

A close-up photograph of a female doctor with brown hair and glasses, wearing a white lab coat and a red stethoscope. She is looking down and to the right, examining the neck of a young child with brown hair. The child is looking back at the doctor. The background is a blurred clinical setting.

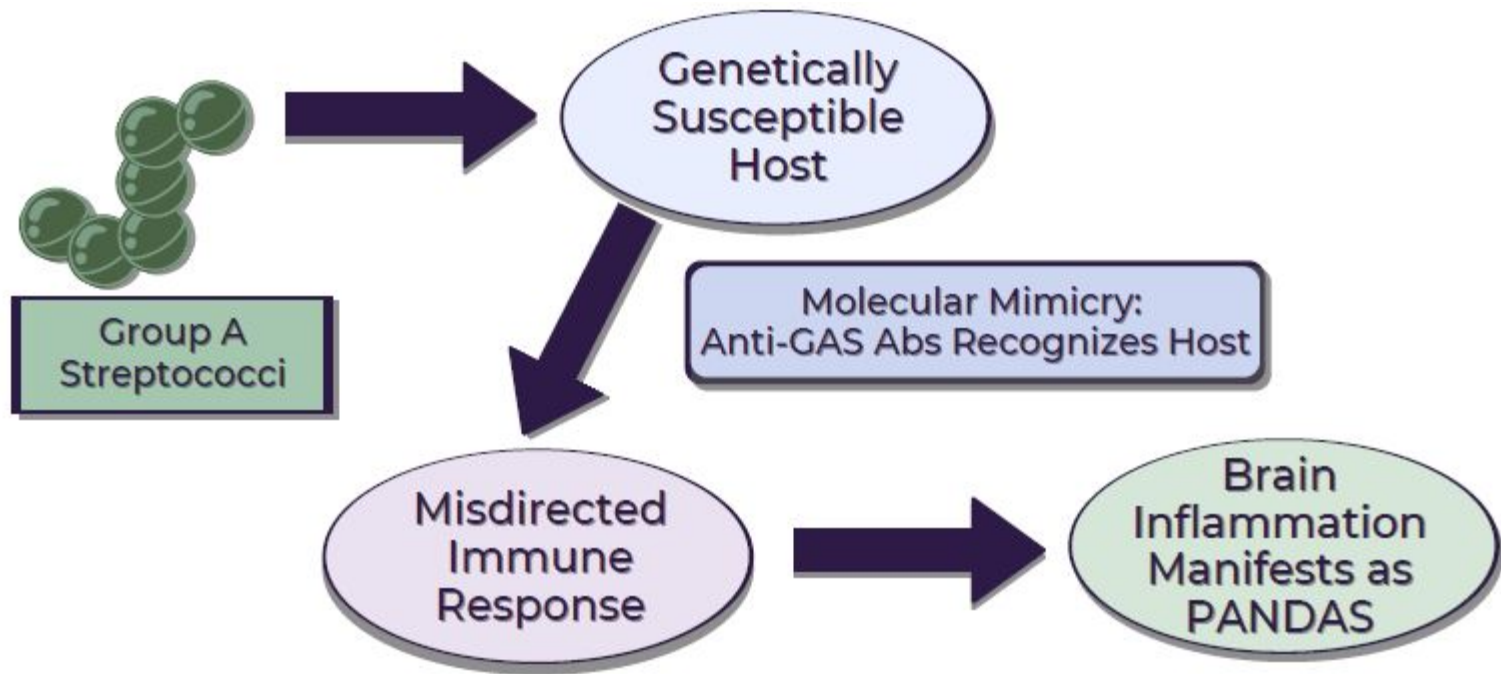
PANS Diagnostic Criteria

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

