

PANDAS/PANS Parent Handout

WHAT ARE PANDAS AND PANS?

PANDAS is an abbreviation for Pediatric Autoimmune Neuropsychiatric Disorder Associated with Streptococcal Infections. The term was first used in 1998 to describe a subset of children and adolescents who have obsessive compulsive disorder (OCD - worries or intrusive, illogical thoughts and/or repetitive behaviors) and/or tic disorders, and in whom symptoms worsen following strep infections such as strep throat or scarlet fever. The PANDAS subgroup is part of a larger cohort of children whose symptom onset is unusually abrupt and dramatic, or Pediatric Acute-onset Neuropsychiatric Syndrome (PANS). PANS is characterized by an unusually abrupt onset of OCD or eating restrictions.

SYMPTOMS:

PANS always involves the abrupt onset of OCD and/or eating restrictions. PANS/PANDAS may occur in children with neurodevelopmental disorders, including autism, and would have similarly abrupt onset. The OCD or restricted eating is accompanied by at least two of the following with the waxing and waning course even with treatment:

1. Anxiety (especially worries about being separated from familiar people or places)
2. Developmental regression (acting much younger than actual age or losing milestones)
3. Extreme mood swings and/or depression (sometimes to the point of suicidal thoughts or attempts)
4. Personality changes, including irritability, aggression or oppositional behaviors
5. Deterioration in school performance due to ADHD-like symptoms of impulsivity, hyperactivity and concentration difficulties; new onset of difficulties with math or reading, deterioration of handwriting or drawing skills, and poor memory
6. Abnormal movements (motor tics, such as eye-blinking, shoulder shrugs, or vocalizations), sensory abnormalities (including new sensitivities to light, sound or textures)
7. Other signs and symptoms, including sleep disturbances, urinary urgency or frequency or new onset of bed-wetting and daytime accidents

SUGGESTIONS FOR PARENTS:

- ▶ **Build a team** of medical professionals for your child that you trust. It is common for a symptomatic child to need collaboration from a pediatrician, immunologist, neurologist, and child psychiatrist/child psychologist to manage symptoms. The treatment options and guidelines for care are evolving; research to find specialists through PANDAS Physicians Network.
- ▶ **Ask provider to help find a support group such as:** www.praikids.org.
- ▶ **Make a medical journal** for your child. Document each and every appointment. Ask for copies of the doctor notes and test results. If possible, go back and request all medical records for your child, including growth charts, since birth – to help document any past illnesses /procedures. Build a timeline for your child and note every major illness or milestone. Bring your journal to every appointment.
- ▶ **Be careful and diligent of germs**, especially when traveling or going to the dentist. Avoid water fountains, when possible. If your child is having a dental procedure (other than a regular cleaning), request an antibiotic prior to the procedure. Strep is known as a common trigger, but it is not the only illness that will cause symptoms to re-occur.
- ▶ **Be transparent** regarding your concerns with your doctor's and school personnel. Consider reassessing expectations and be patient with your child during this period.

For additional information, please reference the following resources:

PANDAS/PANS School Systems Handout
PANDAS/PANS Frequently Asked Questions (FAQs)