

## PANS Diagnostic Criteria

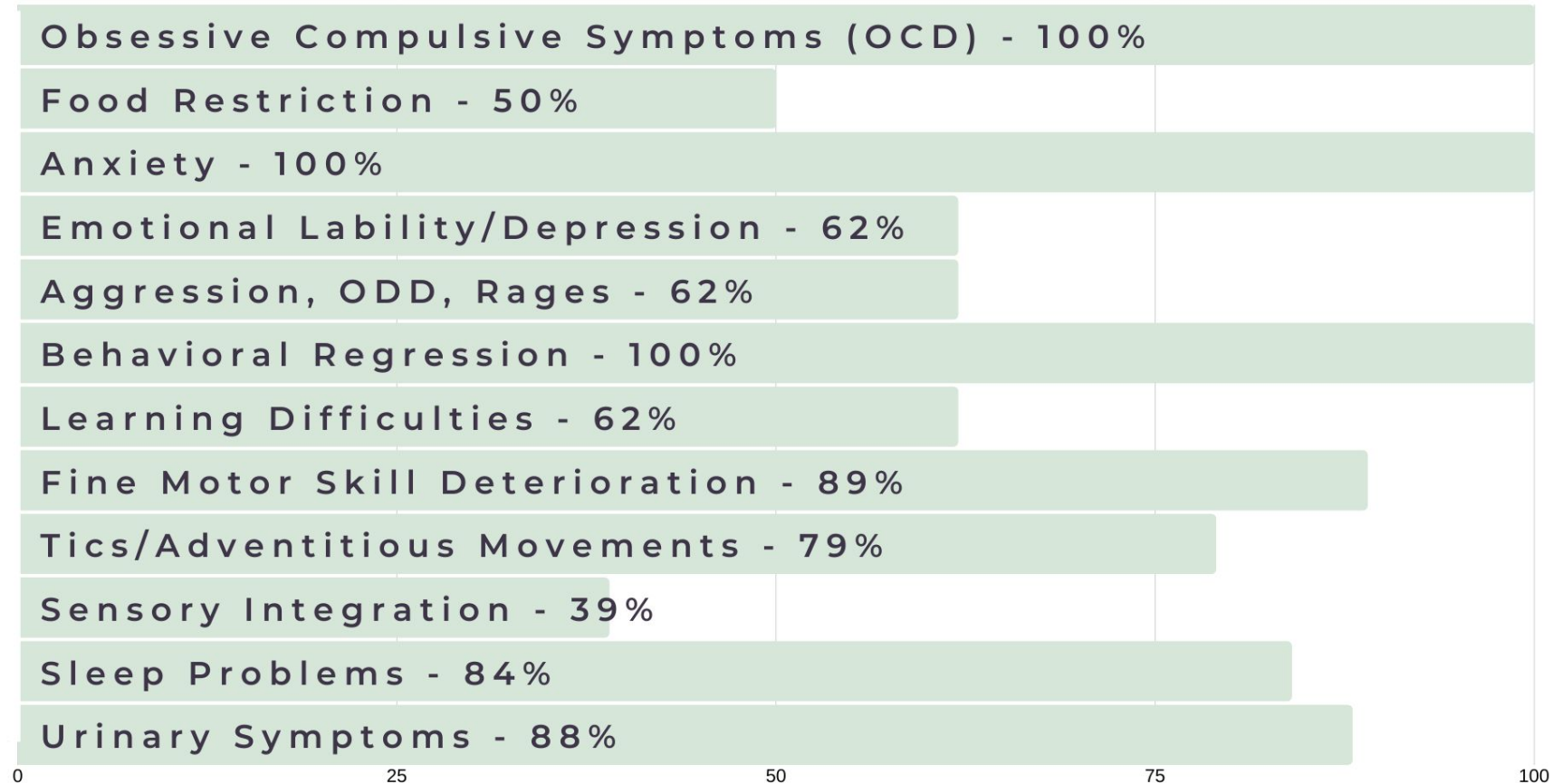
1. Abrupt, acute onset of
  - Obsessive-compulsive disorder or severe restricted food intake
2. Concurrent presence of additional behavioral or neurological symptoms with similarly acute onset and severity from at least two of the seven categories:
  - Anxiety, separation anxiety
  - Emotional lability 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