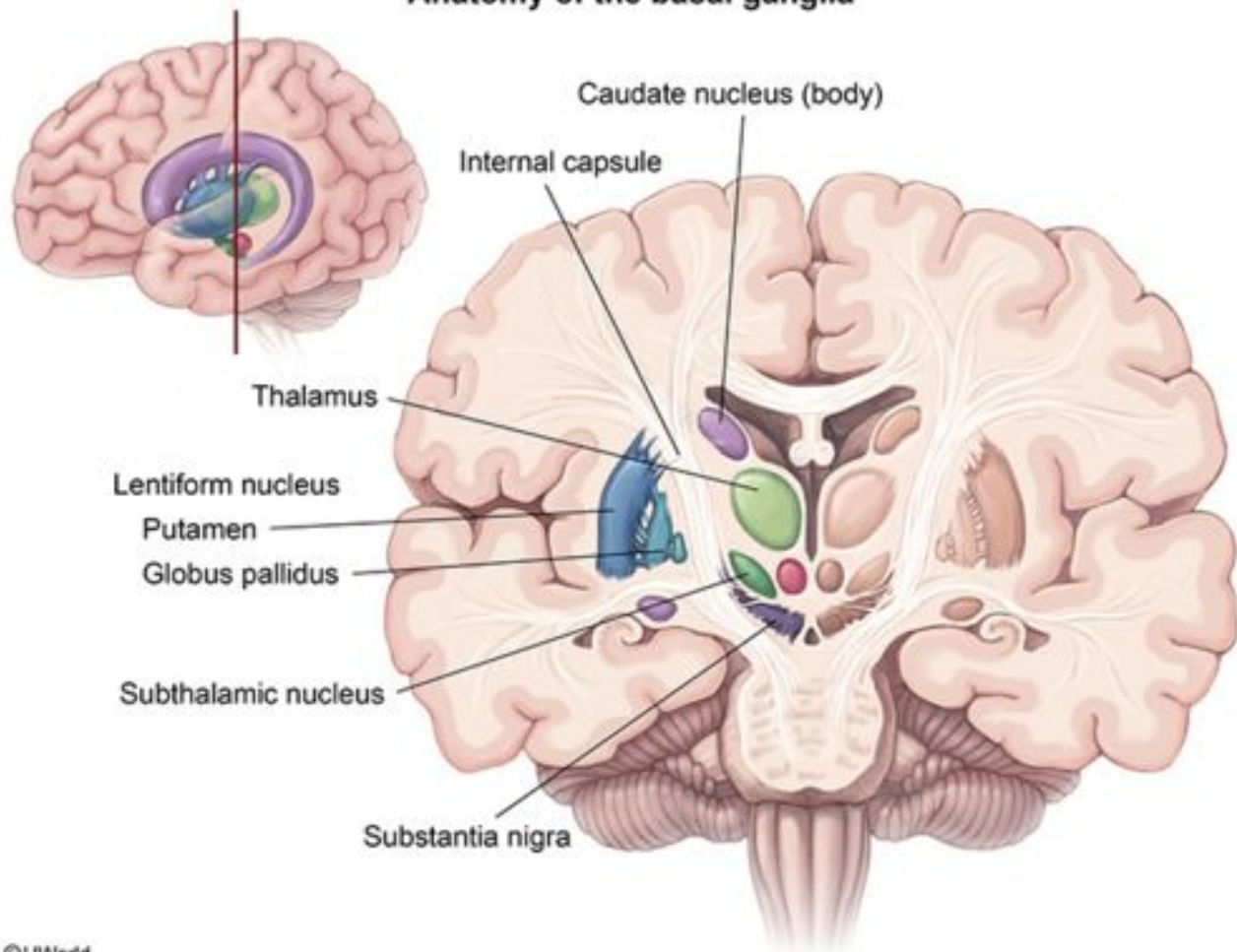
A photograph of four diverse children (two boys and two girls) smiling and posing together outdoors. The boy on the left is wearing a green shirt, the boy in the middle is wearing a blue plaid shirt with a red backpack, the girl in the middle is wearing a dark top, and the girl on the right is wearing a purple patterned top and has her arm around the girl in the middle.

