

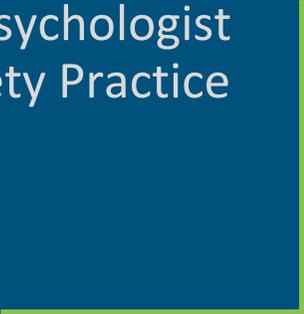


# Understanding and Treating PANDAS

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# Objectives

- 1) Define diagnostic criteria of PANDAS;
- 2) Integrate medical and behavioral presentations into comprehensive case conceptualizations;
- 3) Implement treatment plans that encompass multiple systems.

# What Is PANDAS?

Pediatric Autoimmune Neuropsychiatric Disorders Associated with Streptococcal Infections

Described by an “acute flare” period followed by a relapsing-remitting, chronic-static or chronic-progressive course related to an infectious trigger (e.g. Strep)

The Umbrella disorder, PANS, refers to Pediatric Acute-onset Neuropsychiatric Syndrome

# Diagnostic Criteria

Defined as the rapid onset of obsessive–compulsive disorder (OCD) or eating restrictions and comorbid symptoms from at least two of seven categories:

- anxiety (particularly separation anxiety);
- emotional lability or depression;
- irritability, aggression, and/or severely oppositional behaviors;
- deterioration in school performance [related to attention-deficit/hyperactivity disorder (ADHD)-like behaviors, memory deficits, and cognitive changes];

# Diagnostic Criteria (continued)

- sensory or motor abnormalities;
- somatic signs and symptoms, including sleep disturbances, enuresis, or urinary frequency

Symptoms not explained by a neurologic or medical disorder

# Diagnoses Often Confused with PANDAS

- Obsessive Compulsive Disorder
- Avoidant/Restrictive Food Intake Disorder
- Specific Learning Disorder (e.g. dyscalculia, dysgraphia)
- Adjustment Disorder
- Autism
- Disruptive Mood Dysregulation Disorder
- ADHD

# Preliminary Research Suggests

- Males outnumber females by ~ 2:1
- Symptoms began in early childhood ( $7.3 \pm 2.7$  years)
- OCD (90-96%), Separation anxiety (86–92%), school issues (75–81%), sleep disruptions (71%), tics (60–65%), urinary symptoms (42–81%)
- First-degree family history of autoimmune/inflammatory diseases and psychiatric disorders (71% and 78%, respectively)

# Pathway

Immune-mediated brain disease, involving the caudate, putamen, and other basal ganglia structures.

**TABLE 1: EFFECTS OF BASAL GANGLIA INFLAMMATION**

| Basal Ganglia is a Relay Station through which Run Neurons that Control: | Inflammation may cause:   |
|--|---|
| Mood & emotion   | OCD, Mood lability, Anxiety   |
| Behavior   | OCD, Rage, Developmental regression   |
| Procedural learning  | Handwriting changes, Clumsiness   |
| Motor movements  | Tics, Choreiform movements  |
| Cognition  | Slow processing speed, Memory issues, specific Sensory learning deficits (often Math) |
| Sensory  | Sensitivity to light, sounds, smells, tastes, textures                                |

# Medical Terms “Cheat Sheet”

- Strep swab test
  - rapid throat swab and throat swab culture most common
  - Nasal and perianal swabs less common, but useful
- Titers: ASO and anti-DNase B
  - High levels of anti-streptococcal antibody titers indicate a recent or ongoing strep infection
  - Elevated titers alone do not confirm a PANDAS diagnosis or indicate an active strep infection
- CaM Kinase II
  - Elevated levels indicate factors in serum that may cause an increased stimulation of receptors on nerve cells compared to normal serum.
- Cunningham Panel
  - A series of tests that are commonly administered to look for markers hypothesized to be related to PANDAs - at this time, not supported by research

# Medical Terms “Cheat Sheet”

- Intravenous immunoglobulin (IVIG) therapy
  - May be indicated for moderate to severe PANDAS, high risk of side effects
  - Research supports efficacy of use to treat PANDAS symptoms
  - Thought to “reset” immune system with mechanisms unknown
  - Infusion process >1 hour in 2 consecutive days; often repeated several times over several months or with the next strep infection
  - Immunoglobulin G (IgG)- primary immunoglobulin included in IVIG
- Not frequently covered by insurance
- Flare
  - Used to indicate a current increase in psychiatric and behavioral symptoms related to a recent strep infection

# Psychological Treatment of PANDAS/PANS

When do families seek psychological care?

- Before identification for psychiatric symptoms related to PANDAS

For example:

- School refusal
  - Rages
  - Eating restriction
  - ADHD type behaviors
  - Obsessions and compulsions
  - Sleeping regressions
- During medical evaluation and treatment process
  - After medical treatment, often to address residual symptoms, attachment disruption, trauma, etc.

