New England PANS/PANDAS Association

Who We Are

New England PANS/PANDAS Association is a group of parent and medical volunteers focused on raising awareness of Pediatric Autoimmune Neuropsychiatric Disorder Associated with Streptococcal Infections (PANDAS) and Pediatric Acute-onset Neuropsychiatric Syndrome (PANS).

Our Mission is Simple

To raise awareness of PANS/PANDAS in our community and beyond
To support the medical community in their mission to heal children suffering from PANS/PANDAS
To look for ways to expand the medical care available
To create opportunities to assist families searching for solutions

Cathy Teal, RN
CathyTeal.RN@gmail.com

- R.N for 45 years (Peds, Psych, Oncology, GI, etc.)
- School Nurse 20+ 7 years as school nurse substitute prior
- Mother of a child with Suspected PANS and Grandmother of 13 yr old Diagnosed PANDAS child
- Following PANS/PANDAS since 2000
- My first diagnosed student is now 24 and in Grad School
- Currently have students with Diagnosed PANS
- Assisted with IHCP, 504 & IEP

I have no conflict of interest and have not received commercial support for this presentation
Goals of Presentation

• What is PANS/PANDAS
• How is PANS/PANDAS diagnosed?
• Symptom Overview
• Treatment
• PANS in the School Setting
• Role of the School Nurse

Outcomes

At the end of this presentation, you will:
• Be able to inform school staff how to recognize students signs and symptoms in the classroom
• Increase awareness that Strep, Lyme, Pneumonia can lead to symptoms of OCD and Anxiety
• Document effectively in your Electronic Medical Records.
• Be able to locate and share resources for staff and families

School Nurse News

Keep on the Alert for PANS
• Strep Infections and other illness can trigger a rapid onset of:
  • OCD
  • Anxiety
  • Aggression
  • Food Issues
  • School Regression
  • Sensory issues
  • School Refusal
  • Math Regression
  • ADHD
  • Handwriting Difficulties

“The School Nurse may be the first healthcare professional in a school setting to see a child with a condition which can mimic an acute illness with sudden severe behavior change.”

Know the Signs. Know the Treatments.
My Kid Is Not Crazy
A Search for Hope in the Face of Misdiagnosis

Documentary on PANDAS – Short Trailer
Short Trailer: https://vimeo.com/212986148

SNAP and other EMR's
Track illnesses in your Electronic Medical Record
Add Illnesses in Conditions/Alerts Tab
EMR's can track Classrooms, time of year, etc.
Students are seen at PCP and get who ever is covering that day, or Minute Clinics and Urgent Care, ER's
Join PANS/PANDAS Facebook pages, Message Boards, Forums
Purchase PANS/PANDAS reference books
Go to: NEPANS.ORG and P.A.N.D.A.S. network.org
These sites are full of information. Print FREE materials

What is PANS & PANDAS
Autoimmune/Inflammatory Response
PANS/PANDAS is a misdirected immune response, often with an encephalitic onset, which negatively affects neurologic functioning, resulting in a rapid, acute onset of OCD, restricted food intake or tics along with other neuropsychiatric conditions. Some children suffer debilitating flares while others function enough to continue to go to school but not remotely at the same functioning level.
PANS/PANDAS symptoms may relapse and remit. During subsequent flares, symptoms can worsen and new symptoms may manifest. Initial triggers and secondary triggers may vary. Children are often misdiagnosed as having a psychiatric illness thus prescribed only psychotropic medications rather than treated correctly
What is PANS & PANDAS

Autoimmune/Inflammatory Response

POST INFECTIOUS AUTO-IMMUNE ENCEPHALITIS

“Friendly Fire” - Antibodies created to fight these infections become misdirected and attack the brain, particularly the basal ganglia.

-Molecular Mimicry: Rheumatic Fever and Sydenham Chorea are examples of post infectious autoimmunity due to Molecular Mimicry. Strep evades detection by the immune system as long as possible by putting molecules on it’s own cell wall that look like cells in the body (heart, brain, skin, joints)=Molecular Mimicry. Eventually the body recognizes these cells as foreign and produces antibodies to them. The antibodies trigger an immune reaction to the strep and to the cells that were mimicked.