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



Anatomy of the basal ganglia



Effects of Basal Ganglia Inflammation

Basal Ganglia is a relay station through which run neurons that control:

Mood & Emotion

Cognition

Sensory

Motor Movements

Procedural Learning

Behavior

Inflammation in the Basal Ganglia may cause:

- OCD
- Mood Lability
- Anxiety

- OCD
- Rage
- Developmental Regression

- Sensitivity to:
 - Light, Sounds, Smells, Textures, Tastes

- Tics
- Choreiform Movements

- Handwriting Changes
- Clumsiness

- OCD
- Rage
- Developmental Regression

SYMPTOMS IN DEPTH

Obsessions & Compulsions-100%

Obsessions

- Intrusive Thoughts - recurrent, intrusive thoughts or images
- Perfectionism
- Contamination fears
- Fear/Worries of bad things happening
- Fear of doing something wrong
- Needing things to be "just right," Exactness
- Unwanted thoughts of hurting others
- Unwanted sexual or religious thoughts
- Fear of Vomiting/Choking

Compulsions

- Repetitive, unwanted mental or physical behaviors
- Confessing, Apologizing
- Constant Checking, Counting, Ordering, Arranging, Repeating, Tapping/Touching
- Asking questions
- Excessive reassurance seeking
- Ritualized eating
- Mental compulsions, praying, reviewing
- Frequent confessing or apologizing
- Saying lucky words or numbers

Food Restrictions-17%

50% (non-life threatening issues) &
17% (>10-15% of body mass)

- Fear of contamination, vomiting, choking.
Fears harm will come to himself or others
- Swallowing issues. Texture
- Distorted Body Image –new obsession with body image or weight
- Avoidant/Restrictive Food Intake Disorder (ARFID)

Anxiety-100%

- Linked to OCD symptoms
- Generalized Anxiety - can be constant
- Separation Anxiety is a hallmark of this disorder:
 - Not age-appropriate
 - School Refusal
 - Won't sleep alone
 - If under 12, can't leave mom, if over 12, can't leave the house

Emotional Lability, Depression-62%

- Dramatic personality change - excessively moody
- Emotionally labile
- Depression

Aggression, Rages, ODD-62%

- Rages are often not remembered
- Antecedent not always identified – out of the blue
- Patient often remorseful

Behavioral Regression-100%

- Tantrums
- "Baby Talk," Sucking Thumb
- Refusal/Avoidance to do age-appropriate tasks
- Separation anxiety
- Not acting their age

Tics, Adventitious Movements-79%

- Motor and/or Vocal Tics
- Piano fingers, gait issues, balance issues
- Changes in fine motor skills as well as clumsiness

Learning Difficulties-62%

- Math Skills lost
- Decreased Executive Functioning
- Processing speeds reduced
- Memory loss
- Visual-Spatial skills reduced
- Creativity reduced
- Fine Motor Skill Deterioration – 89%
- Poor Concentration – 90%
- Impulsivity/ADHD Like Symptoms– 70%
- Short Term Memory Issues – 62%

Sleep Problems-84%

- Long bedtime ritual
- Night terrors, night waking
- Decreased REM Sleep in many patients
- Sleeping in bed with parents

Selective Mutism-7%

- Inability to communicate effectively in select social settings, such as school
- Able to speak and communicate in settings where comfortable, secure

Pain

- Persistent, non-specific Abdominal Complaints-79%

General Hypotonia

- Slouching in seat
- Low muscle tone

Sensory Integration-39%

- Sensory Processing Issues
- Hyper/Hypo-sensitivities to
 - Visual
 - Sound
 - Textures/Touch
- Visual hallucination
 - Usually brief, often persistent, lasting for several hours or longer
 - Extremely disturbing and frightening

Urinary Symptoms-88%

- New onset enuresis is common
- Excessive daytime urinary frequency (aka pollakiuria) in the absence of dysuria, fever, or incontinence
- Bedwetting

Hallucinations-9%

- Sensory experiences that appear real but are created by their mind
- Auditory & Visual- triggered by an external stimulus

