MRI Brain Scans Confirm Abnormalities indicating Inflammation (May, 2020)

NIH

- Case control study of 34 PANS children and a control group of 64 without.
- Used 3 Tesla magnetic resonance imaging
- **PANS children had "statistically significant" increased mean diffusivity particularly the deep gray matter** (eg, the thalamus, basal ganglia, and amygdala).
- These diffusion abnormalities are consistent with the cardinal clinical symptoms of these patients, including obsessions, compulsions, emotional dysregulation, and sleep disturbances.
- Further study of MRI is warranted as a potential quantitative method for assessing patients under evaluation for PANS.

JAMA journal article

NWPPN

nwppn.org

# Antibody Marker Identified Yale (June, 2020)

- 27 children who met the strictest criteria for a PANDAS diagnosis and 23 control subjects.
- **IgG antibodies** from children with PANDAS **bind to cholinergic interneurons (CINs) in the striatum** (an area of the brain that is associated with voluntary motor control, among other functions, and is known to be involved in OCD).
- **Post-IVIG serum had reduced IgG binding to CINs, and this reduction correlated with symptom improvement.**


NWPPN

nwppn.org

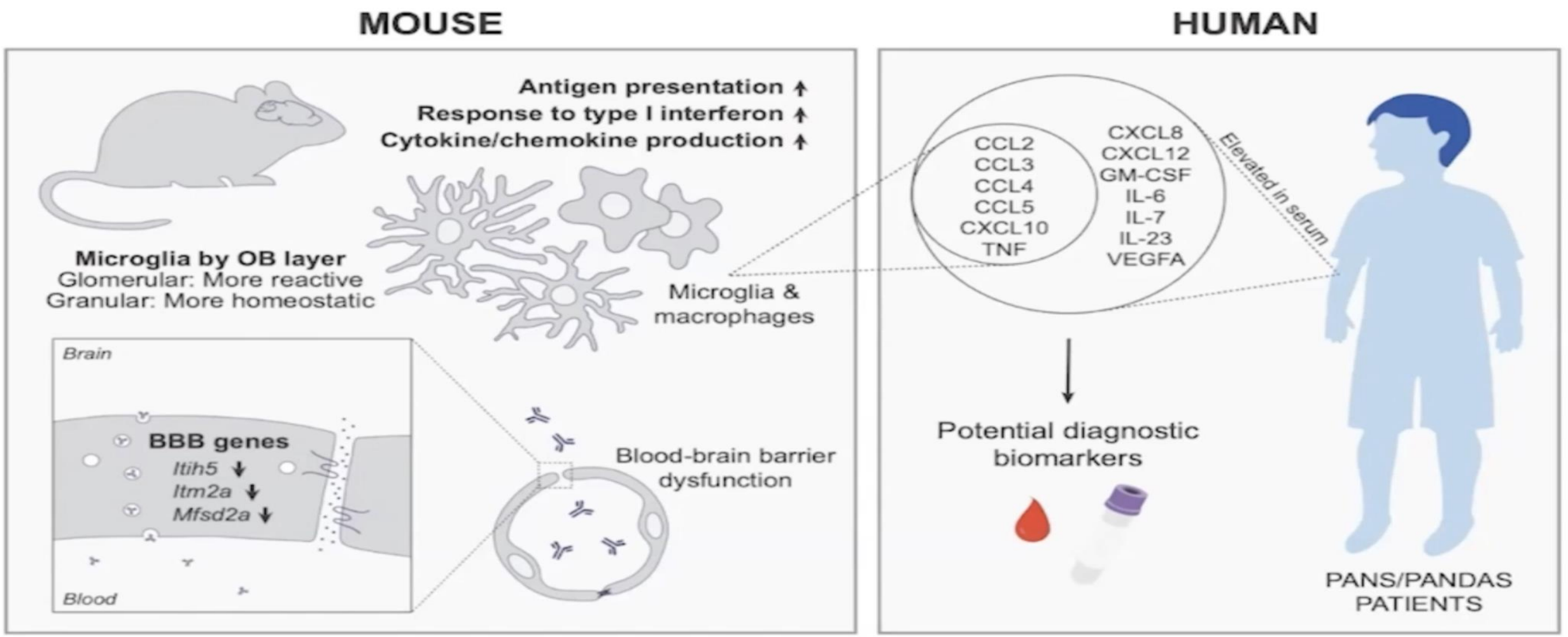
# Elevated antibody binding to striatal cholinergic interneurons in PANS (November, 2024)


- PANS IgG drawn at flare shows elevated binding to CINs in both mouse and human brain.
- Elevated IgG binding to CINs is resolved in the same subject during symptom recovery.
- Reduction of PANS IgG binding to CINs parallels symptom improvement during recovery.
- IgG binding to striatal CINs contributes to the pathophysiology of PANS.

