



Pediatric Acute-onset Neuropsychiatric Syndrome (PANS): An Often-Overlooked Condition in Children



Good morning,
The webinar broadcast will begin shortly.

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Pediatric Acute-onset Neuropsychiatric Syndrome (PANS): An Often-Overlooked Condition in Children



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Program Presentations



Office of Disability Prevention for Children

Pediatric Acute-Onset Neuropsychiatric Syndrome Advisory Council

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Jay Smith

Program manager - HHSC
Office of Disability Prevention for Children



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Office of Disability Prevention for Children

Office of Disability Prevention for Children (ODPC)

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Purpose and Goals

- ODPC works to promote respect, foster understanding, and highlight the importance of prevention and early intervention initiatives in the lives of Texas children and families.
- ODPC also works to prevent developmental disabilities, including those that manifest in utero and during birth, in children ages 0-12.



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Areas of Focus

- Prevention of disabilities caused by maternal health issues during pregnancy.
- Prevention of injuries in children.
- Early identification and diagnosis of disabilities to ensure early intervention and services.
- Address co-occurring intellectual and developmental disabilities (IDD) and mental health (MH) conditions.




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Duties

ODPC's duties include:

- Educating the public.
- Promoting sound public policy.
- Identifying, collecting, and disseminating information and data.
- Collaborating with healthcare providers, stakeholders, and other state agencies.




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Program development specialist - HHSC
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Pediatric Acute Onset Neuropsychiatric Syndrome (PANS)

PANS and PANDAS are clinical conditions defined by the sudden "encephalitic-like" onset of obsessive-compulsive symptoms and/or severe eating restrictions, along with at least two concurrent cognitive, behavioral, or neurological symptoms.




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History

- **1980s** - Investigators at the National Institutes of Mental Health (NIMH) observed a group of children with obsessive-compulsive disorder who had an unusually abrupt onset of post-infectious psychiatric symptoms.
- **1990s** - Investigators began to focus on the association between infections with group A streptococcus, which led to the identification and naming of Pediatric Autoimmune Neuropsychiatric Disorder Associated with Streptococcus (PANDAS).
- **2010** - Experts met at the National Institutes of Health and drafted criteria for PANS.
- **2013** - Formation of The PANS Research Consortium, an interdisciplinary group of researchers and clinicians from academic institutions across the nation dedicated to the study of PANS.



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PANS Advisory Council

- Enacted by HB 2783 (86R)
- Established to advise HHSC and the Legislature on research, diagnosis, treatment, and education of PANS/PANDAS.




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PANS/PANDAS Awareness Day




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PANS & PANDAS

PANS

- Pediatric **A**cute-onset **N**europsychiatric **S**YNDROME

PANDAS

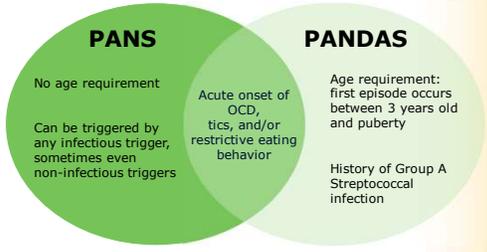
- Pediatric **A**utoimmune **N**europsychiatric **D**ISORDER Associated with **S**treptococcal infections



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PANS & PANDAS (Continued)



PANS	Overlap	PANDAS
No age requirement	Acute onset of OCD, tics, and/or restrictive eating behavior	Age requirement: first episode occurs between 3 years old and puberty
Can be triggered by any infectious trigger, sometimes even non-infectious triggers		History of Group A Streptococcal infection

Source: ASPIRE 2021



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Who Does it Affect?

- The true incidence of PANS/PANDAS is unknown.
- An estimated 1–2% of the pediatric population are affected by PANS, according to the PANS Research Consortium.
- Estimates suggest that about 11,000 children younger than 18 years old develop this illness each year in Texas.



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Who Does it Affect? (Continued)

- Peak age of onset is 6.5 years of age.
- Boys diagnosed with PANS outnumber girls approximately 2:1.
- Children diagnosed with PANS or PANDAS are typically between 1 – 13 years of age, but cases have been observed in older adolescents.
- 60% of diagnoses occur in children between the ages of 4 – 9.

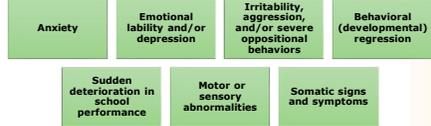


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What are the Symptoms?

- Abrupt onset of obsessive-compulsive disorder and/or severely restricted food intake.
- Concurrent onset of at least two neuropsychiatric symptoms:

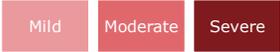



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Symptoms

- Severity varies.



- Symptoms can relapse and remit.
- Symptoms can change during and between flares.

Source: ASPIRE 2021



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Qazi Javed, M.D.

PANS Advisory Council member

Double board-certified integrative medicine physician practicing child, adolescent and adult psychiatry with Integrated Psychiatry Austin

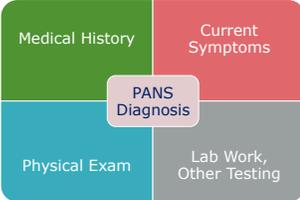
Diplomate, American Board of Integrated and Holistic Medicine




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How is the Diagnosis Made?




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How is it Treated?