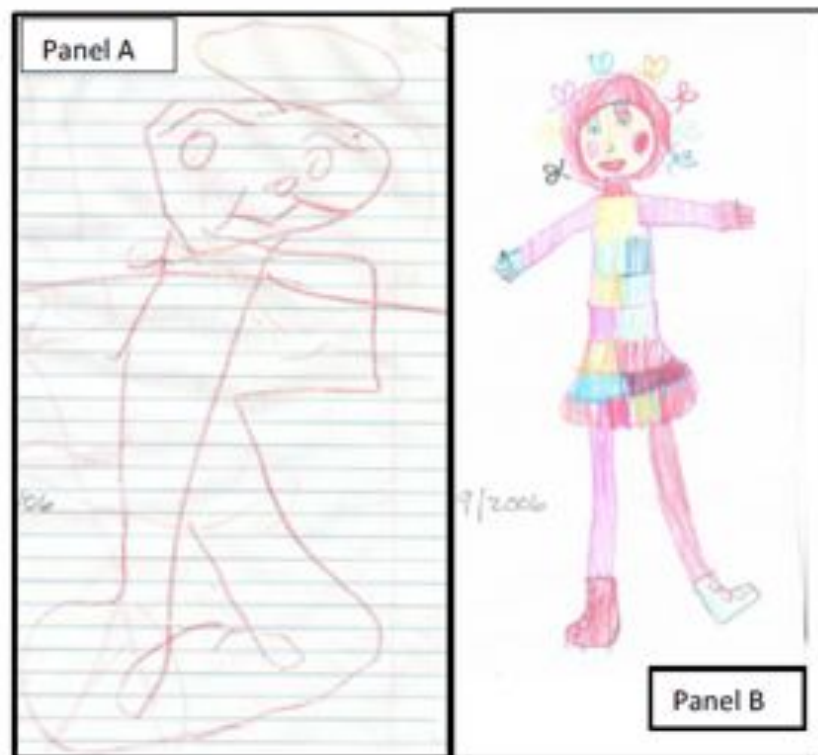
A photograph of four diverse children (two boys and two girls) smiling and posing together outdoors. The children are of various ethnicities and are dressed in casual clothing. The background shows a blurred outdoor setting with greenery and a white railing.

