



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 ± 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/>

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Upcoming Conference March 9 - 10 at Columbia University