




Inflammatory Brain Disorders

Presentation → [panspandas.org.uk](https://www.panspandas.org.uk)

PANS/PANDAS: Impact and Interventions in Schools


Pediatric Autoimmune Neuropsychiatric Disorders Associated with Streptococcal Infections

Pediatric Acute-onset Neuropsychiatric Syndrome

Kathleen (Kate) Maher, MS-PHNA, RN
School Nurse, MSNO Delegate MADPH PANS/PANDAS Advisory Council
May 2025

1

**Show of hands...
PANS/PANDAS in Our Schools**



Objectives


- Become familiar with potential psychiatric and neurological impact of inflammatory triggers
- Identify combined physical and psychiatric symptoms of PANS/PANDAS
- Obtain tools for creating IHCPs, IEPs and 504s, and supporting families during diagnosis and treatment

2

What are PANS and PANDAS?
(PANS PANDAS UK, 2025)

Cognition and Learning

- Dysgraphia
- Dyscalculia
- Sleep issues
- Brain fog
- Visual processing difficulties
- Working memory issues
- Auditory processing difficulties



Social, Emotional and Mental Health

- Emotional and social regression
- Anxiety
- Panic attacks
- OCD
- Issues with regulating emotions
- Self-harm
- Suicidal thoughts

Communication and Interaction


- Regression in language use
- Onset of stuttering
- Regression of coping skills, social awareness, or social language skills
- Trouble with peers
- Reactivity
- Screaming and verbal outbursts
- Tantrums
- Suicidal language

Sensory and Physical Needs

- Tics
- Changes in fine and gross motor skills
- Sensory sensitivities
- Eating disorders
- Enuresis/urinary frequency
- Masking

3

Diagnosing PANS




1. **Abrupt onset** or **abrupt recurrence** of **OCD** or **Restrictive Eating Disorder**
2. Comorbid neuropsychiatric symptoms (at least 2) with a similarly acute onset
 - o **Anxiety**—elevated and/or separation
 - o **Sensory Amplification** or **Motor Abnormalities** (including tics and dysgraphia)
 - o **Behavioral Regression**
 - o Sudden deterioration in **school performance**
 - o **Mood** disorder (irritability, aggression, and/or severe oppositional behaviors)
 - o Somatic signs (including **enuresis**, **urinary frequency**, **sleep disturbances**)
3. Symptoms are not better explained by a known neurologic or medical condition

Clinical Diagnosis (PANDAS Physicians Network, 2023)

4

Key Points

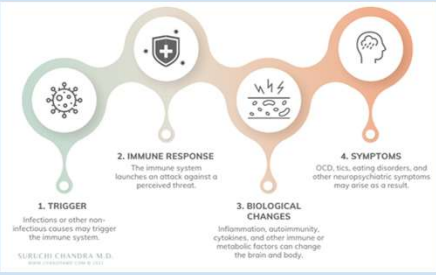


- **Mild Cases**
 - o Outpatient
 - medical
 - psychiatric
 - counseling
 - o In School
 - IHP / 504 / IEP
 - Behavior support
- **Severe Cases**
 - o ER, 911, frequent inpatient stays, DCF, Justice System
 - o Heavy medication (often ineffective due to inflammatory causes)
 - o Homebound education

Hope:
Can heal, return to near normal function

5

How does PANS occur?



1. **TRIGGER**
Infections or other non-infectious causes may trigger the immune system.
2. **IMMUNE RESPONSE**
The immune system launches an attack against a perceived threat.
3. **BIOLOGICAL CHANGES**
Inflammation, autoimmunity, cytokines, and other immune or metabolic factors can change the brain and body.
4. **SYMPTOMS**
OCD, tics, eating disorders, and other neuropsychiatric symptoms may arise as a result.

SURESH CHANDRA, M.D.
(Chandra, 2024b)

6

Alex Manfull

- Writer
- Gifted artist
- Photographer
- Fashionista
- Runner

Promising

- Phillips Exeter
- Princeton University
- Wall Street



Course


- 19yo Strep & OCD
- Providers unfamiliar
- Self dx 5 years later at 24
- 2 more years to see PANDAS provider
- Goal: Educate
- Ready for tx 2018
- Flare
- Aug 2018, 7 year battle at 26 y.o
- Who, where
- Strengths, challenges
- Age

(The Alex Manfull Fund, 2024)

7


Case Study: Academic/Socioemotional Symptoms

- OCD, Perseveration, Rigidity
- ADHD and Decreased Processing Speed
- Increased Anxiety, Frustration
- Rapid and Exaggerated Mood Changes
- Difficulty with Transitions
- Sensory Seeking, Sensory Changes