NWPPN

nwppn.org

# Several microglial/macrophage-derived chemokines are elevated in patient sera




COLUMBIA | COLUMBIA UNIVERSITY DEPARTMENT OF NEUROLOGY

Wayne *et al.* (2023). BioRxiv doi.org/10.1 3.03.10.532135

Screenshot

# Dopamine receptor autoantibody as biomarker-JCI 2024

JCI The Journal of Clinical Investigation

The UNIVERSITY of OKLAHOMA

- 4 cohorts of patients
- Across all cohorts, **D1R AAb titers effectively discriminated PANDAS from healthy controls, confirming their role as biomarkers for PANDAS**, the tic, and OCD immunophenotype of BGE
- Identified D1R as a biomarker for PANDAS/PANS and D2R as a biomarker for SC or PANDAS with choreatic movements
- Disorders associated with GAS sequelae present as a dopamine receptor encephalitis triggered by the predominance of pathogenic autoreactive D1R and or D2R AAbs

NWPPN

nwppn.org

octapharma

# PANS Phase 3 IVIG Study-2025

- Randomized, double-blind, parallel group, crossover, placebo-controlled
- 71 patients, ages 6 to 17 with a confirmed diagnosis of moderate to severe PANS
- IVIG given every 3 weeks for first 9 weeks to IVIG group, then every 3 weeks through week 18 to placebo group
- Measurements utilized; CY-BOCS and Clinical Global Impression (CGI) at weeks 9 and 18.
- CY-BOCS score at week 9 improved in the IVIG group as compared to the placebo group but was not "statistically significant"
- Clinical Global Impression (CGI-I) score at week 9 **was statistically significant** between both groups with a higher improvement in the IVIG group.
- At week 9, placebo group received IVIG through week 18 while the original IVIG group received placebo.

CY-BOCS in both treatment arms **continued to improve through week 18**. The CY- BOCS score improvement was more prominent in the participant group that initially received PANZYGA® until week 9.

NWPPN

nwppn.org

KM

# Post-Infectious Autoimmune Encephalopathy Clinics

+Treating

+Researching

+Educating

- Stanford University
- Harvard University
- Dartmouth University
- UCLA
- University of Arizona
- Banner Children's
- University of Wisconsin
- University of Arkansas
- Greater Regional Health Center-Iowa

HARVARD COLLEGE

Dartmouth Health Children's

Stanford MEDICINE Children's Health

UCLA Health

THE UNIVERSITY OF ARIZONA

Children's Postinfectious Autoimmune Encephalopathy Center

UAMS Health

UW Health University of Wisconsin Hospital and Clinics

NWPPN nwppn.org

Banner Health

SL

# Northwest PANDAS/PANS Network

## Serving Oregon, Washington, Idaho and Alaska-est. 2019

- BOD includes a child psychiatrist at Seattle Children's, child psychiatrist in private practice in Oregon, PMHNP, DNP-FNP, 3 PANS parents and a youth ambassador
- **Support families** who are suspecting this diagnosis
- Maintain a list of **knowledgeable PANDAS/PANS providers** (Primary care, Neurology, ENTs, Behavioral Health)
- **Equip local clinicians** with education, tools, consults, etc.
- **Grant program** for those in financial need
- **Provide education** via 1:1 webinars for providers, practices, community groups/organizations, conferences
- Advocate at the state level for **recognition and access to treatment** for ALL children

NWPPN

nwppn.org

KM

# Northwest PANDAS/PANS Network POLICY & LEGISLATION-OREGON

- 2019
  - Oregon passed a permanent awareness day bill.
  - HB 2511, Insurance mandate bill was defeated by insurance lobbyists.
- 2021
  - Introduced HB 2390 requiring Oregon insurers to provide insurance coverage to children requiring IVIG.
  - Defeated by insurance lobbyists.
- 2022
  - Oregon Health Authority has their Health Evidence Review Commission conduct a robust review of evidence for IVIG coverage and concludes with access to IVIG for children on Medicaid.
- 2023
  - Re-introduce and PASSED an insurance ‘pay parity’ bill for Oregon insurers to align with coverage recommendations made by our Oregon Health Authority.

NWPPN

nwppn.org


CalCoalition Advocates · Following

Fourteen years, every "no," every delay, every fight, and you NEVER stopped. Gabriella, you changed the map and the lives of so many families. Huge co... See more

# When to consider PANDAS/PANS

- PANDAS/PANS are **clinical diagnoses of exclusion**
- **Abrupt onset** of psychiatric symptoms, disordered eating (anorexia, ARFID) or tics
- Parents, caregivers or educators report an **abrupt change in their child** with the new onset of behaviors, psych symptoms or deterioration in school/handwriting.
- **Non-responsive** conventional psych treatment
- **Temporal association** to infection


NWPPN
nwppn.org

# Diagnostic Criteria


## PANS/PANDAS Treatment Guidelines: Mild Case

**Mild: Symptoms are significant and cause disruptions at home and/or school. They occupy a few hours a day.**

PANDAS Physicians Network
PPN
A Division of The Foundation for Brain Science and Immunology

### Initial evaluation and treatment

1. Perform a comprehensive laboratory and clinical evaluation.
2. Look for infections (Throat swab/culture child and family members for strep, check for exposure to Group A Streptococcus through close contacts, inquire about perianal redness or itching which may indicate perianal strep, and check for mycoplasma or other infections, e.g., yeast).
3. While waiting for lab results:
   a. Prescribe 14 days of antibiotics (Penicillin/amoxicillin,[1] azithromycin, cefdinir, Augmentin, or others).
   b. Consider a 5-7 day course of NSAIDs at immunomodulatory dose for 24 hour coverage.[2] (see resource page)
   c. Ensure the family has access to CBT/ERP (Cognitive Behavior Therapy/Exposure and Response Prevention) and parent support.
4. Schedule a follow up appointment.

first line treatment options in ac ating levels of symptom severity.