This autoimmune & post-infection inflammatory, encephalitic reaction results in an acute onset of neuropsychiatric symptoms.

What does PANS really look like?

“An easygoing 15-year-old 10th grader, has always been a good student who has many friends and takes mostly honors classes. John has always been excellent in math.”

Following the flu...he suddenly developed eye blinking, face twitching, and inattentive behavior; he became anxious, argumentative with his teachers and parents, and suicidal, resulting in hospitalization...he suddenly missed relatively easy questions on math tests. He developed obsessions, such as pacing, seeing the volume button on electronics to multiples of 5, and having everything “just so.”

“A bright, well-adjusted first-grade girl...School friendships were numerous, with no identified social problems. The girl rated her teacher as “favorite” and was not overwhelmed by major schoolwork, which she described as “easy.”

“Returned to school after a severe infection. Suddenly appeared severely school phobic: the morning after morning the child became extremely anxious...she crunched in the car, sobbing and clinging to the seat. No amount of coaxing or prodding seemed to alleviate her severe yet unspecified anxiety.”

Before/After Onset

Hand Writing Changes

<table>
<thead>
<tr>
<th>Before Acute Onset</th>
<th>During Rare</th>
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After Onset/During Remission

Behavioral Regression

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<tr>
<th>Acute Illness</th>
<th>Convalescence</th>
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Demonstrates Behavioral
Regressive Self-Portrait

Demonstrates Age
Appropriate Self-Portrait

Relapse & Remittance

Remittance

- Can be gradual
- Can have good and bad weeks

Relapse

- Can be triggered by: new infection, exposure to other’s, environmental challenges (mold, vaccines, etc), stress, injury, etc
- Severity of flares will vary: don’t ignore the less severe relapse
- Flares can happen often or spread out by months or years
- Baseline: Some Patients do not return completely to baseline in between flares. Some symptoms may persist.

Diagnosis

Clinical Diagnosis

- Symptoms – Current and Past Symptoms
- Family History – including Grandparents
  - Often high rates of OCD, SC, Rheumatic Fever and Autoimmune disease
- Physical Exam
  - Rheumatologic work up: 80% have arthralgias, myalgias and other evidence of inflamed joints & muscles
  - Neurologist – evaluate for SC - Choreiform Movements vs Piano Fingers
  - Eyes: dilated or constricted (deer in the headlight), vision issues including distortions, hallucinations of bugs, colors, people
  - Physical signs of strep: Peeling skin on hands or feet, red anal ring, strawberry tongue, Hx of Impetigo.
  - Physical signs of other infection: warts, molluscum, ring worm, ridged nails, etc
  - Trichotillomania (hair pulling) or Skin Picking, recalcitrant sinus infections

Consensus Statement: Clinical Evaluation of Youth with PANS: Recommendations from the 2013 PANS Consensus Conference (JCAP-2014)
Diagnosis

Clinical Diagnosis

- Infectious Disease workup
  - Group A Streptococcal
    Swabs of throat, anal and sometimes skin
  - (ASO) Antistreptolysin O Antibody
  - D Nase B Antibody
  - Streptozyme
- Mycoplasma Pneumonia
- Lyme
- Mono and Herpes
- Immunology Panel (IgE, IgM, IgA and IgG; IgG subclasses)

Clinical Diagnosis LABS continued

- CBC, Comp Metabolic, Thyroid, Iron, Copper, etc.
  (see what has already been done by PCP, ER, etc.)
- ANA, CRP, ESR screen. 80% have pain in joints and muscles
- Possible Rheumatologic work up needed
- MRI – rule out ADEM
- EEG
- Lumbar Puncture – on very sick kids - Must look at (CNS) to rule out Autoimmune Encephalitis