8

Case Study: Physical Symptoms



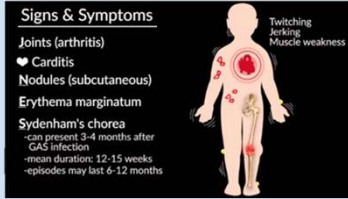
- **Vision** Disturbances and Functional Vision Changes
- **Handwriting** deterioration
- Motor/vocal **Tics**
- **Urinary** Incontinence
- **Food** Restriction / Gagging
- **Sleep** Disturbances
- **Compulsive** behaviors
- **Sensory** seeking

9

Sore Throat vs. "Rheumatic Fever of the Brain"

Sore throat vs. debilitating illness

- Why some people?
 - Autoimmunity
 - Strep infections
 - Siblings
- Strep "hides"
 - Molecular mimicry
 - Membrane proteins
 - Confused antibodies
 - Damage heart, joints
 - PANDAS
 - "Rheumatic Fever of the Brain"



10

What's old is new again: Sydenham Chorea

1685 Autoimmune Response

- Clumsy movements
- Muscle weakness
- Stumbling or falling
- Difficulty speaking clearly
- Difficulty focusing or writing
- Emotional lability
- Facial grimacing or tongue chorea
- "milkmaid sign"
- Tics



[Image link](#)



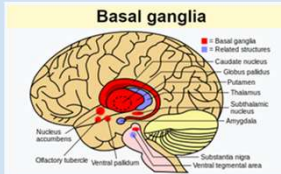
~6 month duration

(Sydenham Chorea, National Institute of Neurological Disorders and Stroke)

Goal: Treat underlying infection, inflammation, Valproic Acid or Carbamazepine

11

Basal ganglia



Motor Learning
Executive Function
Emotional Regulation

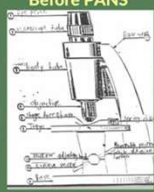
(Lanciego et al., 2012)

12


Handwriting Deterioration

Prior to acute onset of PANDAS, the student could write neatly. After, handwriting becomes almost illegible and not neatly placed on the paper.

Before PANS



During Flare




Look. foundation. (n.d.). Look. <https://www.lookfoundation.org/>

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Behavioral Regression

You can see the difference between the self-portrait during a PANS flare with regression and the self-portrait while the child was healing.

During Flare



In Treatment

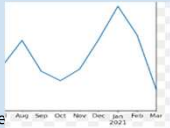


Look. foundation. (n.d.). Look. <https://www.lookfoundation.org/>

14

NIMH Overview


Course of Illness



- Can take weeks to months for strep antibodies to degrade
- Antibodies peak 3-5 weeks after the infection, though may see flares between 2 and 4 weeks.
- After 6 months, the antibodies start to degrade, though they can remain detectable for several months afterward.
- Treatment may include antibiotics for tx and prophylaxis and anti-inflammatories.

PANDAS—Questions and answers. (n.d.). National Institute of Mental Health (NIMH)

15

Progress In MA 

- **S. 613 2019-2020** [An Act relative to insurance coverage for PANDAS/PANS](#)
- **DPH PANS PANDAS Advisory Council to the Commissioner**
 - [MA DPH PANDAS/PANS Advisory Council](#)
 - (MGH, Lurie Center for Autism, Harvard Medical, Tufts)
- **Research:** [MGH Pediatric Neuropsychiatry and Immunology Program](#)

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[MADPH PANDAS/PANS Advisory Council to the Commissioner](#)

(Commonwealth of Massachusetts. (n.d.). *PANDAS/PANS Advisory Council*. Mass.gov.)




The Council is charged with advising the DPH Commissioner on research, diagnosis, treatment and education relating to pediatric autoimmune neuropsychiatric disorder associated with streptococcal infections and pediatric acute neuropsychiatric syndrome (PANDAS/PANS).

Chaired by Elaine Gabovitch, MPA, PANDAS/PANS Advisory Council Chair | Commissioner's Designee
Director, Division for Children & Youth with Special Health Needs, Massachusetts Department of Public Health

17

How Immune Response to Strep Infection Triggers Basal Ganglia Encephalitis



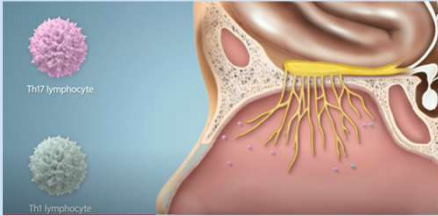
[Breakdown of Blood Brain Barrier in PANDAS/PANS](#)

Dr. Agalliu Department of Neurology at Columbia University Irving Medical Center
(Agalliu / PANDAS Network Official, 2020b)

18

T Cell lymphocytes travel up olfactory nerve to brain.