## 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

# PANS Symptom Frequency

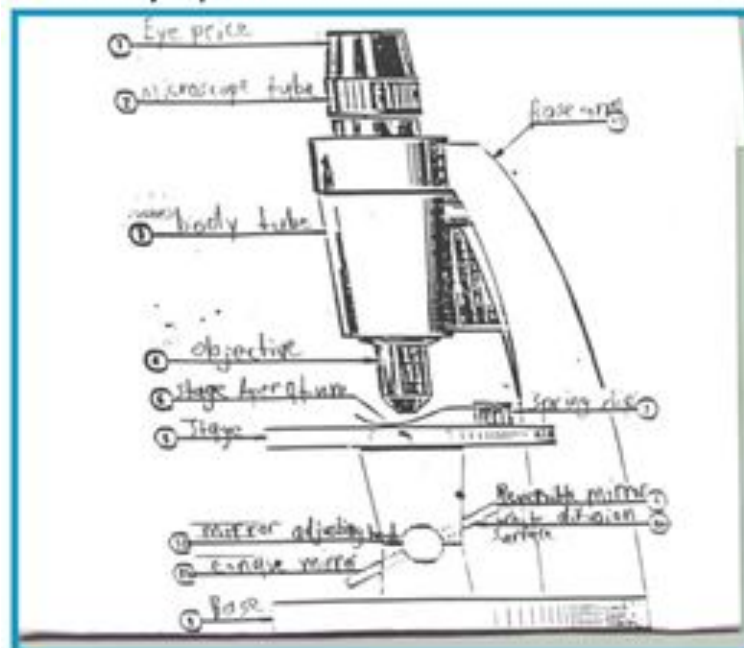




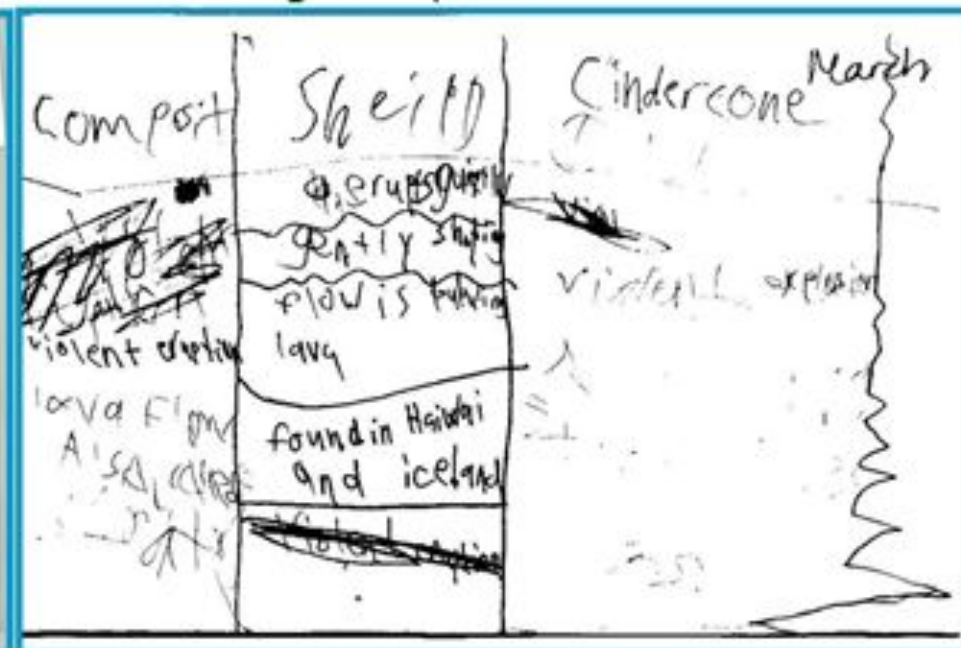
Panel A– Drawing produced during an acute exacerbation of OCD and other symptoms of PANDAS which appears quite messy and immature.