1. Establish that PANS is the correct "diagnosis of exclusion" by completing a comprehensive diagnostic evaluation.
2. Provide symptomatic relief with psychiatric medications and behavioral interventions, prioritizing treatment of symptoms causing the greatest distress and disruption.
3. Treat symptoms resulting from neuroinflammation or post-infectious autoimmunity with anti-inflammatory or immunomodulatory therapies.



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How is it Treated? (Continued)

4. Evaluate the effectiveness of the treatment frequently, making modifications as warranted by improvement or worsening of symptoms. Symptom tracking tools may be helpful.
5. Treatment can be tapered or stopped when symptoms remit, but may become necessary again, given the relapsing-remitting nature of PANS symptoms.



TEXAS
Health and Human
Services

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Individualized Care

Individualized plan:

- Provide symptomatic relief.
- Treat post infectious autoimmunity and/or neuroinflammation.
- Treat source of infection.



Utilizes three complementary Interventions.

Source: Overview of Treatment of PANS, Swedo, MD et al, JCAP-Vol27, # 7, 2017

Source: ASPIRE 2021

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Treatment and Care

Antimicrobial Therapies

- Anti-streptococcal antibiotics.
- Intercurrent infections should be diagnosed and treated promptly.

Immunomodulatory Therapies

- Anti-inflammatories: NSAIDs, corticosteroids.
- Intravenous corticosteroids, Intravenous Immunoglobulin, Therapeutic Plasma Exchange and/or rituximab for moderate-to-severe PANS



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Treatment and Care (Continued)

Psychotherapeutic Therapies

- Psychotropic medications: "start low & go slow" approach
- Cognitive behavior therapy
- Exposure/response prevention
- Eye movement desensitization and reprocessing therapy
- Parent management techniques
- Family and individual therapy, occupational therapy, comprehensive behavioral therapy for tics, habit reversal therapy, play therapy
- Nutrition and diet counseling, inpatient hospitalization, school accommodations, and family support/local support groups



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Challenges

Diagnosing:

- Represents a heterogeneous group of disorders.
- An interdisciplinary illness in which the neuropsychiatric symptomatology, course, and severity varies from patient to patient.
- Insight into disease mechanisms and management of PANS are either unknown or misunderstood by many general practitioners, as it is a relatively newly discovered disease.



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Services

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Challenges (Continued)

Data from an unpublished survey of over 1,000 parents of children with PANDAS and/or PANS:

- Conducted by Moleculera Labs in 2018.
- On average, patients have seen up to **12 medical providers**, requiring **3 years** before receiving a diagnosis.
- At least **20% of patients** with PANDAS and/or PANS experience a delay of **more than 12 months** before receiving appropriate treatment, even after being diagnosed with this type of illness.



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Services

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Impact of PANS

Functioning of the Child

Affected activities of daily living:

- Math
- Handwriting
- Extracurricular activities
- Free play
- Organized sports
- Community and family social participation
- Higher-level thinking, attention, memory, sequencing
- Emotional coping
- Energy and drive

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Impact of PANS (Continued)

Impact on Social Structures

- Interaction with school, family and friends
- Medical system challenges

Caregiver Burden

- High level of caregiver burden
- Difficulty understanding PANS
- Poor family functioning
- Financial struggle

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Impact in the Educational Setting

Considering appropriate school accommodations and support services including, but not limited to:

- **General:** excusing the child's absences and not requiring makeup assignments or tests.
- **Separation anxiety and OCD symptoms:** CBT and ERP strategies; allowing a parent to be in or near the classroom; excusing the child from certain activities, allowing them to complete assignments using alternate methods.
- **Urinary problems:** frequent bathroom breaks, leaving the class without asking permission.

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Impact in the Educational Setting (Continued)

- **ADHD-like behavior:** preferential seating; short, simple instructions; extra time for assignments; earbuds for distractions.
- **Restrictive eating:** additional time for lunch; go home for lunch; separate space for eating.
- **Handwriting difficulties:** use of keyboard; no points off for spelling or penmanship; providing notes; having a note-taker in class; dictating tests and homework; enlarging worksheets; writing on large grid paper; using voice-recognition software or audio recorder.

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Impact in the Educational Setting (Continued)

- **Math difficulties:** using a calculator or times table; working with a resource teacher or tutor.
- **Poor physical or cognitive stamina:** shortening school day with reduced academic load; less homework; rest periods during the day; omitting or adapting physical education requirements.
- **Slowed processing speed:** reducing the number and length of assignments; providing both oral and written instructions, allowing extra time for tests and in-class assignments.

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Resources

- Alliance to Solve PANS & Immune-Related Encephalopathies (ASPIRE): <https://aspire.care/resources/families-parents-caregivers/>
- New England PANS/PANDAS Association (NEPANS): <http://www.nepans.org/resources.html>
- Pandas Physician Network: <https://www.pandasppn.org/resources/>
- Stanford Medicine: <https://med.stanford.edu/pans/patient-care/additional-resources.html>

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Sources

- PANS Advisory Council [Legislative Report](#)
- ASPIRE Alliance to Solve PANS & Immune-Related Encephalopathies
 - <https://aspire.care/what-is-pans/definition/>
 - <https://aspire.care/treating-pans/treating-pans-pandas/>



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[PANS Advisory Council](#)

Pediatric Acute-Onset Neuropsychiatric Syndrome Advisory Council



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Questions




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Thank you



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