(Agalliu / PANDAS Network Official, 2020b)



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T cells and microglia (brain immune cells) release cytokines.

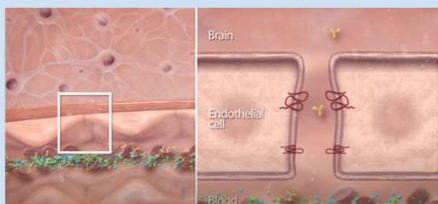
(Agalliu / PANDAS Network Official, 2020b)



20

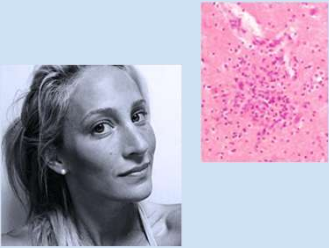
-Cytokines damage endothelial membrane
-Brain's circulatory vessels (blood brain barrier)
-Autoantibodies in the bloodstream to enter the brain.

(Agalliu / PANDAS Network Official, 2020b)



21


Alex's Brain During Flare



- Neurological damage
 - Antibodies attack neurons
 - Scarring parts of the Basal Ganglia
 - Caudate Nucleus
 - memory impairment
 - mood change
 - frontal lobe syndrome
 - Thalamus–Relay center
 - Sensory
 - Motor

22

PANS/PANDAS Pathology




Infection triggers inflammation in the brain causing sudden changes in neurology and producing psychiatric symptoms.

2 min [Student Description](#) of first flare (30:31–32:37)

(New England PANS/PANDAS Association / MA Coalition, 2020)

23

Listen to Families



- Parents can tell you the day and time they saw their child “disappear”
 - “Possessed”
- May have had some symptoms at baseline
- Stress
- Grief
- Embarrassment
- Judgment
- Terror
- Family relationships
 - Marital, Sibling
- **Distinguish SYMPTOMS vs. BEHAVIOR**

[U.S. and International Support Groups](#) (PANDAS Network, 2024)

24

Is this PANS or PANDAS? What do we Do?

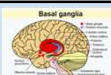
Pre-Diagnosis Steps



- 1) Identify physical and psychological symptoms
- 1) Correlate mental health sx with infection/inflammation
- 1) Identify progression (sudden vs waxing/waning)
- 1) Referral to PCP for testing and treatment of infections*
- 1) Support caregivers with [educational materials for the provider](#)
- 1) [Specialist Referral](#) (PPN, 2024b) to [PANS literate providers](#) (Commonwealth of MA)
- 1) [Diagnostic Flowchart and Treatment options](#) (PANDAS Physicians Network, 2024b)

25

Rule-out Process for a Suspected Case



- 8) [Individualized Health Plans](#) (www.ASPIRE.care, n.d.), Infection Control and [Interventions \(NEPANS\)](#)
- 9) Coordinate Team Approach (Include Administration)
 - [504 Planning for PANS / PANDAS](#) (Aspire / True, 2022b)
 - [IEP Planning for PANS / PANDAS](#) (Aspire / True, 2022e)
10. Monitor Symptoms and Exposures
11. Care Coordination / Absence Management
12. Evaluate and Adapt Based on Outcomes

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2. Hx: Correlate Potential Infectious Triggers

- Staphylococcus
- Mycoplasma pneumonia
- Tick Borne-Lyme, Bartonella, Babesia, Anaplasmosis
- COVID-19
- Coxsackie, EBV, Influenza
- Mold / Environmental Toxins
- UTI, Skin, Sinuses

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Supportive History



- Known Group A Streptococcal (GAS) infection or exposure
- History of pharyngitis or perianal rash or pruritis
- History of impetigo or ecthyma
- Known illness preceding neuropsychiatric changes.
- History of recurrent pneumonia, bronchitis, sinusitis
- History of a tick bite, Lyme disease or other vector borne infections
- History of or active gastroesophageal reflux disease (GERD) or recurrent abdominal pain
- Consider prior response to antibiotics and/or anti-inflammatory medications.

