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PANS (Pediatric Acute-Onset Neuropsychiatric Syndrome) is a medical disorder where a misdirected immune response results in both physical and psychiatric presentations. The diagnostic criteria for PANS are as follows:

1) Abrupt, acute onset of obsessive-compulsive disorder or severe restrictive food intake
2) Concurrent presence of additional behavioral or neurological symptoms with similarly acute onset and severity from at least two of the seven categories:
    a) Anxiety, separation anxiety
    b) Emotional lability or depression
    c) Irritability, aggression, and/or oppositional behaviors
    d) Behavioral or developmental regression
    e) Deterioration of school skills (math skills, handwriting changes, ADHD-like behaviors)
    f) Sensory or motor abnormalities, tics
    g) Somatic signs: sleep disturbances, enuresis or urinary frequency
3) Symptoms are not better explained by a known neurologic or medical disorder
4) Age requirement: none

The true prevalence of PANS is unknown due to poor diagnosis but is estimated to affect 1 in 200 children each year. The average age of diagnosis 3-13 years, though PANS has no age requirement. An estimated 65% of PANS patients have a relapsing/remitting course, meaning the symptoms are improved or gone at times (remitting) and may return (relapsing) (2). During each recurrence, symptoms can worsen, and new symptoms can manifest. While the diagnostic criteria describe an “acute onset,” some children’s initial symptoms are mild, are attributed to developmentally appropriate behavior, or are not diagnosed due to lack of education and awareness about the condition. Symptoms can range from mild to severe, and most children exhibit most of the symptoms. In mild cases, a child may continue to attend school. In severe cases, symptoms can become life-threatening, often due to extreme food restriction or suicidality. Many children with PANS are diagnosed with a psychiatric illness and prescribed psychotropic medications rather than being evaluated and treated for an underlying infection. However, a timely diagnosis and appropriate treatment lead to better long-term outcomes.

PANS can be caused by many triggers that create inflammation in the brain. These can include infections (such as upper respiratory infections, Influenza, Mycoplasma, Lyme and others) as well as metabolic disturbances and other environmental factors. PANDAS is the only known subset of PANS, specifically caused by Group A Streptococcal infections. When a genetically susceptible host contracts an infection such as strep, the human body makes antibodies against the strep. However, the bacteria puts antigens on its cell wall that look like human host tissue. The human antibodies cannot tell the difference between the bacteria and the human tissue, and this is when the misdirected immune response occurs. The antibodies begin attacking

human tissue -- in the case of PANS, neurons in the part of the brain called the basal ganglia (1). The basal ganglia is responsible for voluntary motor control, cognition and reward process, executive functioning, behavior and emotions.

This is still a relatively new diagnosis in terms of medical knowledge.The original researchers always believed PANDAS represents a small fraction of the number of patients with OCD and Tourette's Syndrome (who have tics). However, early on, when neurologists tested these patients for strep and it was not found, they questioned the existence of the condition. There was a national meeting held with proponents of both sides present, and this is where they developed the term PANS (1). A group of experts known as the PANS Consortium issued diagnostic guidelines to help clarify the condition, and these diagnostic guidelines were published in the Journal of Child and Adolescent Psychopharmacology in 2017.The appropriate treatment involves a three-pronged approach including antimicrobial treatment, immunomodulatory treatments, and symptomatic relief with psychotherapeutic treatments.

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My 5-year-old daughter Brielle developed PANS after a common viral infection in October 2019. Over the course of 2 days, she developed the worst case of obsessive-compulsive disorder that I have ever seen as a psychiatrist, believed that she had swallowed worms or a large amount of hair, and began refusing to eat as she believed all of her food was contaminated. She developed a new lipsmacking tic, sensory abnormalities and uncharacteristic aggression. My daughter developed a textbook presentation of PANS. Out of 23 symptoms, she exhibited 19 to a moderate or severe degree. Despite this, she was misdiagnosed by multiple physicians. I was woefully undereducated about this condition despite being a practicing psychiatrist, but I continued to push for answers as I knew her symptoms were not primarily psychiatric in nature. As difficult as this was, we were fortunate to have a quick diagnosis by most standards. She has fully recovered with treatment (ibuprofen, oral steroids, dietary changes and play therapy). Thank you for taking the time to learn about this condition that has affected so many families, and considering how we may improve the chance of recovery for their children as well.

Respectfully,

Tara Richardson, M.D.

Works Cited

1. Swedo, Susan. "A Historical Perspective on PANS". Royal University Hospital i n Saskatoon, Canada. 10 October 2015.

2. Zagor, F., & Kapetanakis, C. (2020, June 20). PANDAS/PANS - The Frequently Misdiagnosed Behavioral/Neurological Syndrome. Retrieved December 10, 2020, from aspire.care/clinicians/natcon-behavioral-health-presentation/

The majority of the graphics used for the oral presentation are courtesy of ASPIRE (The Alliance to Solve PANS & Immune-Related Encephalopathies, www.aspire.care) and/or Susan, Swedo, M.D.