Diagnosis

Roadblocks

PANS is often not diagnosed right away by medical professionals.
- Not all practitioners are PANS literate.
- There are doctors that still believe that PANS doesn’t exist.
- Infectious triggers and symptoms are not always immediately linked.
- Medical testing is only one facet of diagnosis.
- Sudden onset can be missed: Sometimes the infection is treated immediately so initial symptoms are not as severe. Or sudden onset was mild. Or lost in terrible twos/threes
- Symptoms aren’t linked together or blamed on age or another diagnosis (like Autism).
- Symptoms often relapse and remit from year to year so big picture is hard to see.
Three Pronged Approach

- Antimicrobial: Removing the source of the inflammation with antimicrobial interventions.
- Immunomodulatory: Treating disturbances of the immune system with immunomodulatory and/or anti-inflammatory therapies.
- Psychotherapeutic: Treating the symptoms with psychoactive medications, psychotherapies (particularly cognitive behavioral therapy), and supportive intervention.

Treatment Basics

- 14-day course of Antibiotics
- Consider 5-15 days of Prednisone
- Consider IVIG (Intravenous Immunoglobulin) or PEX (Plasma Exchange)
- Consider cont’d full dose or prophylactic dose of ABX
- CBT and/or counseling for residual OCD

Other Treatment Options

- Antifungals
- Anti-Inflammatory
- Antihistamines (H1 & H2 Blockers)
- Extremely low dose SSRIs, increasing slowly
- Tonsillectomy and Adenoidectomy
- Dietary Changes
- Vitamin D3, Omegas, etc

Penicillin, Amoxicillin are often first choices
- Cephalexin, Cefadroxil, Clindamycin, Azithromycin, or Clarithromycin are often required if pharyngitis is persistent or rapidly relapsing.
- Some antibiotics also are anti-inflammatory.
- Some doctors use extended courses of antibiotics, while waiting for neuropsychiatric symptoms to abate.
- Prophylactic doses of antibiotics have not been studied fully but trying to prevent further neural injury may be worth it.
- Continue a year or two after symptoms have resolved. Some continue until they are 18 like in Rheumatic Fever.
- Lasting remission can happen from antibiotics alone in some cases.

NEPANDAS.org
Immunomodulatory Therapy

• Separate guidelines were created depending on severity (mild, moderate-to-severe, extreme/life-threatening severity) on how to treat neuroinflammation or post infectious autoimmunity with anti-inflammatory and/or immunomodulatory therapies.

• Neuroinflammation thought to be part of the cause & development of PANS.

• Immune abnormalities seen in at least 80% of patients

• Immunomodulatory interventions should be combined with other therapies.

• Mild: Antibiotics, “tincture of time” and therapy may suffice. Persistent symptoms may require non-steroidal anti-inflammatory drugs and/or short oral corticosteroid burst. Intravenous immunoglobulin (IVIG) may be indicated. NSAID trials should be 6 weeks long. Their effect can fade over time, important to do recurring discontinuation trials to monitor symptoms. Prolonged use can be handled with precautious measures.

Moderate-Severe:

• Prolonged corticosteroids or repeated high-dose corticosteroids may be indicated. IVIG is typically warranted. Because corticosteroids improvement is not long lasting and prolonged use has permanent side effects, IVIG is preferred. Number of IVIG doses varies.

• Extreme & Life-Threatening: therapeutic plasma exchange is the first-line therapy either alone or with IVIG, high dose corticosteroids and/or rituximab. Five single-volume PEX for 7–10 days are considered optimal.

• Rituximab is indicated with evidence of neuroinflammation or autoimmunity.

• Chronic Condition: For some a “temporary postinfectious pathological immune response has evolved to become a chronic autoimmune condition”. They may need more frequent aggressive immunomodulatory therapies – repeated high-dose methylprednisolone or corticosteroids, rituximab or immunosuppressants.

Psycho-Therapeutic Treatment

• Psychiatric & Behavioral symptoms need to be managed alongside inflammatory and infectious processes treatment.

• Use combination of treatments: psychoeducational, pharmacological psychotherapeutic, behavioral, family, school-based.

• The aim is: decrease suffering & increase adherence to intervention.

• Course of treatment:

  • Patients who recover can discontinue symptomatic treatment

  • Other patients may need constant intervention and accommodation

  • Therapies must be individualized based on symptoms and severity

  • Some may not need pharmacological treatment ever.