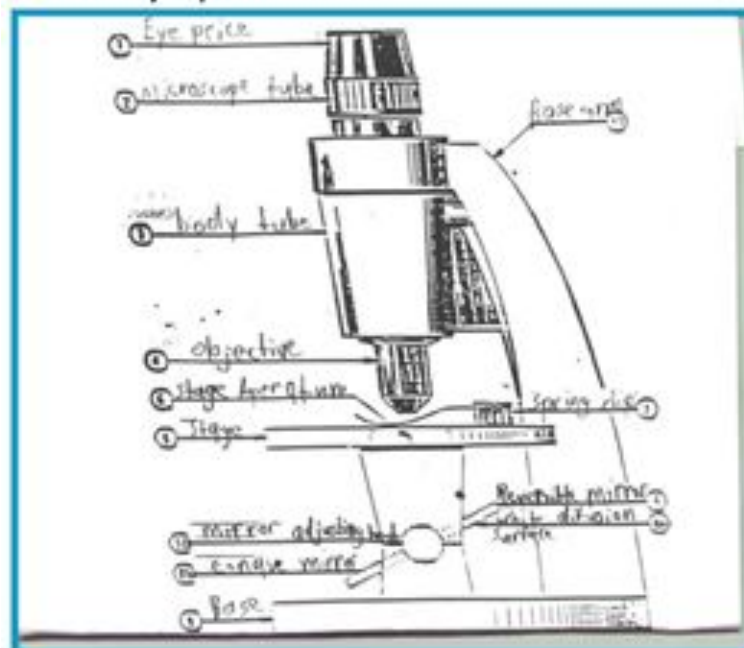
Autonomic Dysfunction

- Dilated Pupils

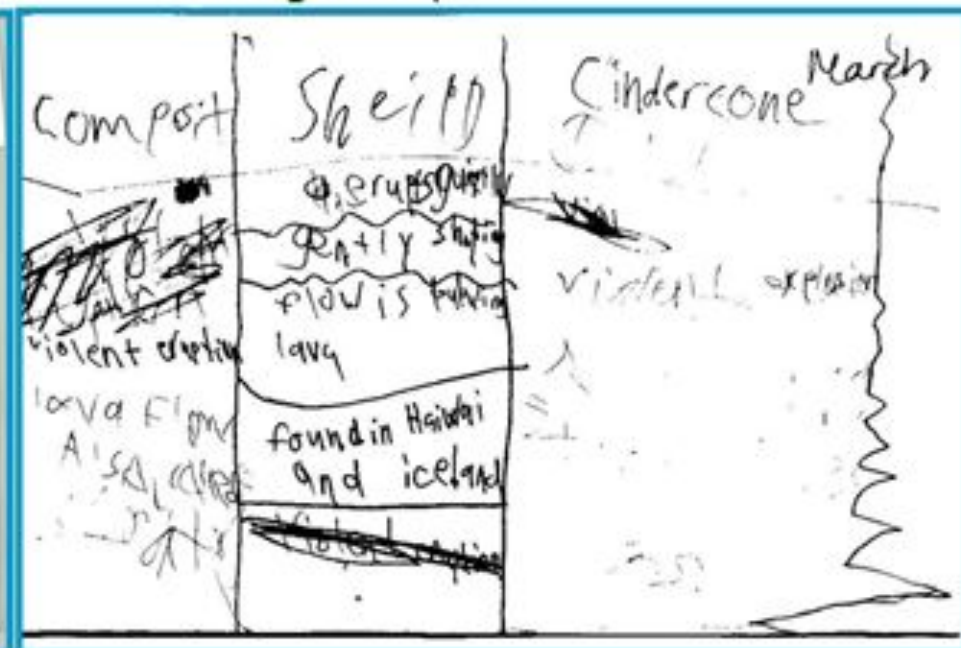
Hyperarousal & Hypervigilance

- "Fight or Flight"