- This session will enable the le d barriers to care while introducing local resources tha the patient and family.

PANDAS/PANS NETWORK
NWPPN
nwppn.org

NWPPN
nwppn.org

SL


# How YOU can help.

+Be AWARE of red flags for these disorders.

+Spread AWARENESS by telling others.

+Encourage others to LEARN about these disorders.

+Have INFORMATION AVAILABLE for those suspecting these disorders.

+SHARE our contact information with others.

+Schedule a FREE presentation for your team.

IT IS VITAL TO **REFER ANY SUSPECTED PANDAS/PANS CASES TO NWPPN** AS MOST PEDIATRICIANS/FAMILY MEDICINE AND EVEN OUR LOCAL HOSPITALS ARE NOT FAMILIAR ENOUGH WITH DIAGNOSING AND TREATING.

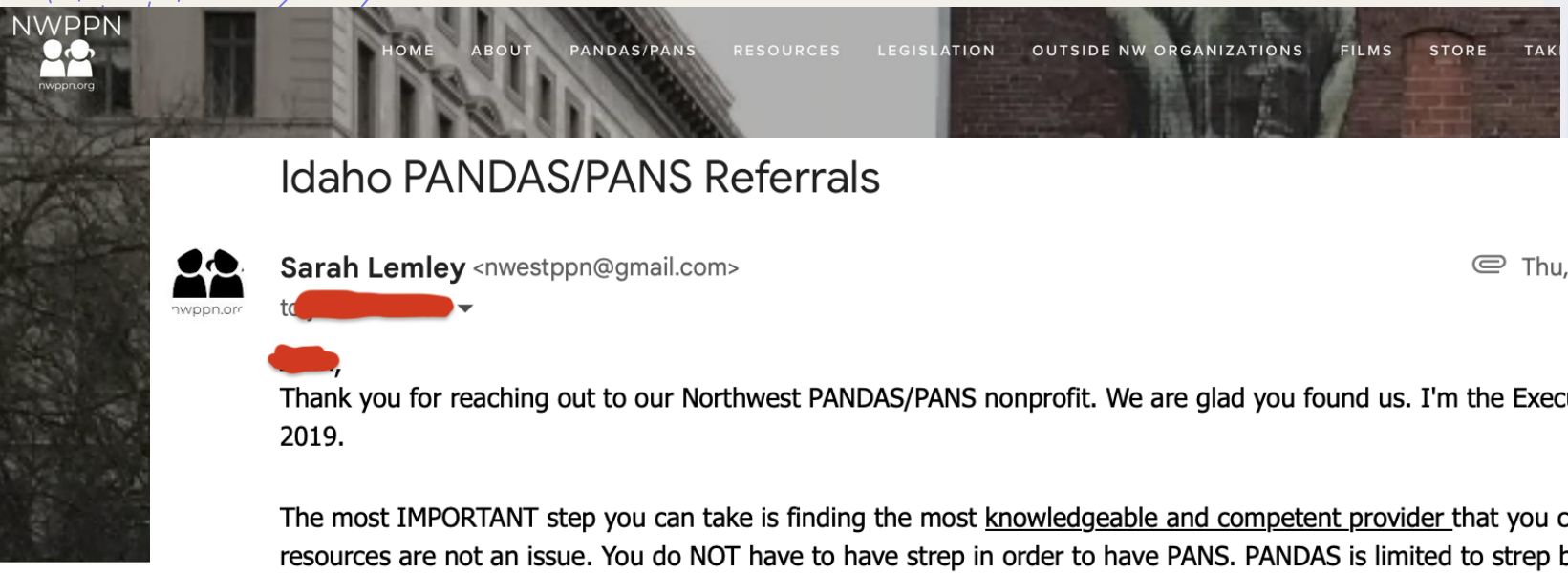
NWPPN

nwppn.org

# What to do if you suspect PANDAS/PANS

SL

NWPPN
nwppn.org




Idaho PANDAS/PANS Referrals

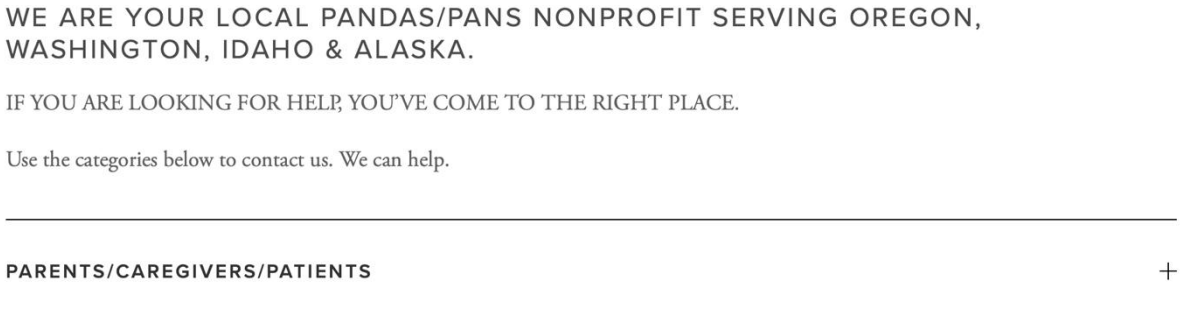
**Sarah Lemley** <nwestppn@gmail.com> Thu, Nov 20, 10:05 AM (1 day ago)

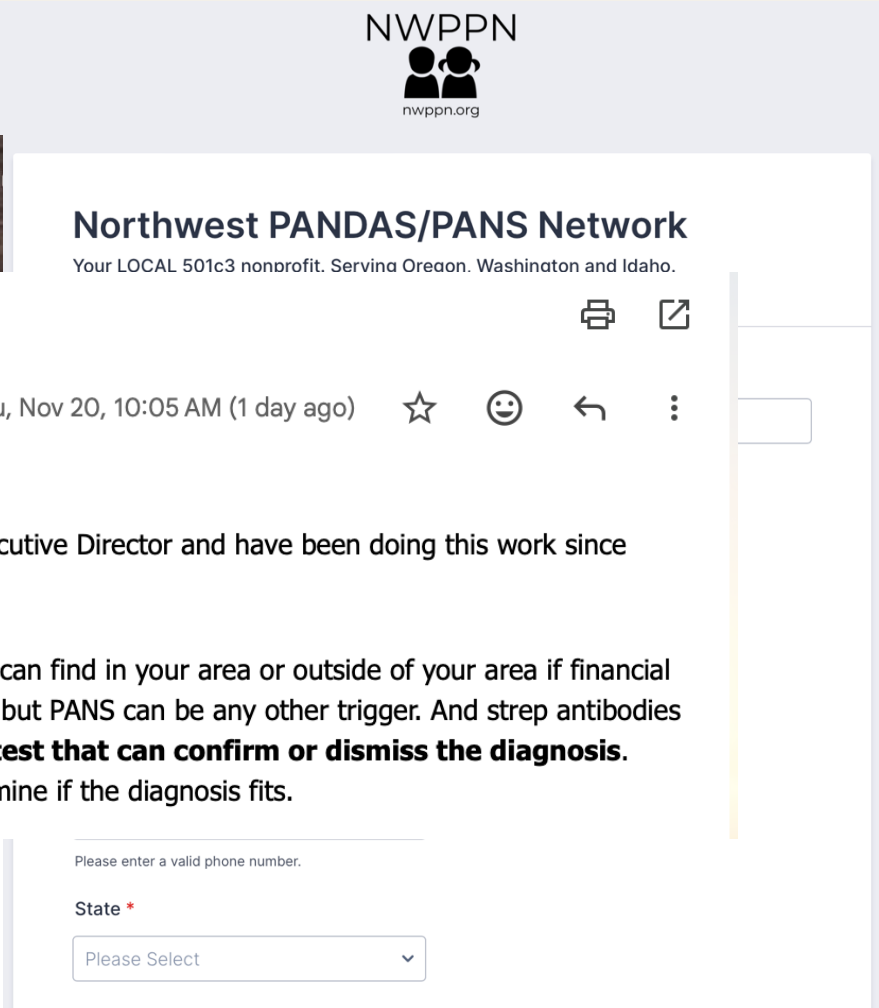
to [redacted]

[redacted],

Thank you for reaching out to our Northwest PANDAS/PANS nonprofit. We are glad you found us. I'm the Executive Director and have been doing this work since 2019.