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

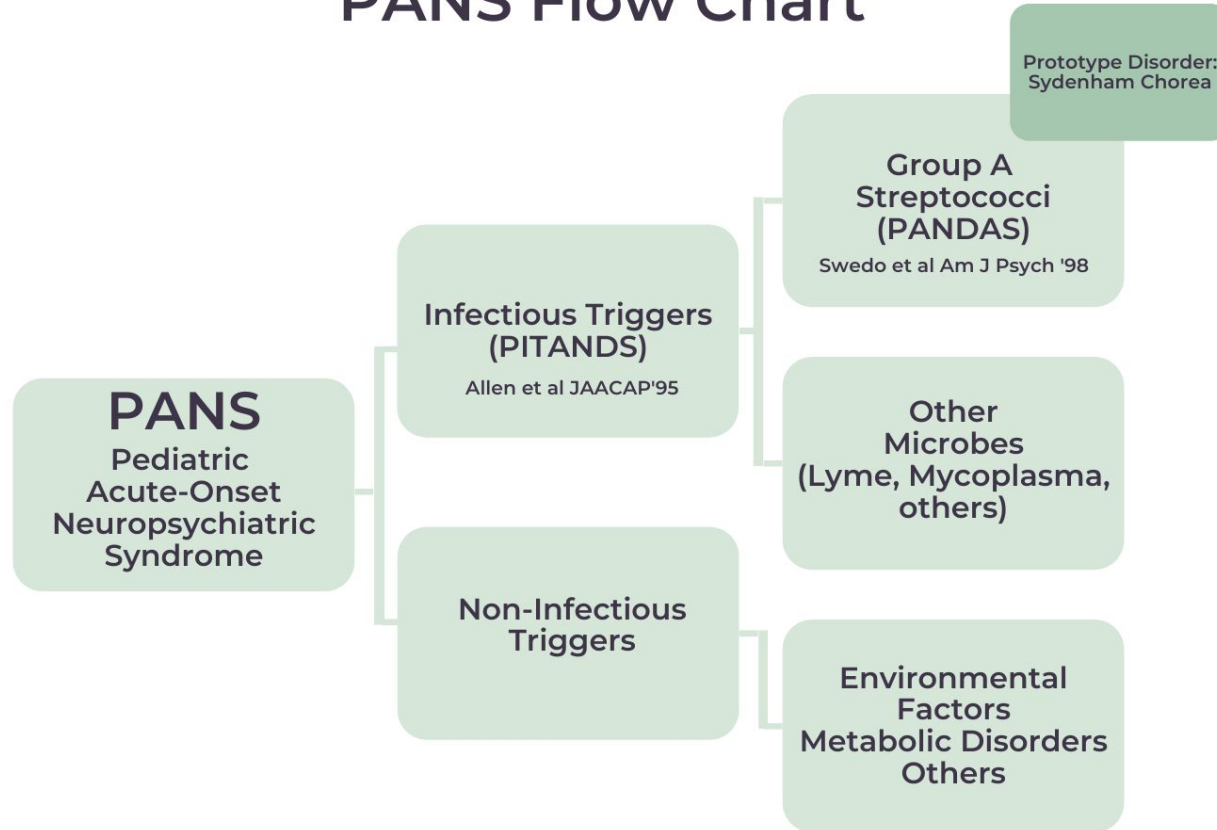
Before symptom onset



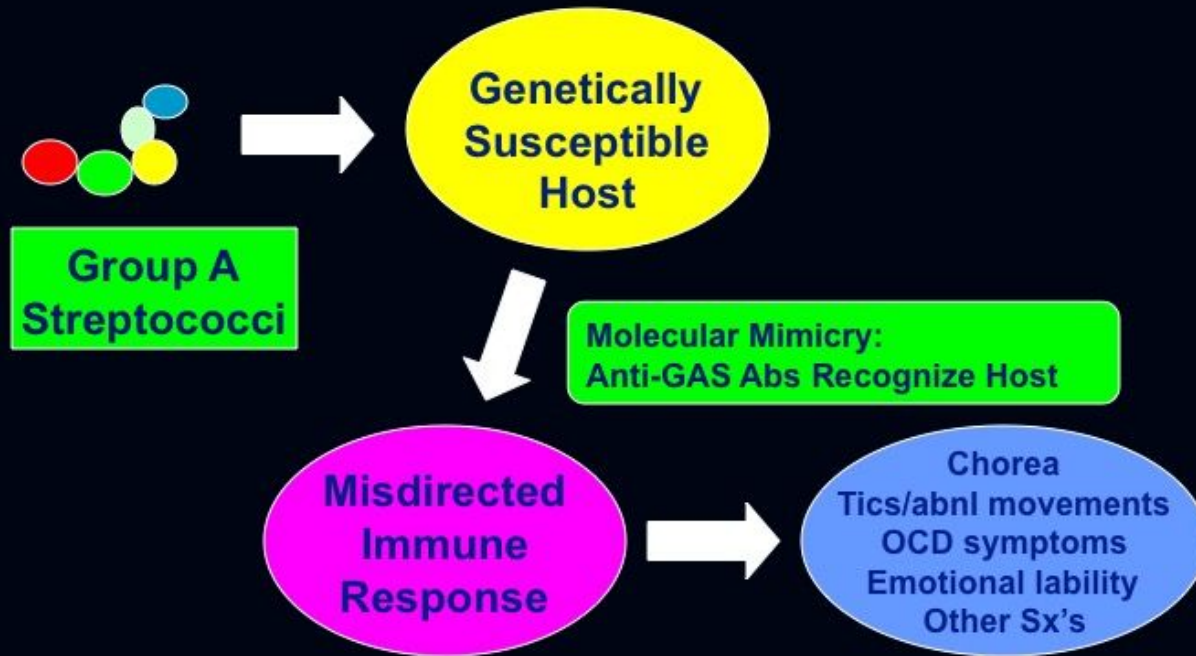
During acute episode



# PANS Flow Chart

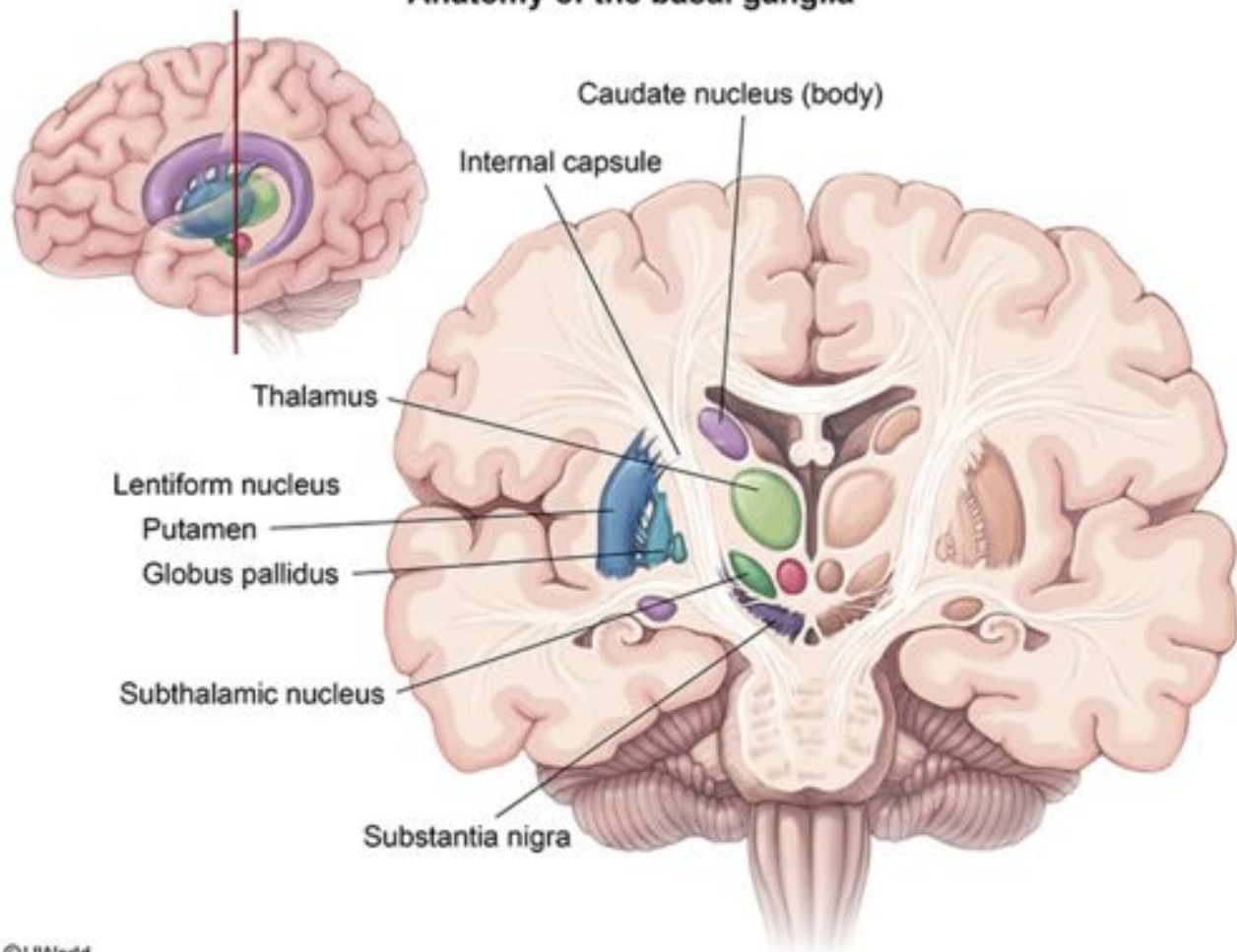


# Model of Etiopathogenesis for Sydenham Chorea and PANDAS



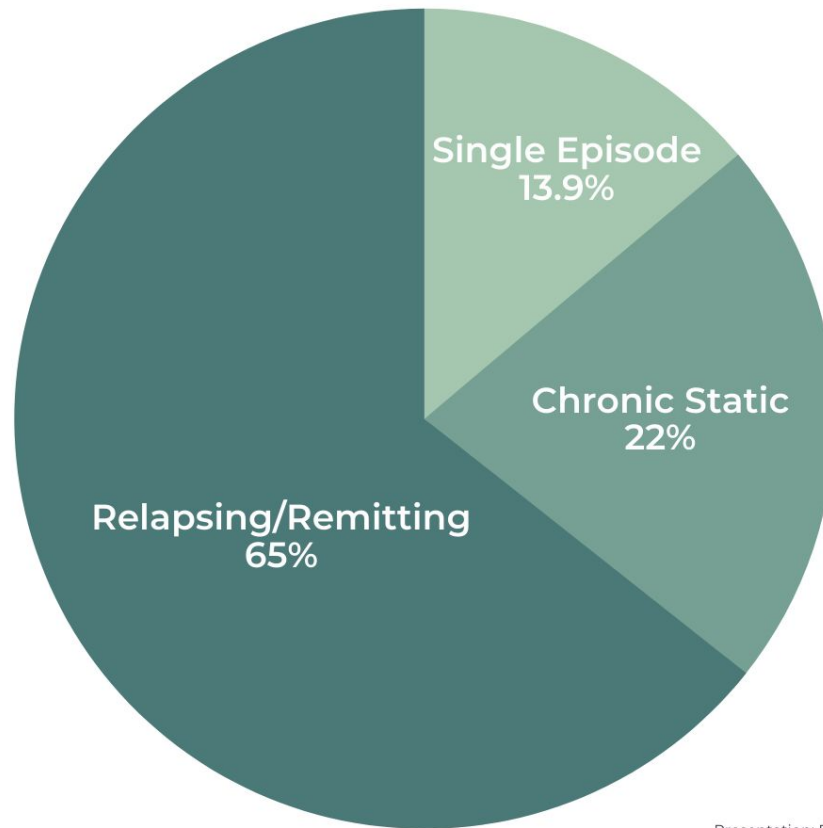
*Slide courtesy of Susan Swedo, M.D.*

## Anatomy of the basal ganglia



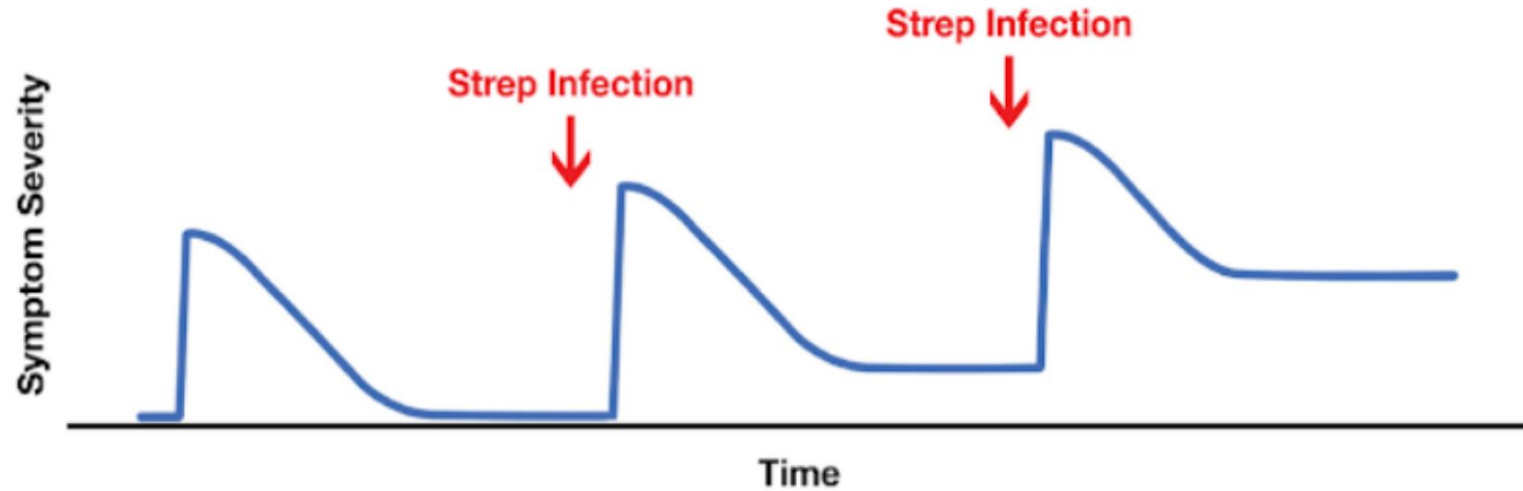


# Stanford PANS Clinic Cohort - Disease Course



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



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

