LEARN ABOUT PANS PANDAS

If your child has new or suddenly increased

Food Avoidance or Eating Restriction

along with other behavior, neurological or cognitive changes, it might be PANS/PANDAS.

"In youth with PANDAS, **food restriction** has been reported to occur in the context of **obsessional fears about contamination**, as well as in the context of the sudden onset of fears of **swallowing, choking, or vomiting** that are often **associated with sensory phenomena** (e.g., the perceived texture or appearance of the food." *Disordered Eating and Food Restrictions in Children with PANDAS/PANS. Toufexis, DO, et al. JCAP Vol 25, 2015*

PANS/PANDAS Symptoms

- OCD
- Severe Food Restriction
- Anxiety, Separation Anxiety
- Mood Swings, Depression
- Irritability, Aggression, Severe Oppositional Behaviors
- Developmental Regression
- Deterioration in School Work, Loss of Math Skills, Handwriting Changes
- Sensory Processing Issues, Tics, ADHD like symptoms
- Sleep Problems
- Enuresis, Urinary Frequency

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PANS/PANDAS
Food Restrictions

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Disordered Eating and Food Restrictions in Children with PANDAS/PANS. Toufexis, DO, et al. JCAP Vol 25, 2015

The rate of eating disorders in children is increasing, especially in males. "Between 1999 and 2006, there was an 119% increase in eating disorder-related hospitalizations for children < 12 years of age." **This increase may be linked to PANS.** The authors of the study hope that a PANS diagnosis will be considered in cases with an acute-onset food restriction or avoidance. **The therapies and outcomes for PANS cases are different than those with ARFID or AN since antibiotics and/or immunomodulatory treatments can be curative.**

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The children in the study met the criteria for ARFID. Most "had a paralyzing fear of some adverse consequence of eating normally," believing they would vomit or choke, and the food was contaminated. The three children, who expressed concerns about "getting fat" or body image, developed those thoughts later.

"Restricted eating also has been reported to occur **secondary to new onset of body image distortions** of being ‘‘too fat’’ or not having a ‘‘six-pack’’."

Study Details:

- *Children in Study-29 (Male-20. Female-9. Ages 5-12)*
- *Infections: GAS Infection-18. GAS Exposure-6. Other Infection-5*

Study Results:

- *Contamination Fears-19 (Germs-12. Poison-3. Allergens , Bleach, Illicit Drugs, "Essence of the Personality of other People"-1 of each)*
- *Vomiting Fears-8, Choking Fears-6, Refused to Swallow Saliva-5, Refused Food for Several Days-5, Concerns about Weight/Shape-3*

What is ARFID?

"**Avoidant and restrictive food intake disorder (ARFID)** is a diagnosis in Diagnostic and Statistical Manual of Mental Disorders, 5th ed. (DSM-V) (American Psychiatric Association 2013). Like other DSM-V disorders, the diagnostic criteria for ARFID describe a specific clinical presentation, without regard for etiology, response to treatment, comorbid symptoms, or even acuity of onset."

#PANSstudies

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Use of Intravenous Immunoglobulin in the Treatment of Twelve Youths with Pediatric Autoimmune Neuropsychiatric Disorders Associated with Streptococcal infections

Miro Kovacevic, MD, Paul Grant, MD, and Susan E. Swedo, MD - JCAP Vol 25, No 1, 2015 - DOI: 10.1089/cap.2014.0067

Abstract: *"This is a case series describing 12 youths treated with intravenous immunoglobulin (IVIG) for pediatric autoimmune neuropsychiatric disorder associated with streptococcal infection (PANDAS). Although it is a clinically based series, the case reports provide new information about the short-term benefits of IVIG therapy, and are the first descriptions of long-term outcome for PANDAS patients."*

Patient A

Patient A was a 7.5-year-oldv with "initial OCD symptoms included intrusive thoughts, contamination fears (urine, saliva), repetitive compulsive behaviors..., the need to remember what foods she ate looked like, and avoidance of foods she feared she would not remember), and reassurance seeking." After several treatments including abx, ivig, steroids and CBT and several relapses, 4 years later she is reportedly doing "very well."

