Testimony of Tara Richardson, M.D.
March 10, 2022

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) and the quick implementation of the correct treatment was a big contributing factor to her progress. 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.

<u>Works Cited</u>

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.

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EDUCATION

07/2013 – 11/2017	University of Kansas School of Medicine, Wichita, KS Psychiatry Residency
07/2009 – 05/2013	University of Kansas School of Medicine, Wichita, KS Doctor of Medicine
06/2008 – 06/2009	University of Kansas School of Medicine, Kansas City, KS Post Baccalaureate Program
08/2004 – 05/2008	University of Kansas, Lawrence, KS Bachelor of Arts in Anthropology

LICENSURES AND CERTIFICATIONS

2019 – Present	Missouri Board of Healing Arts License #2019025536
2018 – Present	American Board of Psychiatry and Neurology Board Certification
2015 – Present	Kansas State Board of Healing Arts Medical License #0438478

PROFESSIONAL EXPERIENCE

06//2019 – Present	Independent Contractor currently working with the following practices and locations: Integrated Psychiatric Consultants, P.A. FreeState Healthcare in Wichita, KS and several associated rural clinics KVC Children's Psychiatric Hospitals Mitchell Co. Hospital Geriatric Special Care Unit and Senior Life Enrichment Program South Central Kansas Medical Center Senior Health Unit in Ark City, KS
12/2017 – 06/2019	University of Kansas School of Medicine – Wichita Department of Behavioral Health and Sciences Clinical Assistant Professor Medical Director of Generations Senior Behavioral Health Unit in Newton, KS Medical Director of Via Christi Psychiatry Residency Clinic in Wichita, KS

PUBLICATIONS

2019	Book chapter on SSRIs in Antidepressants: From Biogenic Amines to New Mechanisms of Action
2018	Journal of Gerontology and Geriatric Medicine: An Individualized Music-Based Intervention for Acute Neuropsychiatric Symptoms in Hospitalized Older Adults with Cognitive Impairment
2017	Expert Opinion on Drug Metabolism and Toxicology: Clinically Relevant Treatment Considerations Regarding Lithium Use in Bipolar Disorder

HONORS AND AWARDS

2019	Recognized IPC Provider Who Went Above and Beyond in 2019
2017	Chief Resident Award
2017	Award for Excellence in Research
2017	KU Psychiatry Departmental GEM (Going the Extra Mile) Award
2016	Resident Award for Excellence in Outpatient Care
2015	Most Outstanding Resident (as voted by medical students)

2013	Best Medical Student Performance in a Psychiatry Elective
2009 – 2013	Marshall and Mabel E. Flowers Scholarship Recipient
2004 – 2008	University of Kansas Watkins-Berger Scholar
2004 – 2008	University of Kansas Honors Program

PROFESSIONAL ORGANIZATIONS

2013 – Present	American Psychiatric Association
2013 – Present	Kansas Psychiatric Association, previously served as Councillor
2013 – 2022	Medical Society of Sedgwick County
2013 – 2022	Kansas Medical Society

PROFESSIONAL ACTIVITIES

2021 – Present	PANS advocacy work with the Neuroimmune Foundation
2020 – 2021	Integrative Psychiatry Institute Fellowship Program
2019 – 2021	Volunteer Faculty at KU School of Medicine - Wichita
2018 – 2019	Resident Faculty Communication Committee
2018 – 2019	Expert Content Review for Kansas Journal of Medicine
2016 – 2017	Scholars in Medicine and Research Training Program
2016 – 2017	Chief Resident
2015 – 2016	Associate Chief Resident
2009 – 2013	Doctors' Notes (KU School of Medicine a capella group)

