



# **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



#### **PANS Flow Chart**

Prototype Disorder: Sydenham Chorea

### Infectious Triggers (PITANDS)

Allen et al JAACAP'95

**PANS** 

**Pediatric** 

Acute-Onset

Neuropsychiatric Syndrome

> Non-Infectious Triggers

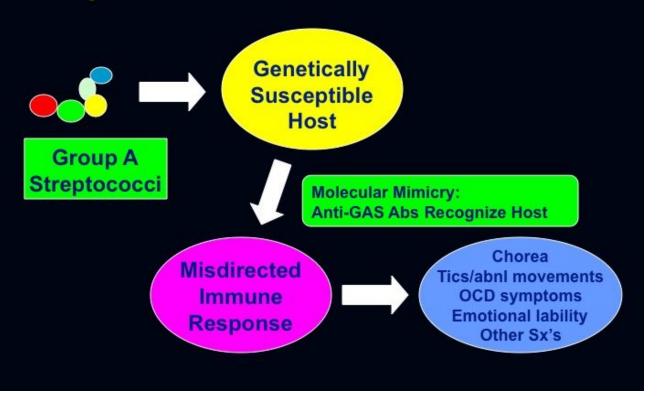
#### Group A Streptococci (PANDAS)

Swedo et al Am J Psych '98

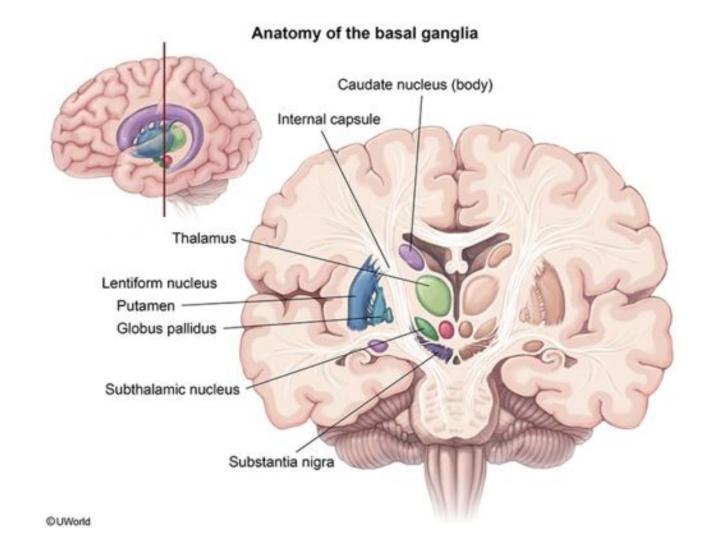
Other Microbes (Lyme, Mycoplasma, others)

Environmental Factors Metabolic Disorders Others

# Model of Etiopathogenesis for Sydenham Chorea and PANDAS



Slide courtesy of Susan Swedo, M.D.





Here are the outstanding members of the PANS Academic Research Consortium:

- Michael Cooperstock, MD, MPH (University of Missouri School of Medicine):
   Pediatrics Infectious Diseases
- · Dritan Agalliu, PhD (Columbia University)

Assistant Professor of Pathology and Cell Biology (in Neurology and Pharmacology)

- Jim Crowley, PhD (University of North Carolina School of Medicine):
   Research Assistant Professor of Genetics
- Madeleine Cunningham, PhD (University of Oklahoma College of Medicine):
   Professor of Microbiology & Immunology
- Jennifer Frankovich, MD (Stanford University School of Medicine):
   Clinical Professor of Pediatric Rheumatology
- Mady Hornig, MD, MA (Columbia University, Mailman School of Public Health): Professor of Epidemiology
- Elizabeth Latimer, MD (Latimer Neurology Center):

Pediatric & Adolescent Neurology

· James Leckman, MD, PhD (Yale University):

Professor of Child Psychiatry, Psychiatry, Psychology and Pediatrics

- Tanya Murphy, MD (University of South Florida):
   Professor of Pediatrics & Psychiatry
- Mark Pasternack, MD (Massachusetts General Hospital):
   Associate Professor of Pediatrics Infectious Disease
- · Christopher Pittenger, MD, PhD (Yale University):

Director, Yale OCD Research Clinic; Co-Director, Neuroscience Research Training Program

• Susan Swedo, MD (National Institute of Mental Health):

Chief Pediatrics & Developmental Science Branch

- Margo Thienemann, MD (Stanford University School of Medicine):
- Clinical Professor of Psychiatry & Behavioral Sciences
- · Wendy Vargus, MD (Columbia University):

Director of Pediatric Neuroimmunology Program

- Jolan Walter, MD (Massachusetts General Hospital):
   Assistant Professor of Pediatrics Allergy & Immunology
- Kyle Williams, MD (Massachusetts General Hospital): Instructor in Psychiatry



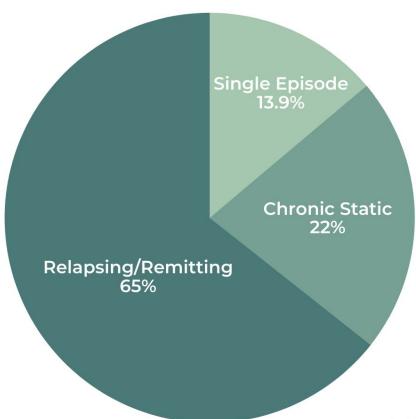
# Who Gets PANS/PANDAS?