  • Some may need adjustments or removal as medical treatments take affect.
Flexibility Needed at School

In Curriculum
- Functioning may change rapidly.
- Appropriate placement and setting may need to be modified.
- Remember each flare and each child is different.

In Attendance
- “School refusal” or phobia of school, sometimes associated with separation anxiety or OCD, is extremely common.
- 50% of children spend time on home instruction or are removed to homeschool or home/hospital permanently
- Attendance should include provisions for frequent absences (medical appointments, health issues, etc.), late arrival, early dismissal, additional breaks due to fatigue, separation anxiety, medical absences (appointments & germ avoidance)

District Strategies & Approaches

Staff Education
- Provide and/or promote general education staff training on the faces of OCD and anxiety in school age children and need for medical treatment in this particular disorder
- Provide district-wide training to school nurses & school psychologists, OT’s and speech language therapists and guidance/school counselors

Notice of Strep in School
- Inform parents if there is an episode of strep in the classroom. It is not necessary for parents to know which child has had strep, just that it has occurred. (Teacher often knows the child was out with strep, not Nurse).
- If a teacher has been diagnosed with strep this too should be communicated. This would include art, gym, guidance, etc.

District Strategies & Approaches

School Nurse
- Early in the school year you may be the person who knows the child better over time than the new teacher.
- Nurse can help report any abrupt changes in behavior, eating habits, or school performance to family.
- Nurse can inform parents of any communicable illness in classrooms. Parents can inform school nurse of any health changes.
- Develop and Monitor Informational Health Care Plans
- School nurses should send out informational notices about the impact of illness such as strep and other illnesses.
- This does not violate privacy laws if: “Your child may have been exposed to strep throat.” “Information such as what is it, why is it important to receive treatment, when can a child return to school, how to prevent its spread.”
We've been seeing a lot of cases of STREP THROAT and a few cases of PNEUMONIA this year. We have a few students who are more susceptible to infections, so it would be helpful if you let me know about your child's illness, so I can keep track of them. A phone call, email or note would be great. The absent notes I get from your doctors never indicate the reason... perhaps you could make a note on the doctors note to help me keep track of this. This includes Stomach Bugs.

The school nurse can be a great source of reference for your child's medical history. Think of it this way... We have your student for 6 years, K-5. During that time, you may have changed doctors, or when you have medical appointments or sick visits, you are seen by a variety of doctors, depending on who is covering that day, or CVS minute clinic or Urgent Care. I will have all these conditions in our School Nurse Electronic Medical Record for future reference.

At school, we get to know your child. We know what they are like when they are well, so when they are sick, we notice the change. But... PLEASE... If your child has been home due to illness, please send a note stating what the problem was, and any details, i.e.: strep throat, ear infections, flu, etc.

Please notify the nurse if your child has received any of the following:

- Strep Throat
- Pneumonia
- Lyme disease
- Coxasijke Virus
- Impetigo
- Concussion
- Stitches
- Broken bones
- Eyeglasses
- Significant injuries
- Changes in medications

If it's an injury, we need a note from you AND a note from their doctor describing the injury, physical limitations, recess or PE restrictions, and a specific date that your child can safely resume normal activities. This is especially true for Gym Class. We will need clear and precise permission from their doctor to resume PE classes, or they will not be able to participate.
Supports & Accommodations

Basic
Student needs and performance may vary widely from week to week
• Behavioral & Sensory supports
• Reduce student’s stress.
• Plan for acute symptom flares.
• Plan for periods when less intensive supports are needed
• Homework Accommodations
• Plan for frequent absences and tardiness.
• Encourage student to avoid germs, clean tables, wash hands, etc

Communication
Students benefit from strong and proactive school communication
• Report any abrupt changes in behavior, eating habits, or school performance to family.
• Inform parents of any communicable illness in classrooms
• Parents will inform school nurse of any health changes.
• Watch for bullying. Children with tics, anxiety and OCD are at risk. Educate classroom if child and family allow.

