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The information in this booklet is
not intended to provide
treatment for PANS and
PANDAS. Appropriate treatment
and advice should be obtained
directly from a qualified and
experienced doctor and/or
mental health professional.

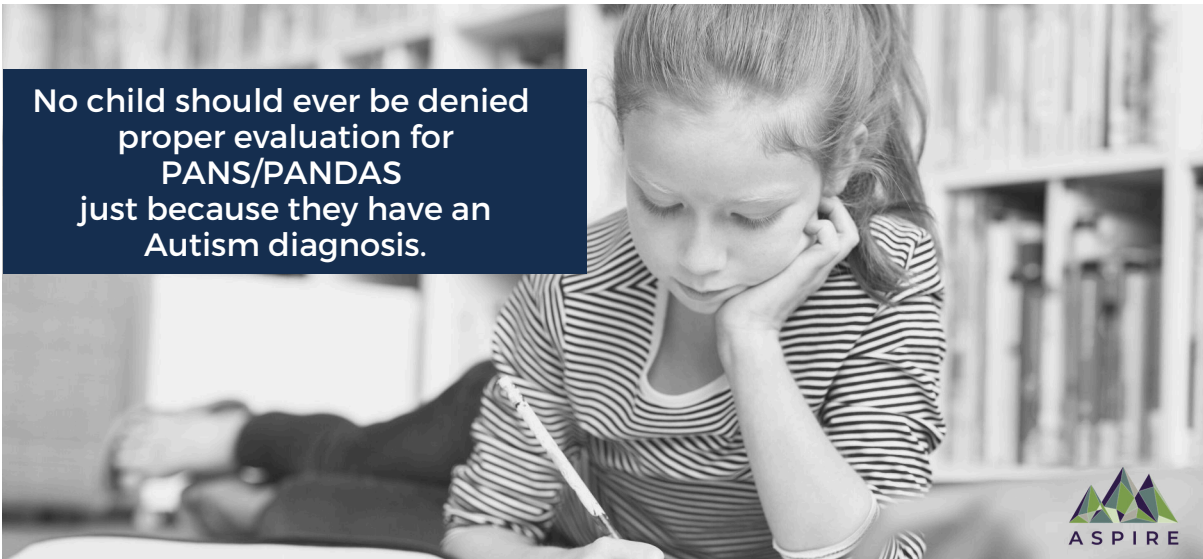
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PANS/PANDAS Guidelines for Children with Autism

PANS/PANDAS Guidelines for Children with Autism

Children who have autism spectrum disorder (ASD or autism) are at risk for the same medical conditions as children without autism. Therefore, they are susceptible to developing Pediatric Acute-onset Neuropsychiatric Syndrome (PANS) and Pediatric Autoimmune Neuropsychiatric Disorder Associated with Streptococcal infections (PANDAS).

However, diagnosing PANS and PANDAS can be more challenging in children who have autism because of the overlapping clinical presentations. For example, ritualized, repetitive behaviors are common to both disorders, so to make a diagnosis of PANS or PANDAS in a child with ASD, there must be an abrupt and discernable change in behavior such as new rituals, restricted food or fluid intake, excessive irritability or a worried/anxious appearance.



No child should ever be denied
proper evaluation for
PANS/PANDAS
just because they have an
Autism diagnosis.



Evaluating for PANS PANDAS

Important to note: Because of the sudden change in behavior, children with and without autism are often referred for psychiatric care without consideration of PANS/PANDAS. As a result, these children may be misdiagnosed and/or receive the wrong treatment.

Please consider PANS/PANDAS in a child (with or without underlying autism) who has an ABRUPT dramatic onset of obsessive-compulsive disorder (OCD) or avoidant restrictive food intake disorder (ARFID) and concurrently develops TWO or more of the following symptoms:

1. Anxiety (particularly separation anxiety)
2. Sensory or motor abnormalities (new sensitivity to light, sounds or textures; deterioration in drawing or handwriting, motor tics or abnormal movements)
3. Behavioral/developmental regression (baby talk, loss of previously acquired skills)
4. Deterioration in school performance (abrupt onset ADHD-like symptoms; inability to concentrate; loss of math skills, cognitive decline, memory loss)
5. Emotional lability (including suicidal depression and hallucinations of any sort)
6. Irritability, Aggression, and/or Severe Oppositional Behaviors
7. Somatic Signs & Symptoms:
 - a. Urinary symptoms (urgency, frequency, new onset of enuresis)
 - b. Sleep disturbances (difficulty falling asleep, REM disinhibition/ restless sleep, insomnia, night terrors, refusal to sleep alone)

While children must exhibit at least two of the comorbid symptoms to meet the criteria for PANS, most children have 4 or 5 new symptoms.