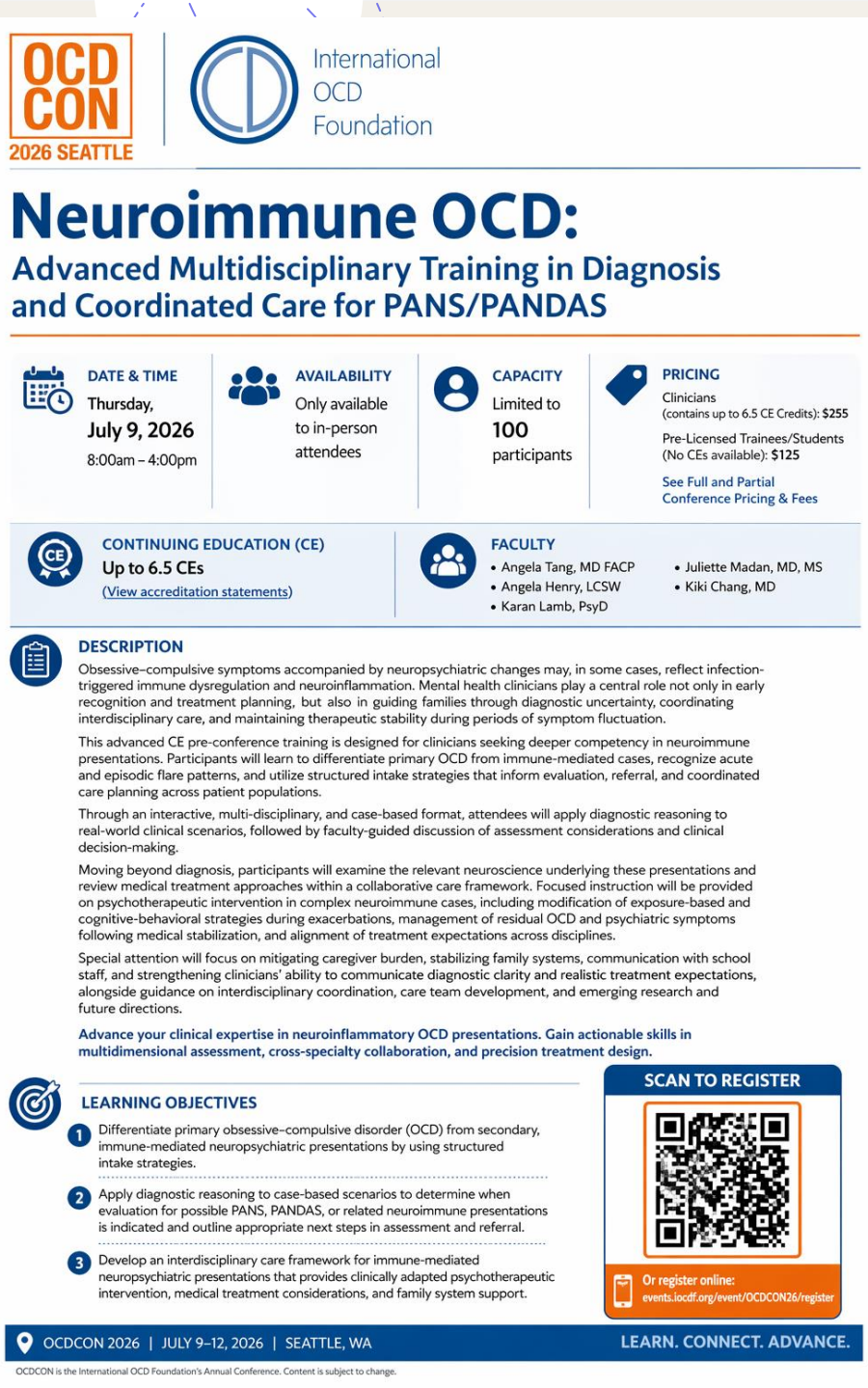
The most IMPORTANT step you can take is finding the most knowledgeable and competent provider that you can find in your area or outside of your area if financial resources are not an issue. You do NOT have to have strep in order to have PANS. PANDAS is limited to strep but PANS can be any other trigger. And strep antibodies are not always elevated when one has strep. PANDAS/PANS are clinical diagnoses meaning that **there is no test that can confirm or dismiss the diagnosis**. Instead, a knowledgeable PANDAS/PANS medical provider must use the published diagnostic criteria to determine if the diagnosis fits.




nwppn.org

**https://www.nwppn.org/**




# Neuroimmune OCD: Advanced Multidisciplinary Training in Diagnosis and Coordinated Care for PANS/PANDAS

## Continuing Education (CE)

Up to 6.5 CEs ( View accreditation statements )

## Faculty

Angela Tang, MD FACP
Angela Henry, LCSW
Karan Lamb, PsyD
Juliette Madan, MD, MS
Kiki Chang, MD

This advanced CE pre-conference training is designed for clinicians seeking deeper competency in neuroimmune presentations. Participants will learn to differentiate primary OCD from immune-mediated cases, recognize acute and episodic flare patterns, and utilize structured intake strategies that inform evaluation, referral, and coordinated care planning across patient populations.

Through an interactive, multi-disciplinary, and case-based format, attendees will apply diagnostic reasoning to real-world clinical scenarios, followed by faculty-guided discussion of assessment considerations and clinical decision-making.

DEPARTMENT OF PEDIATRICS

# Infection, Inflammation, & Mental Health- Mapping the Intersections
## VIRTUAL GRAND ROUNDS

Jennifer Frankovich, MD, MS

Clinical Associate Professor of Pediatrics-Rheumatology
Director of the Stanford PANS Research Program, Co-Director of Stanford Children's Health Immune Behavioral Health Clinic

Thursday
September 24, 2020
8:30 a.m.

