



VIRGINIA ALLIANCE FOR PANS/PANDAS ACTION

PANS/PANDAS IN-SCHOOL PRESENTATION

Inflammatory Brain Disorders triggered by infections,
metabolic disturbances, and other inflammatory reactions



Learning Objectives

- **WHAT** PANS/PANDAS are and the neuro-immune mechanism involved in PANS/PANDAS
- **WHY** it is important to learn about PANS/PANDAS
- **HOW**
 - PANS/PANDAS manifest - identify the signs/symptoms of PANS/PANDAS and how they present in a school setting
 - PANS/PANDAS impacts the family and associated caregiver's burden
- **WHICH**
 - are the treatment guidelines for PANS/PANDAS
 - school/classroom accommodations will foster the child's participation in school, even during flares.
- **WHERE** to look for additional resources for information and referral.



WHAT are PANS/PANDAS

PANDAS

- **Pediatric**
- **Autoimmune**
- **Neuropsychiatric**
- **Disorders**
- **Associated with**
- **Streptococcal Infections**

PANS

- **Pediatric**
- **Acute-Onset**
- **Neuropsychiatric**
- **Syndrome**

“Pediatric acute-onset neuropsychiatric syndrome (PANS) features a heterogeneous constellation of acute obsessive-compulsive disorder (OCD), eating restriction, cognitive, behavioral and/or affective symptoms, often followed by a chronic course with cognitive deterioration.” *

*Gagliano A, Carta A, Tanca MG, Sotgiu S. Pediatric Acute-Onset Neuropsychiatric Syndrome: Current Perspectives. Neuropsychiatr Dis Treat. 2023 May 24;19:1221-1250. doi: 10.2147/NDT.S362202. PMID: 37251418; PMCID: PMC10225150.



WHAT are PANS/PANDAS

PANDAS / PANS are immune-mediated neuropsychiatric disorders

Inflammatory Brain Disorders triggered by infections, metabolic disturbances, and other inflammatory reactions

Initial Trigger of PANDAS

- Group A Streptococcus

Triggers of PANS

- Bacteria
- Mycoplasma pneumoniae (walking pneumonia)
- Borrelia burgdorferi (Lyme disease)
- Other tick-borne bacteria (e.g., Borrelia miyamotoi)/Bartonella
- Environmental toxins
- Mold
- Viruses
- Epstein-Barr virus (EBV, e.g., mononucleosis)
- Herpes Simplex virus
- Varicella (chicken pox)
- Cocksackie (e.g., hand, foot, and mouth disease)
- Influenza
- SARS-CoV-2 (the coronavirus that causes COVID-19)

Other Immune-mediated Disorders

- Multiple sclerosis
- Myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS)
- Myasthenia gravis
- Narcolepsy
- Pernicious anemia
- Rheumatoid arthritis
- Systemic lupus erythematosus
- Type 1 diabetes
- Addison disease
- Amyotrophic lateral sclerosis (ALS)
- Anti NMDA Receptor Encephalitis
- Celiac disease - sprue (gluten-sensitive enteropathy)
- Dermatomyositis
- Graves disease
- Guillain-Barré syndrome
- Hashimoto thyroiditis

They are what happens when the immune system attacks the brain



WHAT are PANS/PANDAS

IS PANS/PANDAS a Mental Disorder?

NO. It is a medical disorder that looks like a mental disorder

SEVERITY SCALE

PANS/PANDAS is not a homogeneous disorder. There is a spectrum of impairment.



Severe / Extreme Case

Symptoms are incapacitating, life threatening, or occupy 71% to 100% of waking hours.



Moderate Case

Symptoms are distressing and interfere with daily activities. They occupy 50% to 70% of waking hours.



Mild Case

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



WHY Learn about PANS/PANDAS

- PANS/PANDAS are often un/misdiagnosed.

Common misdiagnoses are:

- Depression
 - Obsessive Compulsive Disorder
 - Tourett's
 - Anxiety Disorder
 - Oppositional Defiant Disorder
 - Eating Disorder
 - Bipolar Disorder
 - ADHD
 - Learning Disability
 - Autism
 - Schizophrenia
 - Schizoaffective Disorder
- Although we lack reliable incidence studies on PANS/PANDAS, clinical experience suggests that there are millions of kids and adults in our country suffering from this debilitating illness
 - Timely and accurate interventions are key to restoring health
 - Lack of adequate treatment can result in the permanent decline in a child's and young adult's cognitive, social, and emotional functioning
 - School personnel offer unique insight into a child's functioning key for both early diagnosis and prompt treatment. They are paramount in a child's multi-disciplinary treatment plan



HOW does PANS/PANDAS Manifest

PANS is a clinical diagnosis requiring OCD and/or restrictive food intake as well as two or more of the following symptoms:

The diagnosis of PANDAS does NOT require comorbid neuropsychiatric symptoms beyond OCD or tics; however, they are often present





HOW does PANS/PANDAS Manifest

Symptoms

ANXIETY: separation, school refusal, general

EMOTIONAL LABILITY

DEPRESSION

IRRITABILITY

AGGRESSION: oppositional behavior

RAGES

UNUSUAL GAIT & BALANCE ISSUES

URINARY FREQUENCY & INVOLUNTARY URINATION

SLEEP DISTURBANCES

FATIGUE

HALLUCINATIONS

SELECTIVE MUTISM



OCD Obsessive thoughts and/or Compulsive actions and/or

RESTRICTED FOOD INTAKE: fear of contamination, choking, sensory

TICS: vocal and/or motor

BEHAVIORAL OR DEVELOPMENTAL REGRESSION: immaturity, baby talk

SCHOOL AVOIDANCE

DETERIORATION IN SCHOOL PERFORMANCE: handwriting, executive functioning, visual processing, reading comprehension, processing speed, spacial reasoning, and math skills

ADHD: poor impulse control, fidgeting, outbursts

SENSORY: avoidance and seeking

HAIR PULLING & SKIN PICKING



HOW does PANS/PANDAS Manifest

School Avoidance

Difficulties attending school are often the first clear sign of PANS

Range of “avoidance”

- inability to get to school
- difficulty entering the building
- difficulty getting to school on time
- inability to stay all-day
- issues engaging in schoolwork

More extreme “avoidance” is due to separation anxiety.

- separation from parent, or separation from home

Less extreme avoidance issues are likely related to other PANS symptoms.

- ritual completion, sensory issues, fatigue, phobias



HOW does PANS/PANDAS Affect the Family

Caregiver burden is clinically relevant and debilitating in PANS/PANDAS

1. Research has found that brain-related conditions are more highly associated with greater familial distress than are other chronic conditions (Holmes & Deb, 2003).

PANS/PANDAS Inflammatory Brain Disorders triggered by infections, metabolic disturbances, and other inflammatory reactions

2. OCD tends to lead to a high caregiver burden (Storch et al., 2009).

PANS is a brain-related condition that often includes severe OCD symptoms.

3. Families of patients with unstable courses of disease are more likely than those with stable courses to report that they needed respite services in the past 12 months (Nageswaran, 2009).

PANS typically follows an unstable course (Frankovich et al., 2015).

4. Clinical observations consistently reveal that while symptoms improve or remit with treatment, parents' relief is tempered by fear and hypervigilance that the symptoms will recur (Chang, Koplewicz, & Steingard, 2015)

5. Families have reported that their support systems/schools/health care providers may be unaware of or disbelieving about these illnesses, making caregivers feel doubted, thwarted, isolated and abandoned

<https://doi.org/10.1093/jpepsy/jsy014>
<http://www.ncbi.nlm.nih.gov/pubmed/14578544>
<https://doi.org/10.1093/jpepsy/jsy014>

<https://doi.org/10.1007/s10826-008-9225-y>
<https://doi.org/10.1093/jpepsy/jsy014>
<https://doi.org/10.1001/archpediatrics.2008.504>
<https://doi.org/10.1093/jpepsy/jsy014>

<https://doi.org/10.1089/cap.2015.2511>
<https://doi.org/10.1093/jpepsy/jsy014>
<https://doi.org/10.1093/jpepsy/jsy014>





WHICH are the Treatment Guidelines

THREE-PRONGED *Approach*

1. TREATING THE SYMPTOMS WITH PSYCHOACTIVE MEDICATIONS, PSYCHOTHERAPIES (PARTICULARLY COGNITIVE BEHAVIORAL THERAPY), AND SUPPORTIVE INTERVENTIONS.
2. REMOVING THE SOURCE OF THE INFLAMMATION WITH ANTIMICROBIAL INTERVENTIONS.
3. TREATING DISTURBANCES OF THE IMMUNE SYSTEM WITH IMMUNOMODULATORY AND/OR ANTI-INFLAMMATORY THERAPIES.

Overview of Treatment of Pediatric Acute-Onset Neuropsychiatric Syndrome

<https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5610386/>

Clinical Management of Pediatric Acute-Onset Neuropsychiatric Syndrome: Part I—Psychiatric and Behavioral Interventions