(JCAP, 2017)

28

Labs



Rule Out Other Disorders

- Throat culture +/- perianal culture
- ASO titer
- DNase B titer
- M.Pneumonia IgM,IgG
- C.Pneumonia IgA, IgM, IgG
- Lyme Western Blot & C6 peptide
- Tickborne panels
- EBV & CMV panels
- HSV 1/2 panels
- H. Pylori stool antigen or PCR
- Sars-CoV-2 IgM, IgG

- Immunoglobulins
- ANA
- CRP/ESR
- CBC
- Celiac Panel
- Thyroid Panel
- Vit D
- Vit B12/Folate
- Ceruloplasmin
- EKG

(JCAP, 2017)

29

Manifestations of PANS Symptoms in the School Setting (NEPANS)

Manifestations of PANS Symptoms in the School Setting	
<p>BEHAVIORAL Symptoms</p> <ul style="list-style-type: none"> •Obsessive Compulsive Disorder •Obsessive Thinking (Inappropriate Thoughts/Rigid Thinking/Perfectionism) •Eating Issues (Limited Menu/Fear of Choking/Anorexia) •Anxiety (Separation Anxiety/School Refusal) •Aggression (Defiance/Rages) •Age Regression/Immaturity (Tastetrum/Baby Talk) •ADHD (Fidgeting/Outbursts/Poor Impulse Control) •Sensory Issues 	<p>ACADEMIC Symptoms</p> <ul style="list-style-type: none"> •Loss of Math Skills •Decline in Handwriting Skills (Dysgraphia) •Unable to Make Simple Decisions •Poor Short-Term Memory •Decline in Creative Work (Art, Creative Writing) •Avoidance of High Sensory Environments (Art, Music Cafeteria, Physical Ed, etc...) •Loss of Focus on a Single Task •Work Refusal (School Work, Homework etc) •Perfectionism (Erasing thru paper, starting over)
<p>PHYSICAL Symptoms</p> <ul style="list-style-type: none"> •Tics (Motor/Vocal) •Eye Issues (Dilated Pupils, Vision Issues, Hallucinations) •Eating Issues (Limited Menu/Fear of Choking/Anorexia) •Frequent Urination (Trips to the Bathroom) •Unusual Gait •Balance Issues •Chapped Hands or Lips/Mouth •Trichotillomania (Hair Pulling/Skin Picking) •Enuresis 	<p>EXECUTIVE FUNCTION Symptoms</p> <ul style="list-style-type: none"> •Difficulty with Working Memory and Holding Information •Poor Organizational Skills •Time Management Issues •Difficulty Planning/Prioritizing Attention on a Single Task •Difficulty Making Decisions

30

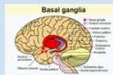
Start General Treatment



- Treat infections
 - Antibiotics
 - Antivirals
- Reduce inflammation
 - NSAIDS
 - Antihistamines
 - Steroids
- Reduce psychiatric symptoms
 - Psychotropics
 - SSRIs
 - Stimulants
- Reduce Tics
 - Guanfacine
 - Carbamazepine
 - Depakote

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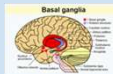
Psychotropics



- Limited efficacy with concurrent inflammation
- "Circuitry" is impacted
- May be able to tolerate small doses."

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Common Misdiagnoses and Rule-Outs



- Tourette Syndrome
- OCD
- ADHD
- Anxiety
- Bipolar Disorder
- Depression
- Eating Disorder
- Autism
- Sensory Integration Disorder

33


Role of the School



- A) Communication with caregivers regarding signs/symptoms
- A) School Accommodations / Modifications
- A) Nurse follow up with providers
- A) Absence management
 - a) Homebound, Hospital
 - b) [DESE Home or Hospital Educational Services](#)

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Potential IHP Interventions: Student Supplies



<p><u>Infection Control:</u></p> <ol style="list-style-type: none"> 1. Education regarding high-touch areas 2. Own unshared materials <ul style="list-style-type: none"> a. Pens/pencils, scissors, etc. 3. Wipes for shared keyboards, instruments, desks 4. Own water bottle, snacks, tissues, hand sanitizer (age appropriate) 5. Own supply of optional masks to self-apply if near others who are coughing as needed 6. Handwashing support before eating as needed 	<p><u>Emotional Support:</u></p> <ol style="list-style-type: none"> 1. Cue cards with coping skills 2. Anxiety reduction worksheets 3. Sensory support <ul style="list-style-type: none"> a. Oral sensory seeking alternatives b. Sensory integration 4. Transition objects
--	--

35

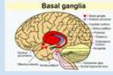
Considerations for IHPs and 504 Accommodations



<ol style="list-style-type: none"> 1. Arrival routine 1. Nutrition 1. Bathroom 	<ol style="list-style-type: none"> 4. Short breaks 5. Seating 6. Desensitization
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Classroom Infection Control Interventions



