

Effects of PANDAS/PANS on Communication: What SLPs Need to Know

Authors: Kathryn Ward, MS, CCC-SLP and Jessica Edelstein, MA, CCC-SLP

Disclosure Statements:
Kathryn Ward has no relevant financial relationships to disclose. Kathryn is a proud parent of a child with PANDAS.
Jessica Edelstein has no relevant financial or nonfinancial relationships to disclose.

Poster Presentation at the American Speech-Language-Hearing Association's National Convention, November 14, 2015

What is PANDAS?

PANDAS stands for Pediatric Autoimmune Neuropsychiatric Disorders Associated with Streptococcal infections.

What is PANS?

Pediatric Acute-Onset Neuropsychiatric Syndromes is the larger umbrella under which PANDAS falls. In PANDAS, the known trigger is strep. In PANS, the trigger may be some other viral or bacterial infection or environmental trigger. Notably, a child's initial trigger may be strep, but they may in the future flare when exposed to other infectious agents as well.

Symptoms? Note: symptoms relapse/ remit, NOT wax/wane

- **Abrupt, dramatic onset** of obsessive-compulsive disorder or severely restricted food intake.
- Concurrent presence of additional neuropsychiatric symptoms, with similarly severe and acute onset, from at least two of the following seven categories:
 - Anxiety
 - Emotional lability and/or depression
 - Irritability and/or severely oppositional behaviors
 - Behavioral (developmental) regression
 - Deterioration in school performance
 - Sensory or motor abnormalities
 - Somatic signs and symptoms, including sleep disturbances, enuresis or urinary frequency.
- Symptoms are not better explained by a known neurologic or medical disorder, such as Sydenham chorea, systemic lupus erythematosus, Tourette disorder, or others.

Important for SLPs:

- *Feeding difficulties
- *Sudden onset disfluencies
- *Changes in executive function and school performance
- *Handwriting deterioration
- *Selective Mutism
- *Sensory abnormalities
- *Behavioral regression, including baby talk



What causes PANDAS/PANS?

“New and evolving research has begun to substantiate that this syndrome involves a misdirected autoimmune process that affects or weakens the blood brain barrier. The region of the brain primarily affected is the basal ganglia. These are a group of structures that act as switching stations in the deepest inner region of the brain. Some of the brain function area managed via the basal ganglia include: movement, cognitive perception, habit, executive “logic based” thinking, emotions and the endocrine system.”

Source: PANDAS Network 2015 Fact Sheet, <http://pandasnetwork.org/wp-content/uploads/2015/09/2015-PNETWORK-fact.pdf>

Management of PANDAS/PANS looks at:

- Treating and preventing infections
- Treating immune disturbances
- Treating symptoms (Cognitive-Behavioral Therapy and/or psychotropic medications)

Communication and Feeding Effects



Researchers hypothesize in children with PANDAS/PANS, the body is creating antibodies that are directed at areas of the brain, including the basal ganglia. Researchers also note that in children with PANS, “[s]peech is often affected, with a variety of notable observations, including “baby talk” secondary to developmental regression, a paucity of speech, (selective) mutism, or new onset of stuttering” (Chang et al, 2015). A connection between the basal ganglia and stuttering has been suggested previously in the literature (Abwender et al, 1998; Gracco, 1991; Caruso, 1991; Giraud et al, 2008; Alm, 2004).

Dr. Gerald Maguire, author of the case study entitled “Stuttering onset associated with streptococcal infection: A case suggesting stuttering as PANDAS” in the Annals of Clinical Psychiatry in 2010, stated:

“I also need to reach out to [...] the **speech-language pathology** community because many of the children are referred there. I think it’s fine to be in forms of speech therapy, but I’m afraid the child may begin a long term course of speech therapy when it could be a PANDAS child who should have the appropriate referral” (Triffiletti, 2012).