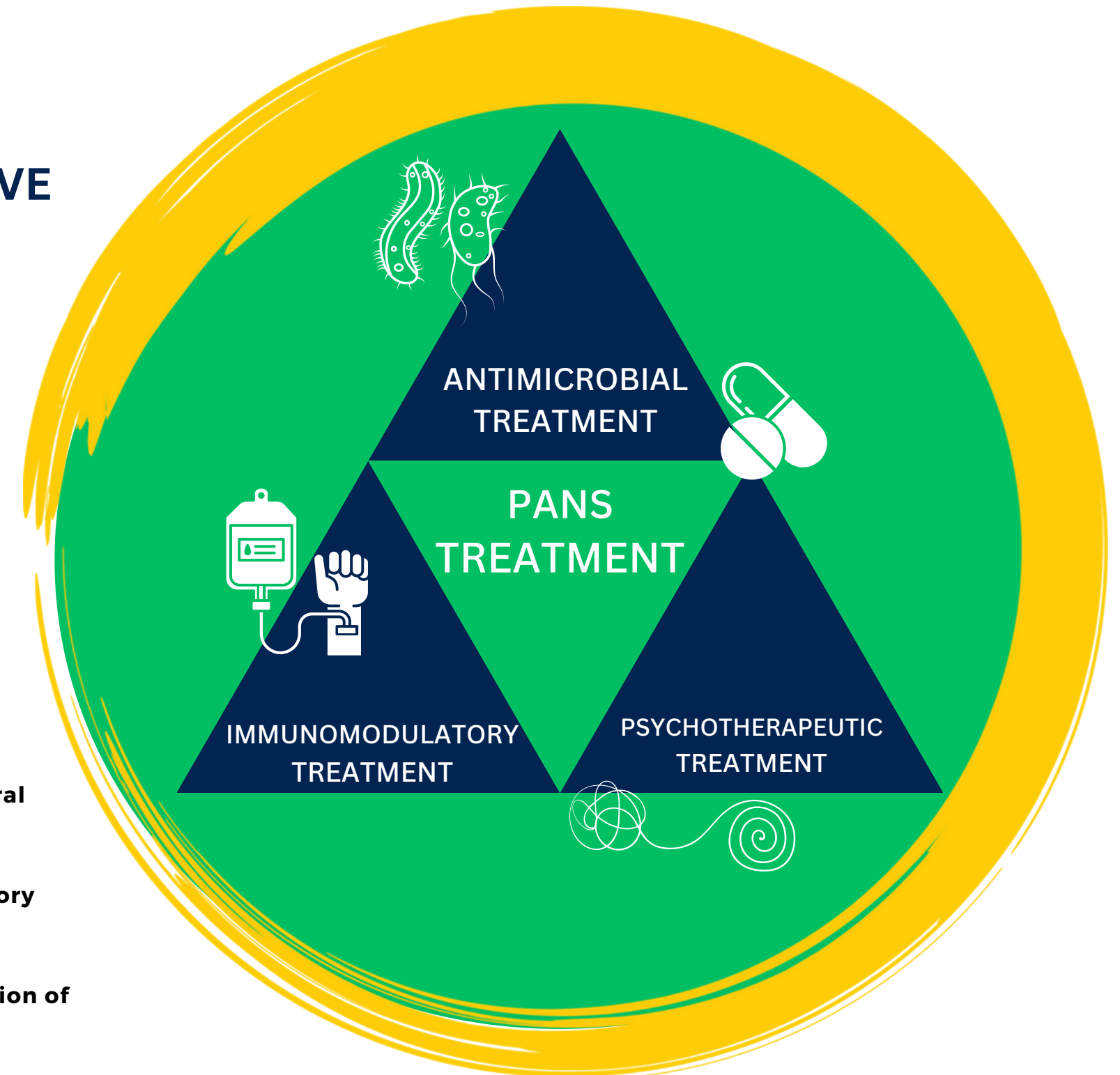
<https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5610394/>

Clinical Management of Pediatric Acute-Onset Neuropsychiatric Syndrome: Part II—Use of Immunomodulatory Therapies

<https://www.ncbi.nlm.nih.gov/pmc/articles/PMC9836706/>

Clinical Management of Pediatric Acute-Onset Neuropsychiatric Syndrome: Part III—Treatment and Prevention of Infections

<https://www.ncbi.nlm.nih.gov/pmc/articles/PMC9836684/>



WHICH are Recommended School Accommodations



School Support

MANY KIDS WITH PANS/PANDAS WILL REQUIRE A 504 OR AN IEP

COMMUNICATION



A team approach with clear communication about symptoms happening in the classroom. Encourage parent communication regarding changes in symptoms and treatment. Notify parents of any illnesses in the classroom

ATTENDANCE



Flexible arrival and departure times - delayed arrival as needed
Excused absences
Opportunities for partial day or online classroom during flare
Staff member to ease transition at arrival and departure

FLEXIBILITY



Adjust to relapsing and remitting nature of disease
Rapid flow in and out of services in response to symptom change
Provide flexibility around deadlines during flares or regressions

BATHROOM BREAKS



Bathroom breaks per student's discretion as urinary frequency is a common symptom in children with PANS/PANDAS

