Supporting Families through PANS/PANDAS Flares with Psychological Interventions and Neuropsychological Assessments

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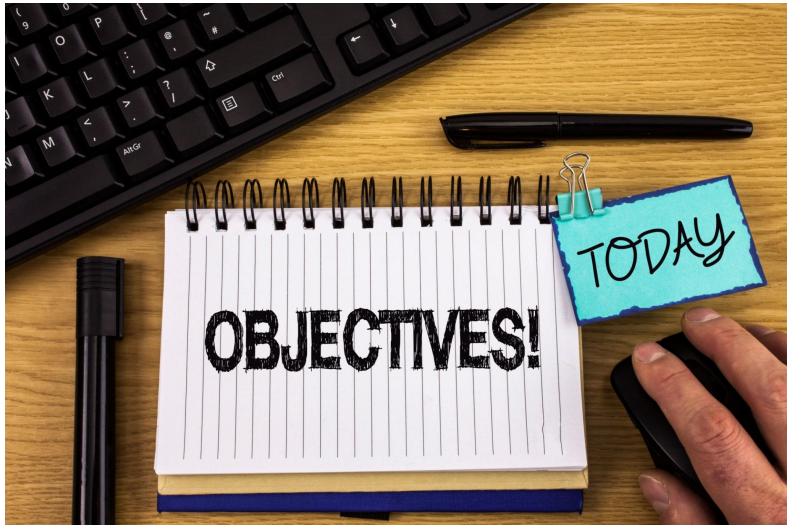
Disclosures

- No conflicts of interest
- No disclosures to share
- Presenters have no financial interests



Learning Objectives

Summarize two key elements of PANS clinical presentation.

Describe three innovative PANS flare treatments and limitations.

Compare neuropsychological testing protocols for PANS flares and personalized treatment plans.