Classroom Supplies

- Tissues
- Hand sanitizer
- Wipes
- Calm corner

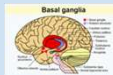
[IHP Sample \(Aspire, 2022\)](#)

Teaching Infection Control

- Covering coughs and sneezes
- Using tissues and hydration to reduce coughing
- Handwashing / Sanitizer
- "Reasonable: cleaning efforts"
- [Glo-Germ Classroom Kit](#)

37

Special Educators / Special Education Administrators



- [504 Planning for PANS / PANDAS](#)
- [IEP Planning for PANS / PANDAS](#)
- [Executive Function Tools](#)

(True/Aspire, 2022)

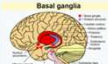
38

Monitor Symptoms and Exposures



- Individuals can be carriers without symptoms.
- There may be a sudden uptick in behaviors as strep or other infections move through the household or classroom.
- A child's immune system can be stimulated and react, even if they never develop a full-blown infection.

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Barriers and Limitations to Treatment and Referral

- Provider awareness
- Provider availability
- Spectrum of complexity
- Ethical research
- Insurance—testing and coverage
 - Psychiatric facilities—testing for infections
- Prevalence data

Multiple Specialists

- PCP
- Psychiatry
- Neurology
- Rheumatology
- GI
- ENT (T/A?)
- Infectious Disease
- Integrative/Functional

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Recent Legislation S.2984 (Bill S.2984, n.d.)

[An Act Promoting a Resilient Health Care System that Puts Patients First](#)

Fact Sheet
December 22, 2020

- This bill requires insurance carriers to cover PANDAS/PANS, ensuring that children with PANDAS/PANS and their families have access to treatment and care.
- The bill also establishes a PANDAS/PANS Advisory Council within the Department of Public Health (DPH) to advise the DPH commissioner on ongoing research, diagnosis, treatment, and education related to PANDAS/PANS.

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13. Referral for Complex and Severe Cases

1. Specialists
 - a. Rheumatology
 - i. [Intravenous Immunoglobulin \(IVIG\)](#) or
 - ii. [Subcutaneous Immunoglobulin \(SCIG\)](#)

IVIG works by blocking the actions of [autoantibodies](#) that mistakenly attack the body's own tissues, including the brain.

- i. [Student Success Story](#)
 - (Start at minute 37:08-41:16)
- a. [MA DPH PANDAS/PANS Advisory Council](#)
- b. [Pandas Physician Network](#)

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Home Based Nursing Care During IVIG

- 1) 4-5 hour IV infusion with loading dose
- 2) Ice pack
- 3) 24-48 hrs peak effect
- 4) Can become ill afterward with flu like symptoms as the immune system tries to regulate this blood product from thousands of donors.
- 5) Adjunct medications and treatments
 - a) Zofran
 - b) Tylenol
 - c) Benadryl
 - d) Ibuprofen

Alternative: Subcutaneous weekly

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Is this PANS or PANDAS? What do we Do?

Pre-Diagnosis Steps



- 1) Identify physical and psychological symptoms
- 1) Correlate mental health sx with infection/inflammation
- 1) Identify progression (sudden vs waxing/waning)
- 1) Referral to PCP for testing and treatment of infections*
- 1) Support caregivers with [educational materials for the provider](#)
- 1) [Specialist Referral](#) to [PANS literate providers](#)
- 1) [Diagnosis and Treatment](#)

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Rule-out Process for a Suspected Case



7. [Individualized Health Plan Considerations](#) (Sample)
8. Infection Control and [Interventions](#)
9. Coordinate Team Approach (Include Administration)
 - [504 Planning for PANS / PANDAS](#) (Aspire webpage)
 - [IEP Planning for PANS / PANDAS](#) (Aspire webpage)
10. Monitor Symptoms and Exposures
11. Care Coordination / Absence Management
12. Evaluate and Adapt Based on Outcomes

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How did we do on our Objectives?

Learning Outcomes:

- Become familiar with potential psychiatric impact of inflammatory triggers
- Identify combined physical and psychiatric symptoms of PANS/PANDAS
- Obtain tools for creating IHCPs and supporting families during diagnosis and treatment

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Key Takeaways

- Genetic predisposition
- Symptoms vs. voluntary behavior
- Anxiety, concentration, and academic abilities can vary week to week
- Demands: consider demonstration of skill and understanding vs. task completion
- Notify caregivers if you see changes
- Great capacity to do well if medically treated
- Flexibility is key!!!
- Early identification of flares can dramatically reduce duration of treatment can be quickly adjusted.
- Infection control can keep students in school

School Management Cheat Sheet



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Questions ?



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