HEALTH/INFECTIONS



Encourage and promote proper handwashing among students
Disinfect desks and frequently used items in the classroom
Coordinate with public health nurse

EMOTIONAL AND SENSORY STIMULATION



Provide a quiet space for student to regroup or let out energy
Provide self-regulation tools for student

FINE MOTOR - VISUAL SPATIAL - MATH



Allow typing instead of written work if handwriting skills are impacted
Calculators as needed during flares

NO BLAMING THE INFLAMMED BRAIN



We do not blame a child for having diabetes or suffering a traumatic brain injury...we cannot blame a child because their brain is inflamed



WHERE to get Information

**A Parents' Guide to PANDAS, PANS, and
Related Neuroimmune Disorders Paperback
June 21, 2019**

by Doran, Amabile, Pohlman, Tumminaro, Korbmacher

**Demystifying PANS/PANDAS: A Functional Medicine Desktop Reference
on Basal Ganglia Encephalitis Paperback
August 10, 2022**

by Nancy O'Hara

**PANDAS and PANS in School Settings Paperback
August 18, 2016**

by Patricia Rice Doran

CLINICAL GUIDELINES

- Thienemann M, Murphy T, Leckman J, Shaw R, Williams K, Kapphahn C, Frankovich J, Geller D, Bernstein G, Chang K, Elia J, Swedo S. Clinical Management of Pediatric Acute-Onset Neuropsychiatric Syndrome: Part I-Psychiatric and Behavioral Interventions. J Child Adolesc Psychopharmacol. 2017 Sep;27(7):566-573. doi: 10.1089/cap.2016.0145. Epub 2017 Jul 19. PMID: 28722481; PMCID: PMC5610394.
- Frankovich J, Swedo S, Murphy T, Dale RC, Agalliu D, Williams K, Daines M, Hornig M, Chugani H, Sanger T, Muscal E, Pasternack M, Cooperstock M, Gans H, Zhang Y, Cunningham M, Bernstein G, Bromberg R, Willett T, Brown K, Farhadian B, Chang K, Geller D, Hernandez J, Sherr J, Shaw R, Latimer E, Leckman J, Thienemann M. Clinical Management of Pediatric Acute-Onset Neuropsychiatric Syndrome: Part II-Use of Immunomodulatory Therapies. J Child Adolesc Psychopharmacol. 2017 Sep;27(7):574-593. doi: 10.1089/cap.2016.0148. Epub 2017 Jul 19. PMID: 36358107; PMCID: PMC9836706.
- Cooperstock MS, Swedo SE, Pasternack MS, Murphy TK. Clinical Management of Pediatric Acute-Onset Neuropsychiatric Syndrome: Part III-Treatment and Prevention of Infections. J Child Adolesc Psychopharmacol. 2017 Sep;27(7):594-606. doi: 10.1089/cap.2016.0151. Epub 2017 Jul 19. PMID: 36358106; PMCID: PMC9836684.



WHERE to get Information

- **Virginia Alliance for PANS/PANDAS Action:** vaforpa@gmail.com
- **VDH:** <https://www.vdh.virginia.gov/epidemiology/epidemiology-fact-sheets/pediatric-autoimmune-neuropsychiatric-disorders-associated-with-streptococcal-infections-pandas/>
- **PANDAS PHYSICIANS NETWORK:** <https://www.pandasppn.org/>
- **THE ALEX MANFULL FUND:** <https://thealexmanfullfund.org/>
- **ASPIRE:** <https://Aspire.care/>
- **EXPAND:** <https://expand.care/welcome/the-european-immuno-neuropsychiatric-association/#:~:text=EXPAND%20is%20a%20pan-European%20patient%20advocacy%20organization%20for,and%2For%20immunological%20problems%20with%20psychiatric%20and%2For%20behavioral%20symptoms.>
- **THE INTERNATIONAL OCD FOUNDATION:** <https://iocdf.org/>
- **THE JBC PANS AND PANDAS FOUNDATION:** <https://www.jbcfund.org/>
- **MENDING MINDS FOUNDATION:** <https://mminds.org/>
- **MOLECULARA LABS:** <https://www.molecularabs.com/>
- **NEUROIMMUNE FOUNDATION:** <https://neuroimmune.org/>
- **NEW ENGLAND PANS/PANDAS ASSOCIATION:** <https://nepans.org/>
- **NORTHWEST PANDAS/PANS NETWORK:** <https://www.nwppn.org/>
- **PACE FOUNDATION:** <https://pacefoundation4kids.org/>
- **PANDAS NETWORK:** <https://pandasnetwork.org/>



*In memory of all those whose life has been cut short due to immune-mediated
post-infection neuro-psychiatric disorders*

*let "...no life ever again be cut short - or interrupted - by any neuroimmune disorder."
(The Alex Manfull Fund)*



Together We Stand