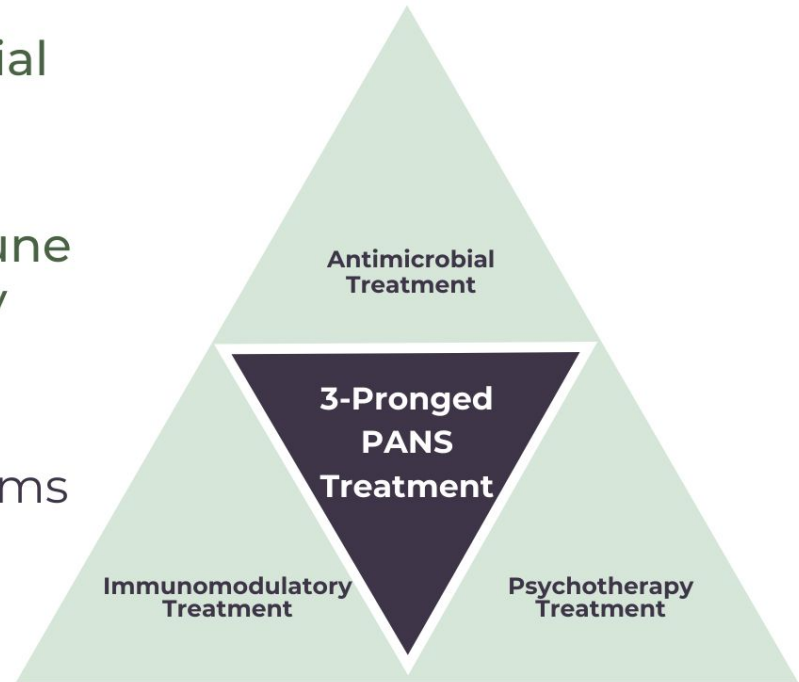
- **Michael Cooperstock, MD, MPH (University of Missouri School of Medicine):**  
*Pediatrics Infectious Diseases*
- **Dritan Agalliu, PhD (Columbia University)**  
*Assistant Professor of Pathology and Cell Biology (in Neurology and Pharmacology)*
- **Jim Crowley, PhD (University of North Carolina School 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*

# Three-Pronged Treatment Guidelines

PANS treatment utilizes three complementary modes of intervention to treat the patient 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

Timely  
Diagnosis

+

Appropriate  
Treatment

=

Better  
Recovery  
Rate





# 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											Symptom Change Rating					
	Never	Mild/infrequent			Moderate				Severe/frequent				Score Staff will fill in	In past month or specify time _____			
	0/NA	1	2	3	4	5	6	7	8	9	10		New	Same	Better	Worse	
1. Obsessions																	
2. Compulsions																	
3. Food refusal/avoidance																	
4. Anxiety (fears/phobias, separation anxiety)																	
5. Mood swings/moodiness																	
6. Suicidal ideation/behavior																	
7. Depression/sadness																	
8. Irritability																	
9. Aggressive behaviors																	
10. Oppositional behaviors																	
11. Hyperactivity or impulsivity																	
12. Trouble paying attention																	
13. Behavioral regression																	
14. Worsening of school performance																	
15. Worsening of handwriting/copying																	
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)																	

For items 1-4, any suddenly worse? \_\_\_\_Yes \_\_\_\_No If yes, please describe: \_\_\_\_\_

# of hours/day involved in obsessions: \_\_\_\_\_ # hours/day involved in compulsions/rituals: \_\_\_\_\_