VIRTUAL
WEBEX ONLINE PLATFORM:

### Learning Objectives
1. Give examples of a well-defined inflammatory disorder that can present with psychiatric symptoms.
2. Review the general approach to treating inflammation based neuropsychiatric disorders like Sydenham's Chorea, Lupus, PANS/PANDAS, etc.

### Target Audience
Department of Pediatrics and School of Medicine faculty, community pediatricians, residents and students are welcome to attend this weekly lecture to learn about pediatric topics, research and challenging clinical cases. This activity is open to the public.

### Course Objectives
Pediatric Grand Rounds are designed to discuss and evaluate evolving diagnostics and therapeutics as they relate to general and sub-specialty pediatrics, and describe community and academic resources relevant to contemporary pediatric practice. At the conclusion of this activity, participants will be able to discuss, assess and manage care of children with either normal or complex care requirements.

### Accreditation
OHSU School of Medicine is accredited by the Accreditation Council for Continuing Medical Education to provide continuing medical education for physician.

### Credit
OHSU School of Medicine designates this live activity for a maximum of 1.0 AMA PRA Category 1 Credits™. Physicians should claim only the credit commensurate with the extent of their participation in the activity.

Pediatric Grand Rounds Director Holger Link, M.D.

For questions please contact Bridget Murrieta Murrieta@ohsu.edu 503-494-2067

This presentation has been sponsored by:
Northwest PANDAS/PANS Network
www.nwppn.org

OHSU DOERNBECHER CHILDREN'S Hospital

DEPARTMENT OF PSYCHIATRY: GRAND ROUNDS

# Pediatric Acute Onset Neuropsychiatric Syndrome (PANS)

## Recognition and Treatment of an Often Overlooked Syndrome in Children

**Kiki Chang, M.D.** Psychiatrist, Private Practice; Co-Founder, Stanford PANS Clinic; former Director, Stanford Pediatric Bipolar Disorders Program and Professor of Psychiatry and Behavioral Sciences

- Consider the various neuropsychiatric symptoms of PANS and the overlap with other conditions such as Tourette's, OCD, and Depression.
- Identify different possible etiologies of PANS/PANDAS, including auto inflammatory and infectious.
- Compare different treatment strategies for youth with PANS, including psychiatric, immunomodulatory, and antibiotic treatments.

**Tuesday, October 6**
12:00 - 1:00 p.m.

**Livestream** (Remote Attendance Only)
http://echo360.org/section/239826d6-781a-4cbd-aea6-af8a754d03be/public

This presentation has been sponsored by:
Northwest PANDAS/PANS Network www.nwppn.org

For more information please contact:
Micaela Sandoval Jones sandovmi@ohsu.edu 503-494-4818
or visit www.ohsu.edu/psychgrandrounds

OHSU

PeaceHealth
The Spirit of Health

PEDIATRIC GRAND ROUNDS
VIRTUAL ONLINE

# ASSESSMENT AND TREATMENT OF CHILDREN WITH PANDAS/PANS SYMPTOMS: A PEDIATRICIAN'S PERSPECTIVE

**TUESDAY**
November 8th, 2022
12:30-1:30. P.M. PST

Microsoft Teams meeting
Click here to join the meeting
1 Category I credit

Presented by:
Melissa McCormack, MD, PhD
Wholistic Pediatricians,
Winchester, MA

**LEARNING OBJECTIVES**
AFTER THIS EDUCATION, LEARNERS SHOULD BE ABLE TO:
1. IDENTIFY NEUROPSYCHIATRIC SYMPTOMS REQUIRING FURTHER MEDICAL EVALUATION.
2. IDENTIFY MEDICAL DISORDERS THAT CAN PRESENT WITH NEUROPSYCHIATRIC SYMPTOMS.
3. EVALUATE PATIENTS FOR PANDAS/PANS AND OTHER NEUROIMMUNE DISORDERS.
4. INITIATE TREATMENT FOR PATIENTS DIAGNOSED WITH PANDAS/PANS.

Accreditation Statement:
PeaceHealth St. Joseph Medical Center is accredited by the Washington State Medical Association to provide continuing medical education for physicians.

PeaceHealth St. Joseph designates this live activity (Pediatric Grand Rounds) for a maximum of 12 *AMA PRA Category 1 Credits™*. Physicians should claim only the credit commensurate with the extent of their participation in the activity.

This activity meets the criteria for up to 12 hours of Category I CME credit to satisfy the relicensure requirements of the Washington State Medical Quality Assurance Commission.