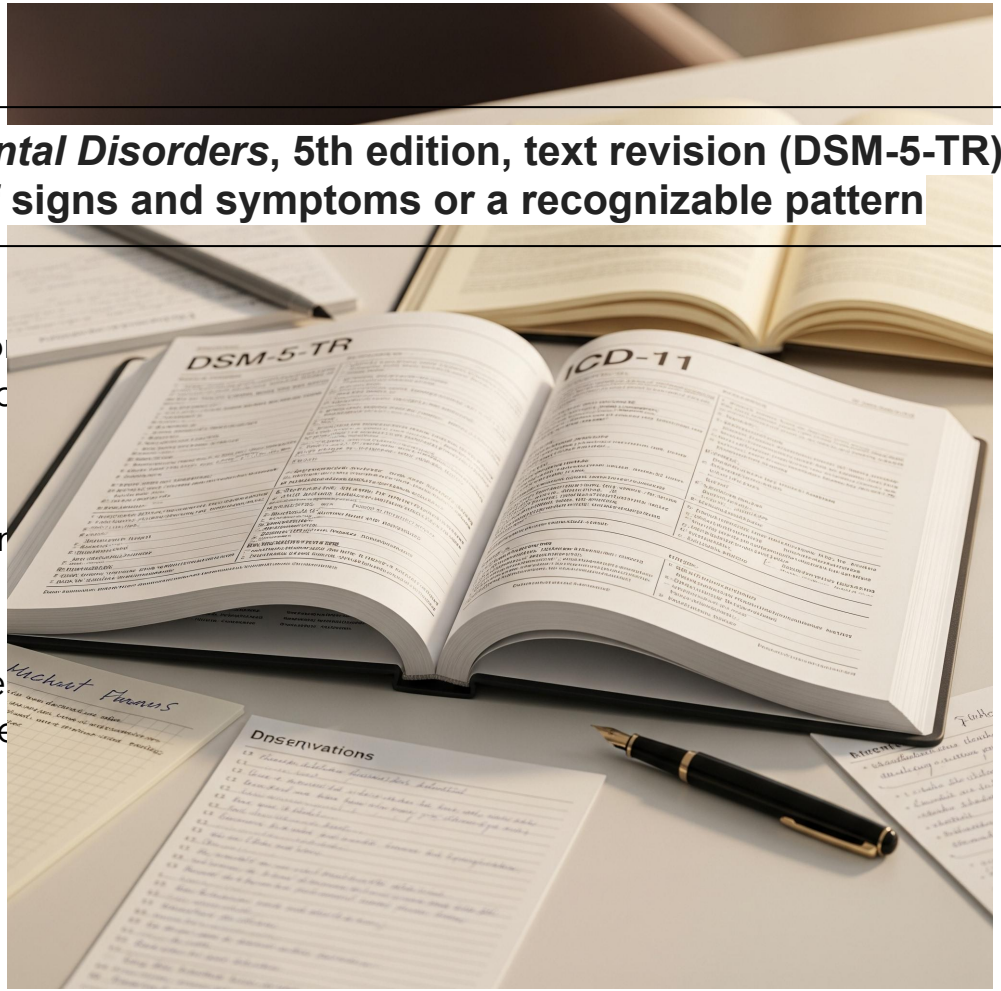
DESCRIPTION OF SYMPTOMATOLOGY

DSM-5-TR/ ICD-11

***Diagnostic and Statistical Manual of Mental Disorders*, 5th edition, text revision (DSM-5-TR) *DOES NOT* include PANS as a cluster of signs and symptoms or a recognizable pattern**

- PANS can be classified as Obsessive-Co
  Related Disorder Due to a Known Medic
  (code 294.8; or F06.8)

- The International Statistical Classificatio
  and Related Health Problems (ICD-11)
  - PANS NOT included
  - PANDAS included as part of "othe
    disorders involving the immune me
    elsewhere classified" (D89.89)



Vreeland, 2025 article add reference DOI: 10.4324/9781003517429-13

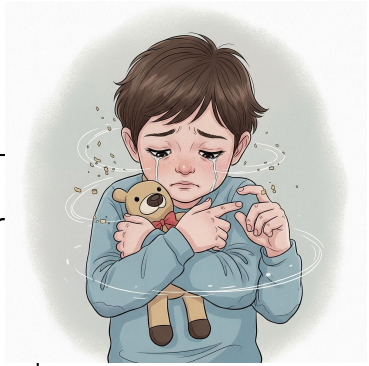

PANS
Lyme Disease
Mycoplasma
Streptococcal
Influenza
Covid
Mononucleosis
Inflammatory Reactions

Prevalence & Onset

- Abrupt-onset OCD estimated in up to 5% of pediatric OCD cases
  - Of the 700,000 - nearly 3 million kids with OCD, roughly 35,000 to 140,000 children with PANS or PANDAS.
  - UNDERESTIMATE: PANS includes abrupt-onset restrictive eating which are not include (Kapphahn, 2025).
  - Adult with autoimmune disorders: 15 million
- Average age of onset 6-8.5 years (Stanford data)
- Slight male predominance
  - Siblings have a higher rate of immune disorders
  - First-degree relatives have up to a a ten-fold increase in rates of OCD, tic disorders, and acute rheumatic fever (Chan et al, 2020)
- *Families with high incidences of both autoimmune disorders (67-80 %) and psychiatric disorders (51-78%)*
- Comorbid inflammatory disease, reactive or persistent arthritis, immune deficiencies,inflammatory back pain, enthesitis related arthritis (Ma et al 2023)

Frick et al., 2018. Frankovich et al 2015, M. Johnson et al 2019, Swedo et al 2015

Neuropsychiatric Symptoms: PANS



PANS criteria include sudden onset of obsessive-compulsive disorder (OCD) or severely restricted food intake. Two of the following seven criteria are also required to make a diagnosis:

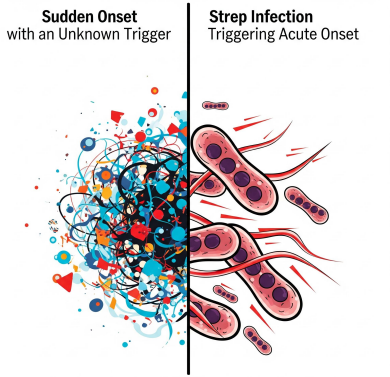
- Anxiety.
- Emotional lability (mood swings) or depression.
- Irritability, aggression or oppositional behavior.
- Behavioral (developmental) regression.
- Sudden deterioration in school performance.
- Motor or sensory abnormalities including tics or involuntary movements.
- Somatic signs and symptoms, like sleep disturbances or bedwetting (enuresis).