Before symptom onset



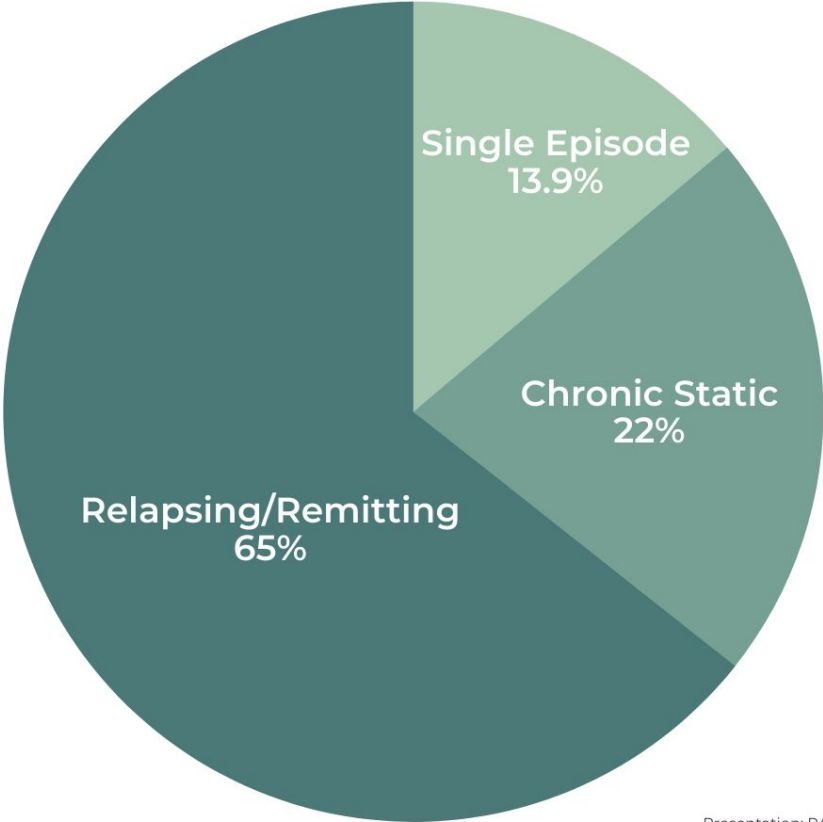
During acute episode





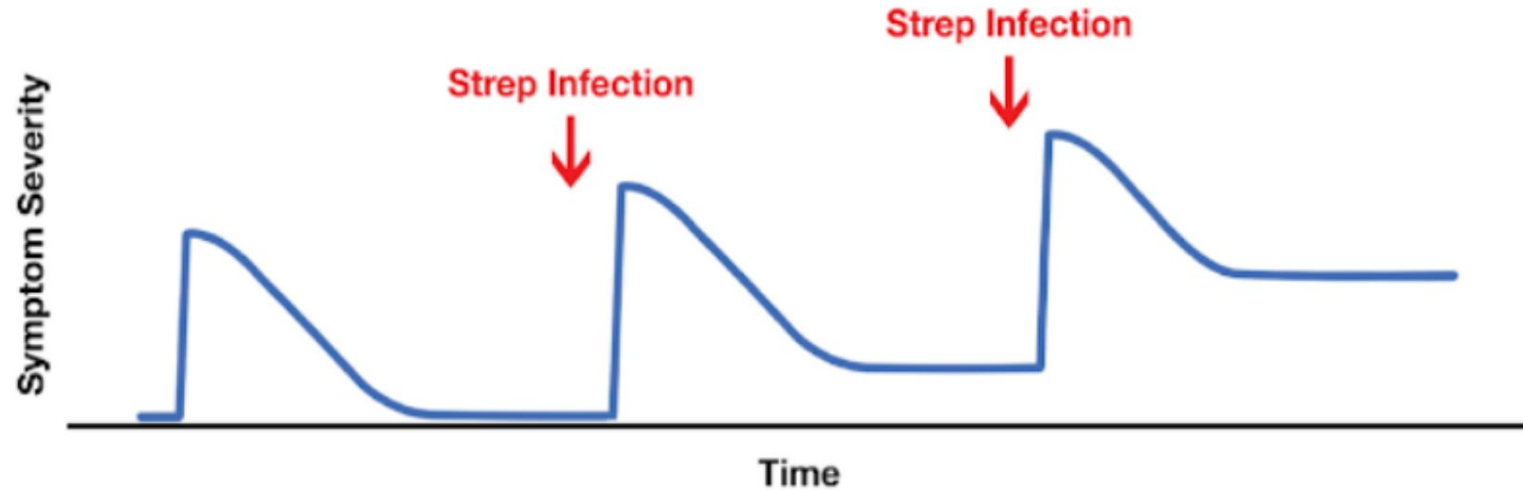


Stanford PANS Clinic Cohort - Disease Course



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.