Those most frequently seen include:

- Separation anxiety (98%)
- Urinary frequency/urgency, enuresis (90%)
- Inability to concentrate (90%)
- Hyperalert (“deer in the headlights”) appearance (80%)
- Irritability (70-80%) and/or physical aggression (60%)
- Sleep disorders (80%)
- Hyperactivity (70%)
- Cognitive decline (60-70%) – especially shortened attention span, memory loss, difficulty concentrating, loss of math skills or changes in visuospatial perception
- Tics (50-60%)

Diagnosing PANS PANDAS

1

Review Symptoms,
Medical History,
Physical Exam

If it is PANDAS (due to a recent STREP infection), you may see on physical exam:

- Peeling fingers and toes
- Palate petechiae
- Scarletina rash
- Damaged nail bed vasculature
- Red ring around the anus (perianal strep)
- Choreiform movements (“piano playing fingers”)
- Strawberry tongue
- Sore throat
- No signs except behavioral changes as above

2

Draw Labs to
Understand Infections
and Immune System
Function

Note: The strep findings are most likely early and the choreiform findings are later.

3

Perform Imaging or
Other Testing to Rule
Out Other Conditions

Consider other triggers of PANS:

- Mycoplasma, Influenza, Coxsackie virus, Candida, virus or other infections
- Anesthesia
- Environmental exposures
- Stress

What do we see at school in a child with Autism and abrupt onset of PANS/PANDAS

- Increase in going to the bathroom OR gone too long – urinary frequency, OCD in toileting, dressing or handwashing
- Behavioral regression and loss of developmental milestones – separation anxiety, baby talk, toileting, social regression
- Change in energy levels – hyperactivity, or students too exhausted to perform or make it through the day due to sleeping issues
- Loss of executive function – disorganized, attentiveness, decision making, memory, time management, planning, following directions
- Increase in lateness, absences
- Child refuses to come into the school / clings to parent
- Increased rigidity or repetitive behaviors
- Increase or new onset of motor or vocal tics

With an ABRUPT onset of behavioral symptoms, a comprehensive medical evaluation is required before making a diagnosis of PANS/PANDAS. To ensure an accurate diagnosis, it is important to exclude other causes of acute-onset neuropsychiatric symptoms, including:

- Encephalitis (infectious, cerebral vasculitis)
- Child abuse, sexual abuse, psychological trauma
- Toxins, medications, illicit drugs
- Tumors, strokes

In any child (with or without ASD), PANS/PANDAS is a CLINICAL DIAGNOSIS, which is based on the history and physical examination. No lab test can rule it in or out. However, some laboratory studies may be helpful in determining if the child has an infectious trigger for their symptoms, or if there is underlying immune dysfunction.

- Cultures of sites commonly infected with bacteria or viruses, such as nasopharynx, throat, perianal region, sinuses
- Inflammatory markers – These tests are good assessments of underlying inflammation and can identify other conditions such as rheumatological conditions. (CRP, ESR, ANA)
- Infectious markers –These tests can provide information on recent infections, but they should be interpreted with care. (ASO, antiDNaseB Ab, mycoplasma IgG, IgM)
- Baseline laboratory studies, such as CBC w/ differential, chem panel, thyroid testing