# Possible Clinical Roles

- CBT therapist
  - Exposure/response prevention, psychoeducation, skills training, parent training, cognitive restructuring
- Consult-Liaison with medical provider(s)
- Psychological Testing for School supports
- Case manager
- Parent coaching
- Crisis Management

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# Possible Treatment Team

- Pediatrician (manages day-to-day care)
- Psychiatrist
- Infectious Disease Dr  
/Rheumatologist/ Neurologist/  
Allergist
- Nutritionist/Dietitian
- Feeding Specialist
- Individual Counselor (CBT and/or Trauma specialist)
- Family/Parenting coach
- In home Behavioral Specialist (as needed)
- 504 Coordinator/SPED Coordinator
- Psychological Testing for school supports

# Case #1: “Sammy”

Sammy is a 6-year-old boy who presented with recent abrupt onset of

- Contamination, somatic, and harm worries
- Repetitive behaviors, including checking and reassurance seeking
- Separation anxiety
- Hyperactivity and increased noncompliance
- Sleep difficulties
- Writing, speaking, and adaptive skill regressions

His physician diagnosed PANDAS and initiated antibiotics one week prior to intake.

# History

- Biological factors:
  - History of autoimmune disorder at 2 years
  - PANDAS diagnosis and penicillin initiated one week prior to intake
- Psychological factors:
  - Unremarkable psychiatric history.
  - Family history significant for anxiety and depression.
  - Intrusive images and fears about contamination, body, and harm with
    - Compulsive avoidances, reassurance seeking, repeating, and checking. (CYBOCS 22)
  - Separation anxiety in the context of presenting intrusive thoughts.
  - Hyperactive, emotionally and behaviorally dysregulated a few hours per day.

# History

- Social factors:
  - Adequate family support; living with married, employed parents.
  - Teacher reported more behavior management difficulties in the 2 weeks prior to intake.
  - Typical peer relationships

# Biopsychosocial Conceptualization

- Initial symptoms consistent with PANDAS: an abrupt behavioral response to the neuroinflammation produced by his body's response to a streptococcus infection.
- Primary Diagnosis of Obsessive-Compulsive and Related Disorder Due to Another Medical Condition.
- High risk for development of negative attributions, learned avoidance patterns, parental reinforcement of anxious behaviors, learned helplessness, and alienation of support figures.

# Intervention: Medical involvement

- Referred family to medical specialist at parents' request when treatment resistance suspected.
- Consulted with physician by phone.
- Provided documentation of symptoms and progress to specialists to aid medical evaluation.
- Provided similar documentation to insurance carriers supporting an appeal of a denial of Sammy's medical treatment.
- Integrated medical/biological processes into family's understanding of presenting problems.

# Psychological Intervention

- Exposure-based cognitive behavior therapy (CBT) to target OCD, introduce skills, and support coping and adjustment
- Flexible session formats included combinations of individual, family, and parent-only as needed to support coping and skill acquisition.
- Psychoeducation provided to Sammy and his parents about OCD, anxiety, differential attention, and PANDAS.

# Psychological Intervention (continued)

- Exposure and Response Prevention (E/RP) facilitated in session and assigned as homework.
- Behavioral token system implemented to increase motivation to confront fears.
- Parent training sessions and parent-child interaction support were added as indicated.

# Intervention: Social System Support

- Evening and weekend appointment times offered to prevent further taxing school and work attendance requirements.
- Assessment and communication of academic regression
- Communication established with teachers to support their awareness and understanding of PANDAS.
  - 504 accommodations
  - Behavior management recommendations
- Facilitation of parent support-seeking and coping

# Medical Progress

- Antibiotic treatment response
  - Temporary remission
- NSAIDS and 5-day steroid dose as next step
  - Temporary remission
- Intravenous immunoglobulin (IVIG) treatment
  - Slow response but remission over 4-week period
- Penicillin and IVIG repeated after another strep infection.
  - Given the intravenous and intensive nature of IVIG treatment, therapy emphasized coping support during these periods.

# Psychological Progress

- Rapid improvement in contamination and somatic OCD
- Unpredictable occurrences of novel fears and impulse control problems
  - Inconsistency complicated skill generalization
  - Significant strain on family's coping resources over time
- Overall improvement over 18-month period.
  - CYBOCS <10 with shorter duration and intensity during flares
  - Addressing faulty beliefs more effective during remission

# Psychological Progress (continued)

- Referrals for psychiatry, neuropsychology, and parenting specialist provided to comprehensively understand and address residual difficulties during remission.
  - Superior intelligence with executive functioning weaknesses
  - Trials of SSRI and stimulant medication

# System Progress

- Peer difficulties following chronic, recurrent PANDAS features
- Family stressors accumulated over time:
  - Parent job change
  - Fatigue
  - Financial strain secondary to medical costs
  - Conflict between parents and within in parent-child relationship
- Intensified parent training and PCIT to improve interaction quality and adaptive functioning.
- Academic progress satisfactory with accommodations

# For More Information

PANDAS Physician Network

<https://www.pandasppn.org/>

PANDAS Network

<http://pandasnetwork.org/>

Upcoming Conference March 9 - 10 at Columbia University