* Sudden onset OCD and/or restricted food intake and at least 2 of the following…

Considered a subset of autoimmune encephalitis

(PANDAS Network, 2025a)

Neuropsychiatric Symptoms: PANDAS subcategory of PANS



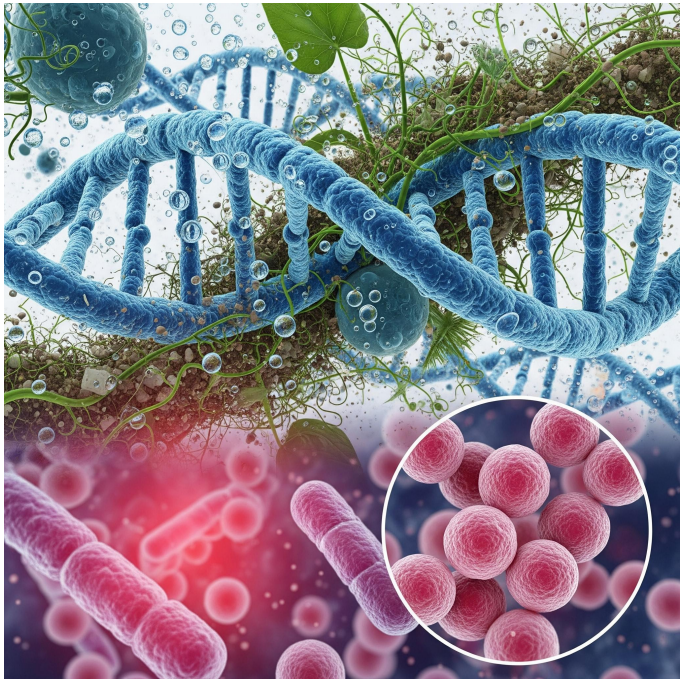
Sudden onset OCD and/or TIcs and at least 2 neurological symptoms

1. Abrupt onset of OCD, or dramatic, disabling tics.
2. An episodic symptom course, or relapsing-remitting course of severity.
3. Pre-pubertal onset.
4. Presence of neurologic and neuropsychiatric abnormalities.
5. Occurrence of a strep infection before symptom onset.

- PANS onset is often acute and sudden
- PANDAS onset is typically acute, within 2-3 days
- PANS trigger MAY BE unknown, WORK to identify it
- PANDAS is triggered by strep infection
- Both show dramatic neuropsychiatric symptoms
  PANDAS patients often present after the window of opportunity to diagnose GAS - so prefer term PANS
  PANDAS is often described as a form of basal ganglia autoimmune encephalitis

PANS/PANDAS Triggers

- Genetic predisposition
- Environmental stressors
- Autoimmune disorder (Harvey, et al., 2018)
- Suggested link between maternal autoimmune disorders and childhood OCD/tics (Murphy et al., 2010).
- Blood tests MAY show signs of inflammation markers.
    - Absence of standard inflammatory markers does not preclude an early inflammatory process or brain specific process.
- Evidence for a related post-infectious pathogenic mechanism (Cutforth et al., 2016; Vreeland et al., 2023).
- Not better explained by known neurologic or medical disorder, such as Sydenham chorea, systemic Lupus Erythematosus, Tourette syndrome (Swedo 2012)



Some have called this autoimmune OCD or Immune-mediated OCD

WHAT HAPPENS IN THE BODY?

"PANS/PANDAS are proposed to be post-infectious, immune-mediated syndromes that are characterized by an abrupt and severe symptom onset, a relapsing and remitting course, and specific comorbid symptoms."

Vreeland, et al. 2025

What is Autoimmune Encephalitis?