SPONSORED BY: NORTHWEST PANDAS/PANS NETWORK (NWPPN)

NWPPN nwppn.org

# Northwest Grand Round Recordings Available on our Website

# Continuing Education

- Northwest Grand Rounds
  - "Infection, Inflammation & Mental Health- Mapping the Intersections"with Jenny Frankovich, M.D. of Stanford and Director of Stanford PANS Clinic
  - "Pediatric Acute Onset Neuropsychiatric Syndrome (PANS): Recognition and Treatment of an Often Overlooked Syndrome in Children" with Kiki Chang, M.D., former co-director of Stanford PANS Clinic
  - "Childhood Post-Infectious Autoimmune Encephalitis" with Michael Daines, M.D. of Children's Post-Infection Autoimmune Encephalopathy Center of Excellence at University of Arizona
  - Assessment and Treatment of Children with PANDAS/PANS Symptoms: A Pediatrician's Perspective *with Dr. Melissa McCormack, Pediatrician*
- How Immune Response to Strep Infection Triggers BGE Breakdown of Blood Brain Barrier PANDAS/PANS Video Department of Neurology at Columbia University
- The Psychologist's Role in Supporting Those Impacted by PANS PANDAS ,Presented by Amy B. Young, Psy.D.

NWPPN

nwppn.org

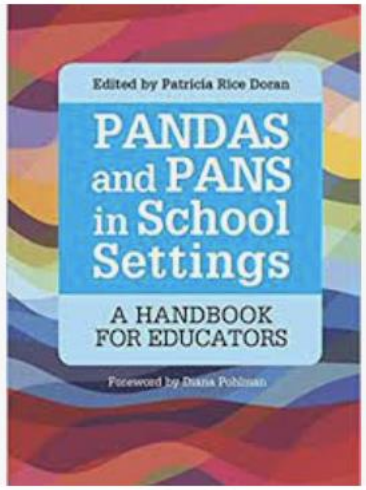
# PANDAS/PANS Non-Profits

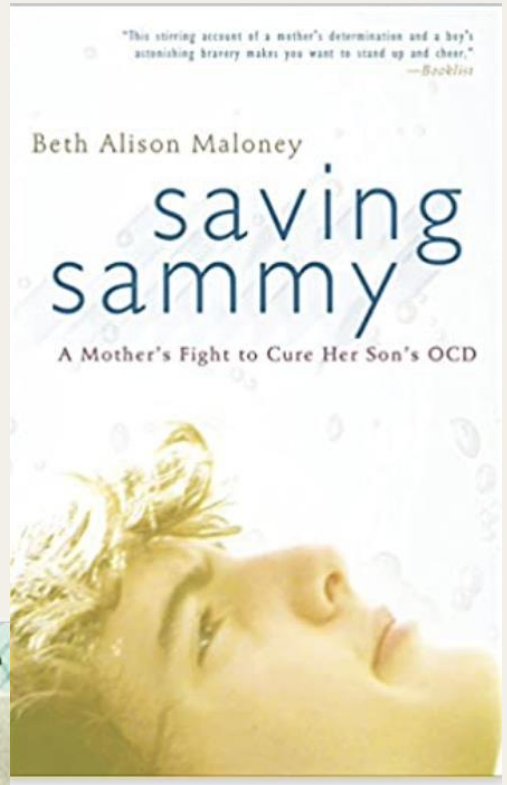
- Northwest PANDAS/PANS Network-visit us at www.nwppn.org
- **PANDAS Physician Network (for medical/behavioral health providers)**
  **www.pandasppn.org**
- ASPIRE-National PANDAS/PANS nonprofit