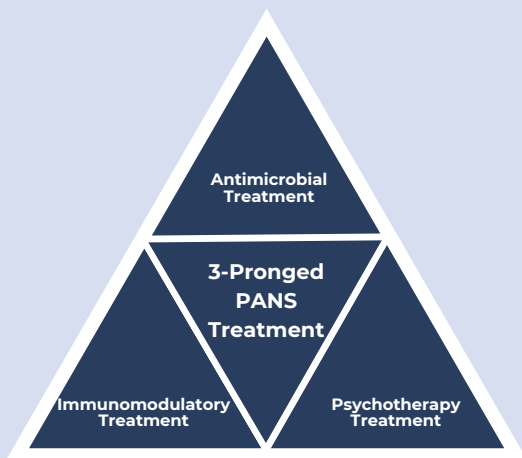
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Treating PANS PANDAS

The treatment of PANS/PANDAS is multi-dimensional, reflecting the complexity of the underlying disease mechanisms. A typical treatment plan will include each of the following:



“Treatment of PANS involves a three-pronged approach that utilizes psychiatric medications when appropriate to provide symptomatic relief, antibiotics to eliminate the source of neuroinflammation, and anti-inflammatory and immune modulating therapies to treat disturbances of the immune system.”

Overview of Treatment of PANS-JCAP Vol27, 2017 - Swedo, MD, Frankovich, MD, MS, Murphy, MD, MS

- Treat the Source – Eradicate documented/presumed infections with antimicrobials.
- Treat the Symptoms – Provide relief for the child’s specific symptoms through use of medications and behavioral interventions. Family therapy may also be helpful.
- Treat the Immune System – Restore normal immune function through use of immunomodulatory

The specific interventions to be employed will depend on the child’s clinical presentation and symptom severity. The PANDAS Physicians Network provides flowcharts summarizing care for Mild, Moderate, and Severe/Extreme cases of PANS/PANDAS.

Please see: <https://www.pandasppn.org/flowchart>

Overview of PANS Treatment Guidelines

- Initial course of antibiotics/antimicrobials (up to 30 days) if an infection is suspected
 - Penicillin, Amoxicillin-Clavulanate, Azithromycin, Clarithromycin, Cephalexin, Cefadroxil, Cefdinir depending on suspected/proven infection and local resistance
- Anti-inflammatory and antihistamine oral medication
- Antibiotic/antimicrobial prophylaxis with an ongoing concern for infection
- Cognitive Behavioral Therapy, Parent Management Techniques
- Immunotherapy/ Immune modulation based on severity
 - Diet/Probiotic/Anti-inflammatories/Steroids
 - IVIG, Plasmapheresis

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General Principles for Treating PANS PANDAS

- Establish the correct diagnosis – ACUTE ONSET
- Provide symptomatic relief and comprehensively treat symptoms causing the most distress (Thienemann et al, J Child Adol Psychopharm, 2017)
- Treat infections – therapeutic and prophylactically (Cooperstock et al, J Child Adol Psychopharm, 2017)
- Treat neuroinflammation and post-infectious autoimmunity with anti-inflammatory and immunomodulatory interventions (Frankovich, J Child Adol Psychopharm, 2017)
- Evaluate the effectiveness of treatment, modifying as warranted by relapsing and remitting symptoms (Swedo et al, J Child Adol Psychopharm, 2017)

If a child has sudden regressive Autism, they should be evaluated for PANS/PANDAS.

If a child has sudden worsening of symptoms associated with Autism, they should be evaluated for PANS/PANDAS.

If a child with Autism has new behaviors or symptoms that correspond to the PANS/PANDAS diagnostic criteria, they should be evaluated for PANS/PANDAS.

About ASPIRE

Our Mission

To improve the lives of children and adults affected by PANS, PANDAS, and related encephalopathies.

Our Vision

We aspire to create a world where children and adults affected by PANS, PANDAS and related encephalopathies obtain a timely diagnosis from informed providers and receive effective, proven and affordable treatments and support in all areas of daily living, without discrimination.

PANS is a devastating disorder but recovery is possible. Early diagnosis and treatment lead to improved outcomes. Unfortunately, many PANS/PANDAS patients do not receive a timely diagnosis or appropriate treatment due to a lack of education about this medical condition. When access to care is delayed, symptoms can worsen and become chronic. ASPIRE aims to improve the lives of those affected by PANS by closing the gap between the onset of symptoms and the start of treatment.