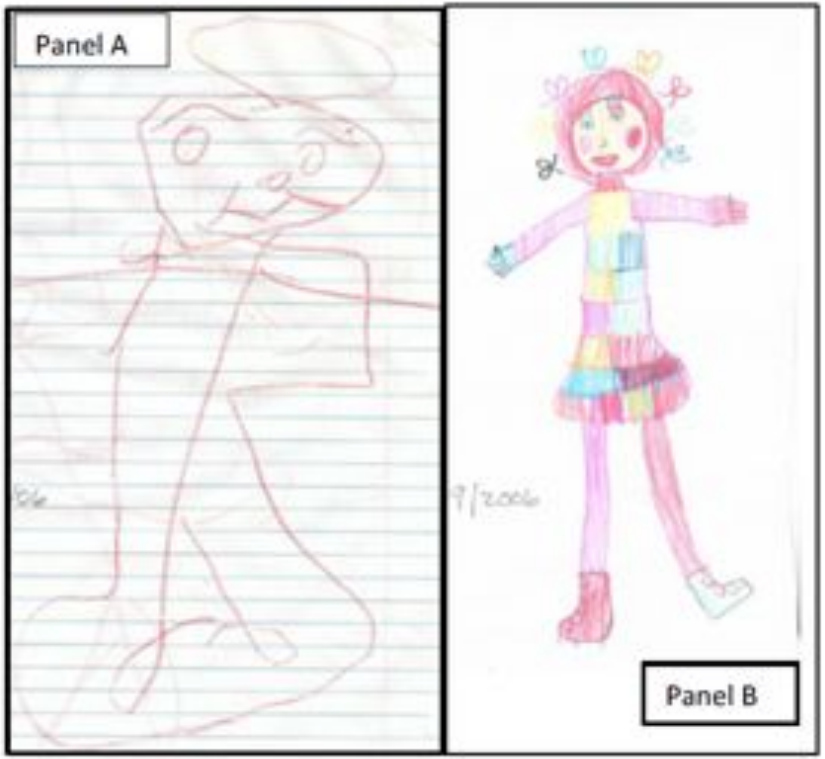
PANS Diagnostic Criteria

1. Abrupt, acute onset of
   - Obsessive-compulsive disorder or severe restricted 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:
   - Anxiety, separation anxiety
   - Emotional lability or depression
   - Irritability, aggression, and/or oppositional behaviors
   - Behavioral or developmental regression
   - Deterioration of school skills (math skills, handwriting changes, ADHD-like behaviors)
   - Sensory or motor abnormalities, tics
   - 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

Kiki Chang et al, 2015

Who Gets PANS/PANDAS?

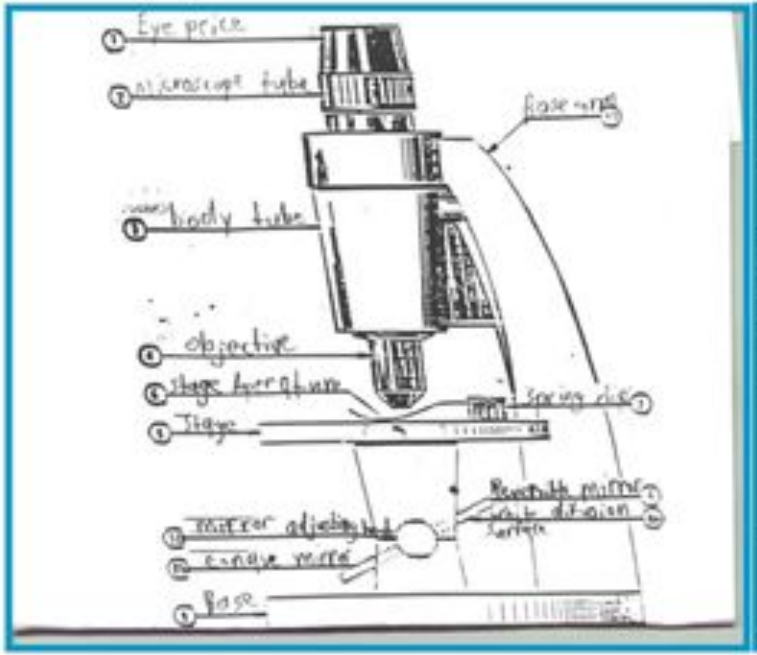
- **How Many Have PANS?** Estimated at 1 in 200
- **Average Age of Diagnosis:** 3-13 years old
- **Peak Age of Onset**: 4-9yrs (69%)
- **Below Age 8:** 4.67 Boys: 1 Girl
- **Above Age 8:** 2.6 Boys: 1 Girl
- **No Age Requirement:** Symptoms can continue into adulthood & adult-onset can happen
- **Family History:** 70% of PANDAS families a have history of autoimmune or strep related illness