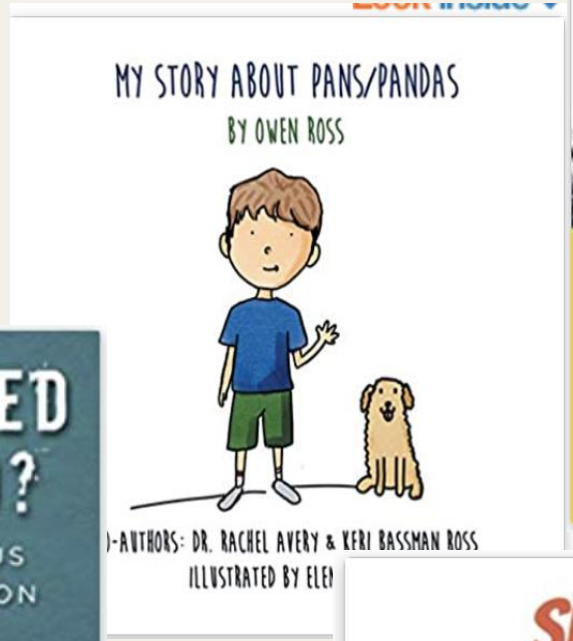
www.aspire.care

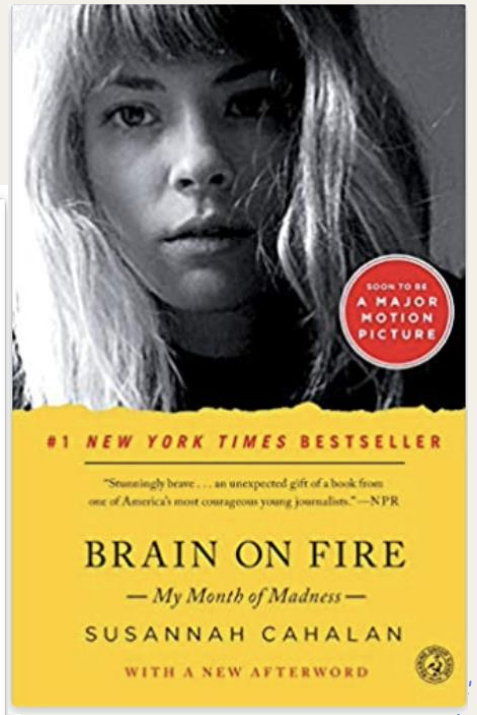
NWPPN
nwppn.org

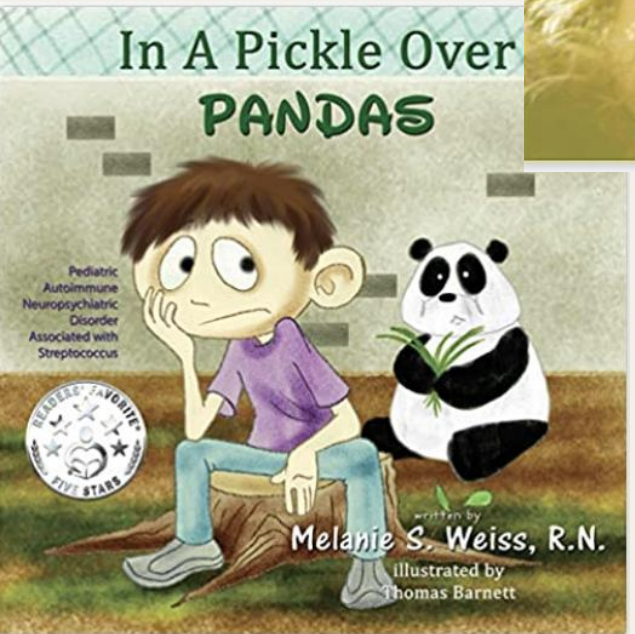
# Books on PANDAS/PANS/AE

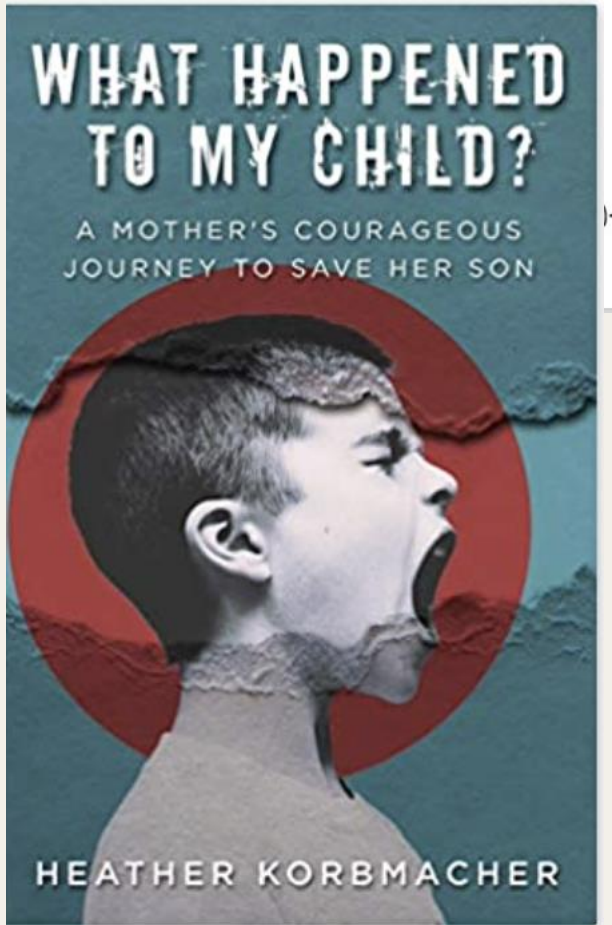



# PANDAS/PANS In the Media

- Magazine Features
  - Newsweek, "Sudden Obsessions, Tantrums: What Is PANS in Kids?", 5/20
  - The Atlantic, "A Strange New Culprit Behind Eating Disorders", 10/19
  - Mad in America, "The Unsung Psychiatric Impact of Strep Throat", 5/18
  - The Pediatric Infectious Disease Journal, "A Pediatric Infectious Disease Perspective on Pediatric Autoimmune Neuropsychiatric Disorder Associated With Streptococcal Infection and Pediatric Acute-onset Neuropsychiatric Syndrome", 7/19
  - American Nurse Today, "What you need to know about the strep throat complication of PANDAS", 11/18
  - Nursing Journal, "PANDAS, What nurses need to know", 8/19
- TV SPECIALS
  - ABC 20/20: "PANDAS", 7/18
- DOCUMENTARIES
  - My Kid is Not Crazy-Award Winning Documentary by Tim Sorel on Amazon
  - Stolen Childhood-Canadian Documentary on YouTube
  - Forgotten Children-UK Documentary on YouTube

NWPPN
nwppn.org

NWPPN
nwppn.org

Thank you for allowing us to present on PANDAS/PANS today!