As indicated by the diagnostic criteria, children with PANDAS/PANS may present with feeding challenges as part of their symptoms. Feeding challenges are present in approximately 1 in 5 cases.

source: <https://www.pandasppn.org/ppn-pans-diagnostic-guidelines/>

Restricted food intake in PANDAS/PANS may be a result of OCD symptoms. These can present as fears of choking or vomiting, contamination fears (toxins, germs, cleanliness, too many calories), guilt (not deserving to eat), and sometimes sensory issues. Refusal to eat or drink can also be a compulsion (e.g., can't eat out of fear that harm will come to someone else or themselves). Body dysmorphia can sometimes develop if the restricted intake continues.

What can SLPs do?



Most importantly, SLPs should acquaint themselves with the symptoms of PANDAS/PANS. Although there is no “typical” presentation of symptoms, clinicians should keep in mind the diagnostic criteria outlined by the NIMH. Children seen for a fluency evaluation may present with comorbid symptoms including OCD, motor or verbal tics, urinary frequency, sleep difficulty, degradation of handwriting ability, emotional lability, changes in eating habits/food refusals, or developmental/behavioral regressions.

- **Look for co-morbid symptoms during evaluations. Do symptoms relapse/remit?**
- **Ask about a family history of frequent strep infections, rheumatic fever, or autoimmune disease in patient histories.**
- **Inquire if communication or feeding difficulties tend to come and go, particularly during or after an illness.**
- **Pay attention to sudden onset.**
- **Treat the communication or feeding symptoms in conjunction with medical management.**
- **Make appropriate referrals when necessary.**

Resources and References

- Moleculera Labs <http://www.moleculeralabs.com> (full text of the JCAP articles on PANDAS/PANS under Physicians resources menu tab)
- PANDAS Network <http://pandasnetwork.org/> (find a PANDAS/PANS specialist by state)
- PANDAS Physician Network <https://www.pandasppn.org/>
- Chang, K., Frankovich, J., Cooperstock, M., Cunningham, M.W., Latimer, M.E., Murphy, T., Pasternack, M., Thienemann, M., Williams, K., Walter, J., Swedo, S.E. (2015). Clinical evaluation of youth with Pediatric Acute-Onset Neuropsychiatric Syndrome (PANS): recommendations from the 2013 PANS Consensus Conference. *Journal of Child and Adolescent Psychopharmacology*, 25(1), 3-13.
- Fournier, A. (2012, April). What school psychologists should know about streptococcal infections. *School Psychology: From Science to Practice*. (5.1). Retrieved from <https://psychology.illinoisstate.edu/grad/diversity/recruitmentandretention.pdf>.
- “Information about PANDAS.” [n.d.]. *National Institute of Mental Health*. Retrieved from <http://www.nimh.nih.gov/labs-at-nimh/research-areas/clinics-and-labs/pdnp/web.shtml>
- Maguire, GA, Viele, SN, Argwal, S, Franklin, DL. Stuttering Onset associated with streptococcal infection: A case suggesting stuttering as PANDAS. *Annals of Clinical Psychiatry*. 2010 Nov;22(4):283-4. Retrieved from https://www.aacp.com/pdf%2F1110%2F1110ACP_Letters_Agarwal.pdf.
- Swedo, S. and Grant, P. (2010, March 28). PANDAS: A Model for Autoimmune Neuropsychiatric Disorders. *Primary Psychiatry*. Retrieved from http://www.stlocd.org/handouts/Pandas_Autoimmune.pdf.
- Trifiletti, Rosario. (2012, December 13). *House Calls with Dr. Trifiletti-Stuttering and OCD* [audio podcast]. Retrieved from <http://www.blogtalkradio.com/radiopandas/2012/12/13/house-calls-wdr-trifiletti--stuttering-ocd>.
- Tona, J. and Posner, T. (2011). PANDAS/PITAND: Recognizing and treating children with Pediatric Autoimmune Neuropsychiatric Disorders in OT. *Pandas Network*. Retrieved from <http://pandasnetwork.org/wp-content/uploads/2013/09/PANDAS-PITAND-and-OT.pdf>.

Please contact the authors with any questions or comments at kellyward@gmail.com or jedelberry@yahoo.com