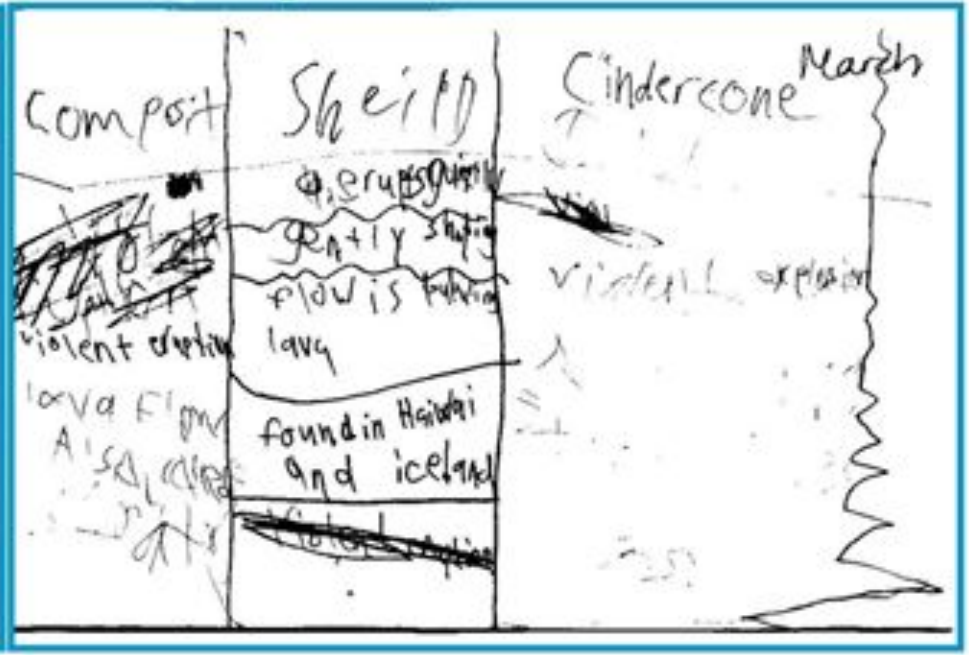
Panel A– Drawing produced during an acute exacerbation of OCD and other symptoms of PANDAS which appears quite messy and immature.

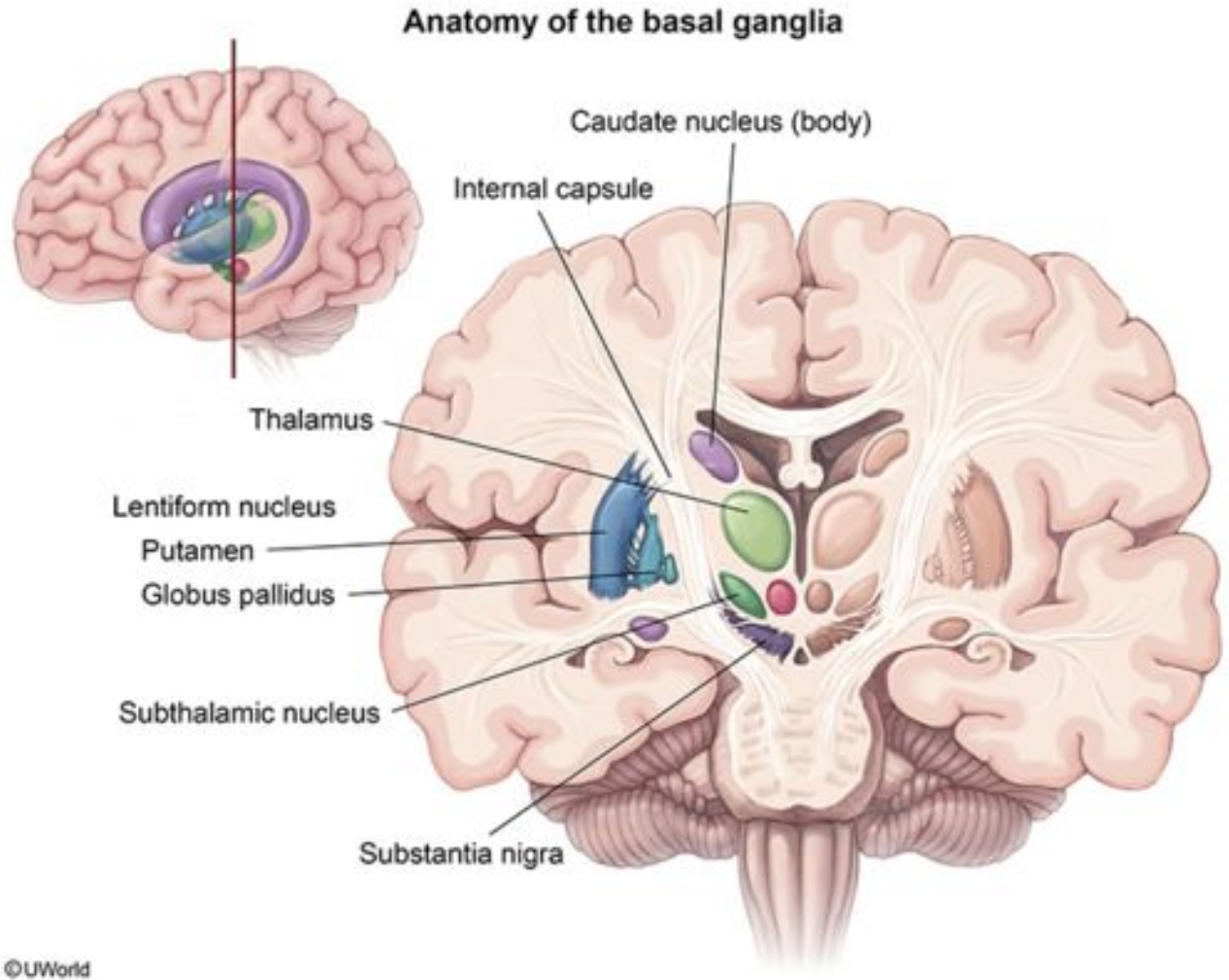
Panel B – Age-appropriate picture drawn after treatment with IVIG and symptomatic improvement.