Common Supports/Accommodations

OCD
• Compulsions:
  • Alter work sequence
  • Identify & substitute less disruptive behavior
  • Timer for transitions
  • Computer for erasing issues
  • Space to release compulsions (tap, touch, count, etc.)
• Obsessions:
  • Special words/prompts to interrupt obsessive thoughts
  • Allow spell check at times
  • Other interruptive actions

Anxiety
• Relaxation Techniques
• Safe Place

Mood Changes:
Includes: Rage/aggression & Emotional Lability
• Calming Techniques
• “Safe Space”
• Negative discipline escalates affect. Their world is falling apart but they need a safe place where they can be and want to be, even fighting fears that they have left home.
Common Supports/Accommodations

**ADHD**
- Extended Time
- Frequent Breaks
- Exercise Breaks
- Written Directions
- Preferential Seating
- Fidget Tools

**Math**
- Math Facts, Formula Sheets, Calculator
- Extended Time, Shortened Assignments
- Manipulatives

**Dysgraphia**
- Keyboard/Assistive Technology
- Built-Up pencils
- Graph paper/raised line paper

**Language**
- Extra Time
- Assisted Technology
- Speech Therapy

**Memory**
- Management: Lists, Timers, Calendars
- Repetition of information
- Review Time
- Recording devices

**Organization**
- Assignment books
- Homework Binder
- Long Term School Project Plans
- Projects broken down into segments

**Sensory**
- Sensory Supports: proprioception, pressure, weighted vests, noise cancellation headphones, yoga balls
- Sensory Seeking: varying tactile input, fidget toys
- Sensory Defense: low light, quiet space

**Mobility Issues**
- Adaptive PE
- Physical Therapy
- Field Trip accommodations/support

**Tics**
- Nurse Breaks
- Reading/Writing: Assistive Technology
- Vocal Tics: Less reading aloud
- Testing Modifications

**Urinary Frequency**
- Low-key Bathroom Access
- Tracking

**Fatigue**
- Time to rest
- Healthful snack
- Late arrival
P. Weintraub – Discover Magazine 2017
Hidden Invaders
Infections can trigger immune attacks on kids' brains, provoking devastating psychiatric disorders.

Recent Studies

School Resources

Books

• PANS and PANS in School Settings: A Handbook for Educators by Patricia Rice Doran

• PANS, CANS, and Automobiles: A Comprehensive Reference Guide for Helping Students with PANDAS and PANS by Jamie Candelaria Greene

NEPANS Handouts

NEPANS has several school focused handouts. Please see the website or contact us directly.
Resources

NEPANS

- PANS Information, School Resources, Conference Videos, Research, Meetings, Support Groups, Awareness Materials, Articles, PANS Family Stories, Newsletter and more!
- Follow us on Facebook too!
- Website: http://www.nepans.org
- Facebook: http://www.facebook.com/NEPANS
- Email: CTPANDASPANS@gmail.com

General

PANDAS Physicians Network http://pandappn.org
PANDAS Network http://www.pandasnetwork.org
Outcomes Review

At the end of this presentation, you will:

• Be able to inform school staff how to recognize students signs and symptoms in the classroom
• Increase awareness that Strep, Lyme, Pneumonia can lead to symptoms of OCD and Anxiety
• Document effectively in your Electronic Medical Records.
• Be able to locate and share resources for staff and families

Catherine Teal, RN School Nurse PANS/PANDAS Educator 2018

Resources

New England PANS PANDAS Association
www.nepans.org
Sample IHP’s
Pandas Network www.pandasnetwork.org
PANDAS Physician Network www.pandasppn.org
North East Meet Up Groups
http://nepans.org/resources/northeastmeetupgroups.html
Journal of Child and Adolescent Psychopharmacology
Jan./Feb. 2015 and Sept. 2017

Books

Saving Sammy, Beth Alison Maloney, Crown Publishers 2009
Books

In a Pickle Over PANDAS, Melanie S. Weiss, R.N.

A Child's Introduction to Understanding PANDAS,
Elizabeth Gibbs, PANDAS Network 2012

When Your Child Has Lyme Disease: A Parent's Survival Guide, Sandra K. Berenbaum, LICSW and Dorthy Leland,
Lyme Literate Press, 2015