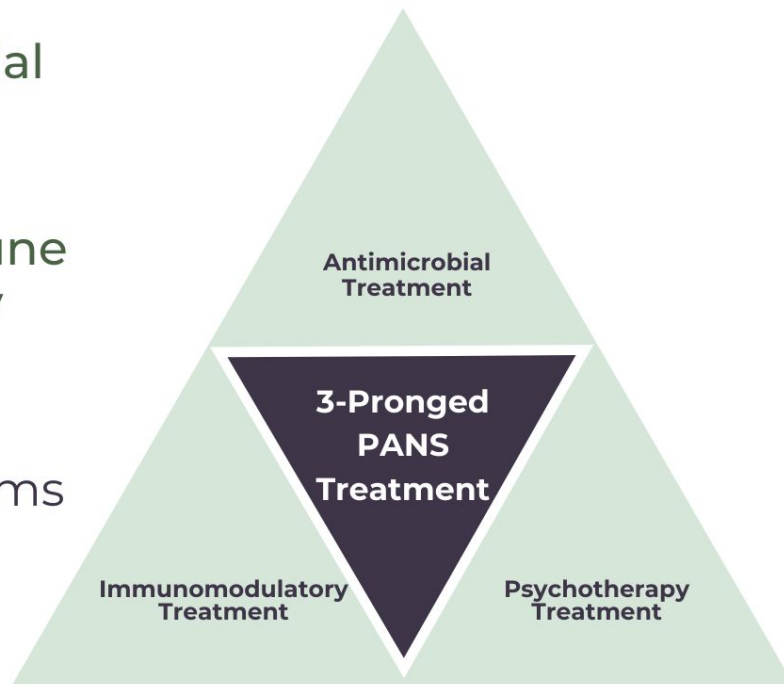
Sue E. Swedo, MD, NIH Scientist Emerita, NIMH

Three-Pronged Treatment Guidelines

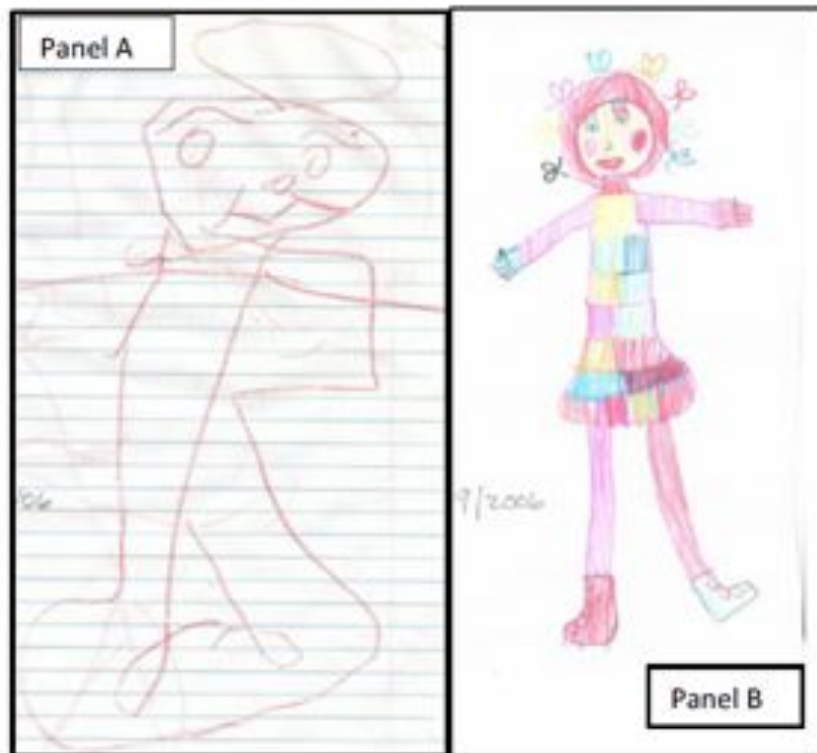
PANS treatment utilizes three complementary modes of intervention to treat the patient completely.



- **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



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.

Improving Outcomes



Timely
Diagnosis

+

Appropriate
Treatment

=

Better
Recovery
Rate