Before symptom onset



During acute episode




Anatomy of the basal ganglia
Caudate nucleus (body)
Internal capsule
Thalamus
Lentiform nucleus
Putamen
Globus pallidus
Subthalamic nucleus
Substantia nigra
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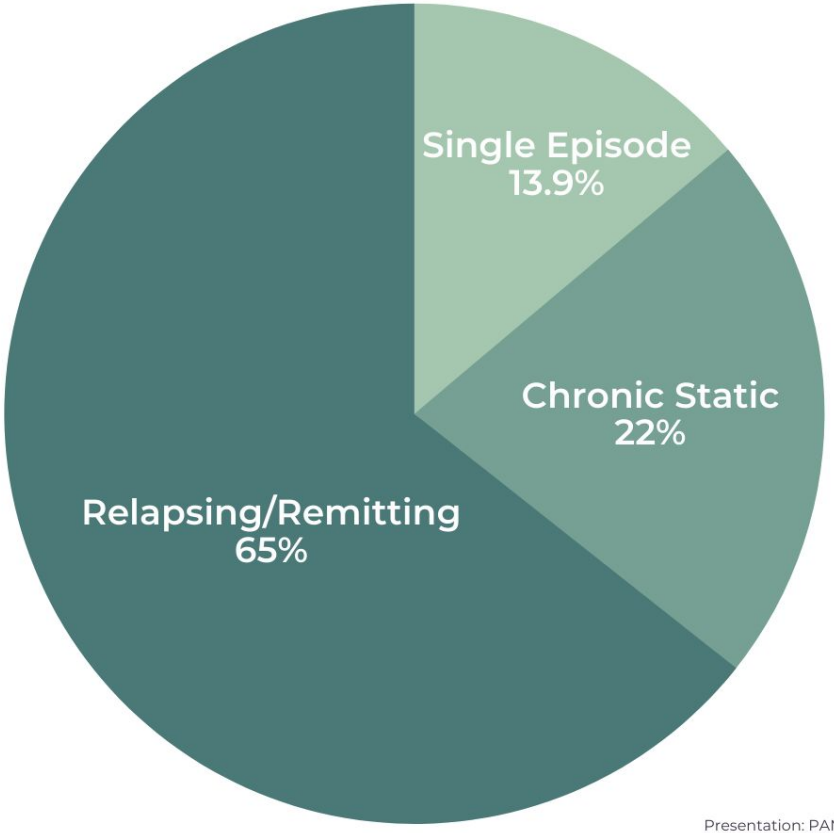
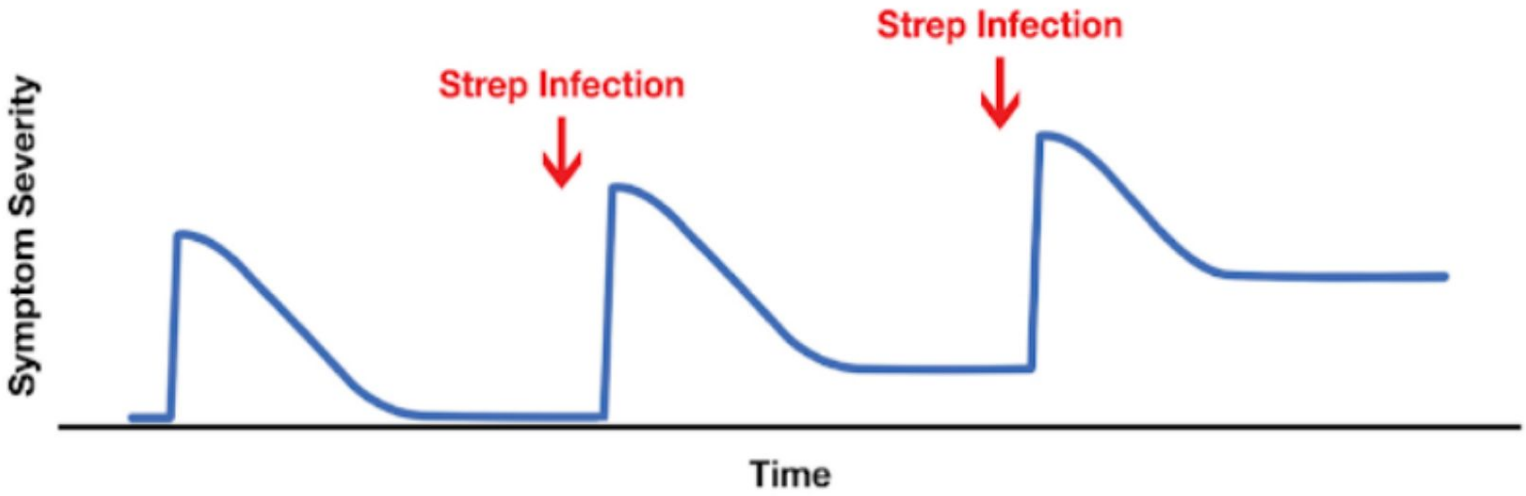
Stanford PANS Clinic Cohort - Disease Course