Patient D

Patient D was a 9.5-year-old boy who "developed a fear of choking and chronic abdominal pain, and the resultant food refusal led to a 4.5 kg (20%) weight loss, hospitalization, and tube feedings. These symptoms persisted for *1 year prior to his evaluation and treatment." He was given prednisone, IVIG and prophylactic antibiotics resulting in a full remission for a year at the time of follow up.

Patient G

Patient G was a 9-year-old boy with a history of sudden onset OCD, anxiety, and tics. He later developed more severe sudden onset severe PANS symptoms. "Most significantly, he developed compulsive, recurrent vomiting of all foods and liquids, including water, leading to a 7 kg weight loss. He was diagnosed with postinfectious gastroparesis, and fed exclusively via nasojejunal tube." A steroid burst brought temporary improvements. IVIG created dramatic improvement, which allowed him to resume normal food intake orally and the removal of his nasojejunal tube. He did have some residual vomiting, which did not result in weight loss but did interfere with normal life. A second round of IVIG resulted in complete remission. He was still in remission at three-year follow up.

Patient L

Patient L was an 8-year-old boy who along with OCD and other PANS symptoms had "a number of ill-defined abdominal complaints that prompted a gastroenterological evaluation (with negative results) and that eventually led to the patient's complete refusal to eat. The patient lost nearly 25% of his body weight (declining from 22 kg to 17 kg) and was hospitalized numerous times for tube feedings and psychiatric interventions." Several SSRI's showed no benefit. Amoxicillin provided small improvement in symptoms and allowed for stabilization in weight loss. Steroids and IVIG created remarkable improvements and the patient "was able to visit a restaurant (a previously unacceptable venue) and to eat a meal without difficulty." A second round IVIG was needed after progress stalled and since, recovery has held firm.

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Clinical Case Rounds in Child and Adolescent Psychiatry: Certain Eating Disorders May Be a Neuropsychiatric Manifestation of PANDAS: Case Report

Cynthia V. Calkin MD; Carlo G. Carandang MD, ABPN (Dip) J Can Acad Child. Adolesc Psychiatry. 2007 Aug; 16(3): 132–135. PMID: 18421369

This case report describes an eight-year-old with PANDAS, OCD, Anorexia Nervosa (AN). "The OCD symptoms were not confined to the Eating Disorder (ED) and the ED symptoms were not exclusively OCD-based." "This case suggests that EDs, in some cases, may be an autoimmune-mediated neuropsychiatric manifestation or clinical sub-type of PANDAS. The patient in our case rapidly recovered from his ED and OCD. Perhaps by considering the proposed pathophysiology of PANDAS and by targeting the management of future GABHS infections, the usual course of EDs and OCD could be altered in patients believed to have an autoimmune etiology."

The patient is an eight-year-old boy with "significant weight loss," behavior changes, and recurrent GAS infections. After being taught healthy eating at school, he began reading food labels and avoiding certain foods. He began looking in the mirror and expressing concerns about his weight. Then he refused to eat his mother's food as he was distrustful of what she was putting in it. So he only at packaged foods that he determined safe. As a result, he was only eating 200 calories a day. After another strep infection, he developed tics and often did rituals before being able to eat; stating that they, "helps me to relax" and "It distracts me from the images in my head" as intrusive thoughts led him to think that he "must do the hand thing before you eat or the food will poison you" and "your Mommy is a criminal and contaminating your favourite things." He knew these thoughts were not real, but he was not able to prevent himself from doing them. Additionally, "he developed rules such as having to walk only on his father's right side so as to not 'give off (his) fat cells to people walking by."

"His weight dropped 8kg secondary to his food refusal and he was admitted to hospital at 75% ideal body weight with a score of 33 (extremely severe OCD) on CY-BOCS (Children's Yale-Brown Obsessive Compulsive Scale) (Scahill et al., 1997).... It was our opinion that he had PANDAS and he was diagnosed with OCD and AN." His treatment included re-feeding via an ED protocol, psychiatric medications, one was tolerated while one was not. He received CBT. As he continued to have PANDAS flares, he was given clarithromycin and started to gain weight. "After three weeks of treatment his CY-BOCS score was 19 (moderate OCD) and all choreoform-like movements had ceased. After five weeks of treatment he was no longer having any OCD thoughts and he was not engaging in any ritualistic behaviours." Once he was at a normal weight, he had a tonsillectomy and has remained stable for 11 months.

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