- 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

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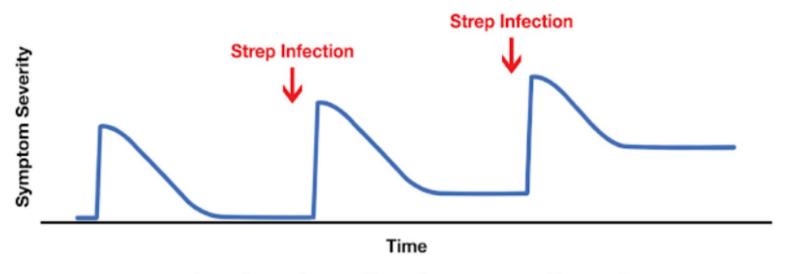
## Stanford PANS Clinic Cohort - Disease Course





# 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

# **Improving Outcomes**

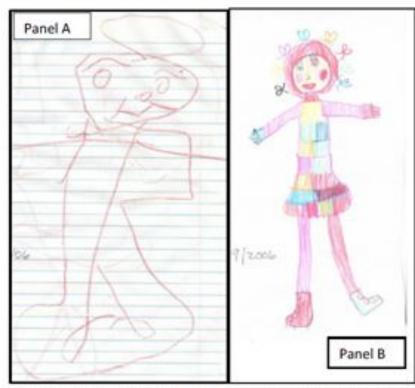


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# **PANS Symptom Frequency**



Obsessive Compulsive Symptoms (OCD) - 100%
Food Restriction - 50%
Anxiety - 100%
Emotional Lability/Depression - 62%
Aggression, ODD, Rages - 62%
Behavioral Regression - 100%
Learning Difficulties - 62%
Fine Motor Skill Deterioration - 89%
Tics/Adventitious Movements - 79%
Sensory Integration - 39%
Sleep Problems - 84%
Urinary Symptoms - 88%

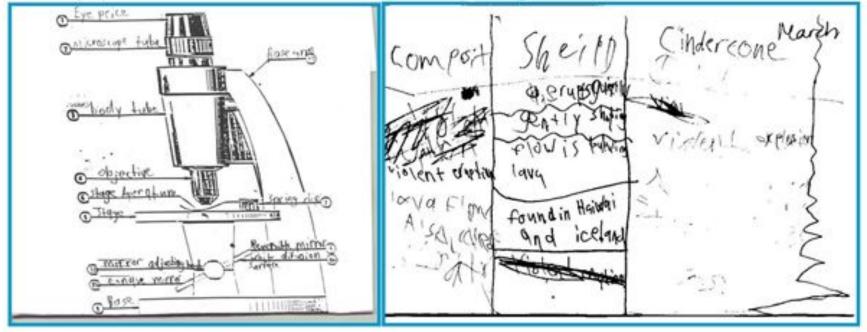


Panel A- Drawing produced during an acute exacerbation of OCD and other symptoms of PANDAS which appears quite messy and immature.

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

Before symptom onset

During acute episode

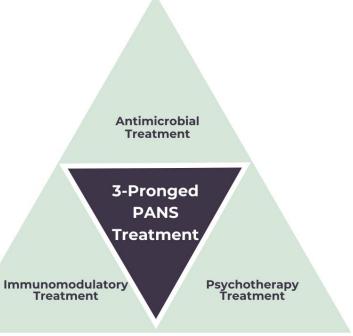


## **Three-Pronged Treatment Guidelines**



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





## **PANS RATING SCALE**

#### PEDIATRIC NEUROPSYCHIATRIC SYMPTOM RATING

Name/Subject ID:	Date:	Completed by: ☐ Mother	□ Father □ Other	

Symptom type:		Please check box 0-10 to best represent severity and frequency											Syr	nptom Ch	ange Rati	ng
	Never Mild/infrequent			Moderate				Severe/frequent			Score	in past month or specify time				
	0/NA	1	2	3	4	5	6	7	8	9	10	Staff will fill in	New	Same	Better	VVorse
1. Obsessions																
2. Compulsions						2 0				9						
3. Food refusal/avoidance																
<ol> <li>Anxiety (fears/phobias, separation anxiety)</li> </ol>																
<ol><li>Mood swings/moodiness</li></ol>																
6. Suicidal ideation/behavior									i.							
7. Depression/sadness																
8. Irritability																
9. Aggressive behaviors						10			1	8						
10.Oppositional behaviors																
11. Hyperactivity or impulsivity																
12.Trouble paying attention																
13.Behavioral regression																
14. Worsening of school performance										8						
15. Worsening of handwriting/copying	- 3															
16. Sleep disturbances																
17. Daytime wetting or bedwetting																
18.Urinary frequency																
19.Bothered by sounds, smells, textures, or lights																
20.Hallucinations																
21.Dilated/big pupils																
22.Tics (movements)																
23. Tics (sounds)																