Presentation: PANS Diagnosis & Assessment, Thienemann MD, Willett MD Phd

Repeated Flares Can Move Baseline



Do symptoms go back to baseline between flares?

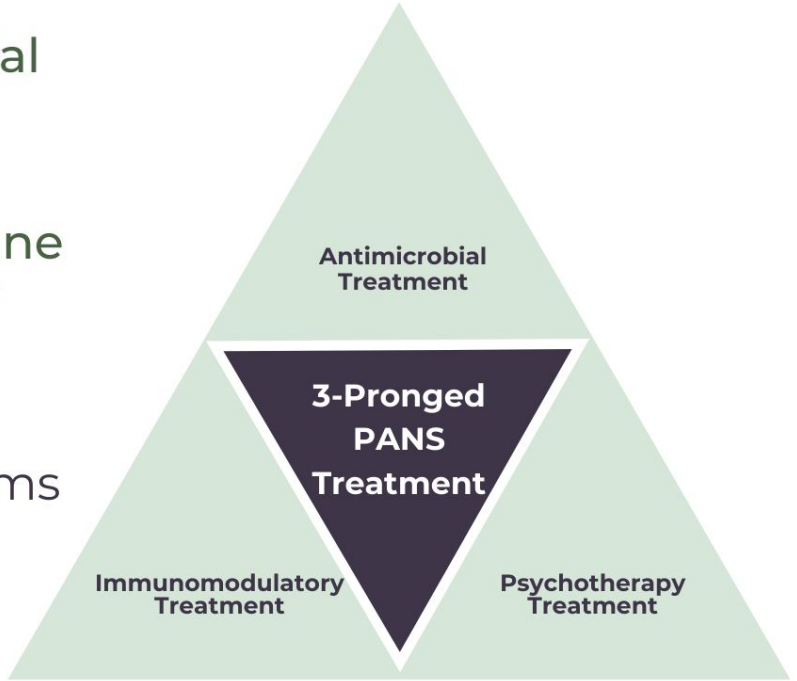
Not always. Some symptoms can remit completely while others are reduced but not back to baseline. Timely and appropriate treatment results in better outcomes.

Sue E. Swedo, MD, NIH Scientist Emerita, NIMH

Three-Pronged Treatment Guidelines

PANS treatment utilizes three complementary modes of intervention to treat the patiently completely.

- **Inflammatory Source**: Remove the inflammatory source with **antimicrobial treatments**.
- **Immune Dysregulation**: Treat the disrupted immune system with **immune modulating** and/or **anti-inflammatory** interventions. Protocol depends on severity and disease course.
- **Symptomatic Relief:** Alleviate symptoms with **psychotherapeutic treatments**, including therapy & medications as appropriate to each symptom.



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

Improving Outcomes