PANDAS- Comes into the system via Group A STREP Infection such as oral/peri-anal STREP, scarlet fever, impetigo

PANS- The cause of PANS is unknown in most cases, but is thought to be triggered by infections, metabolic disturbances, and other inflammatory reactions (think- Mycoplasma pneumoniae, influenza, Epstein-Barr virus, Lyme disease, and other viral or bacterial infections may also trigger PANS

Strep, other invaders- Strep, bacteria, mold, Lyme Disease, etc. that invade the body (A)

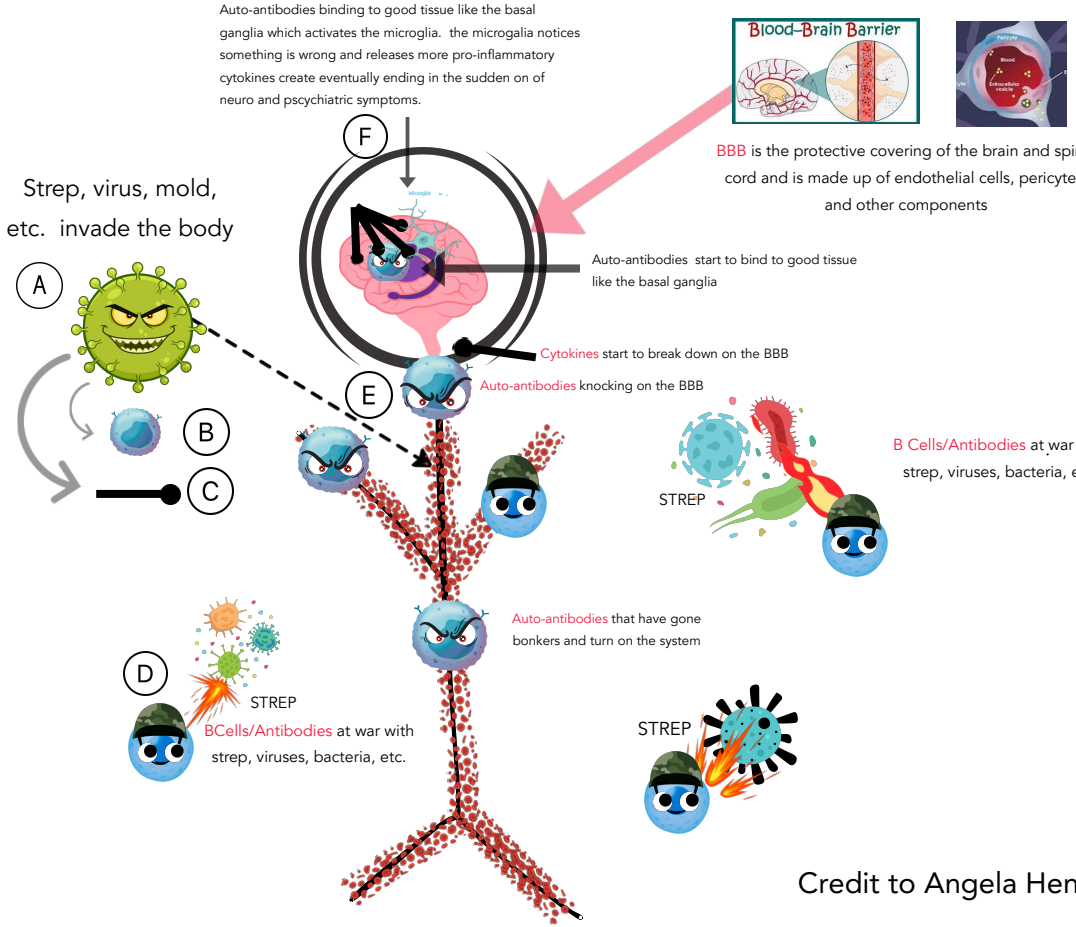
T-Helper Cells- Go to war against the strep/other viruses/infections by activating B cells, which produce antibodies and also activate pro-inflammatory proteins called cytokines (B)

Cytokines- Trigger inflammation and for the immune system to do it's job. They cover the microglia cells and then the microglia cells react by secreting more cytokines which triggers more inflammation and affect the basal ganglia which causes the nueropsych symtoms. (C)

B Cells- Antibodies that fight the strep, but can sometimes get confused between strep and or good tissue such as the basal ganglia (D)

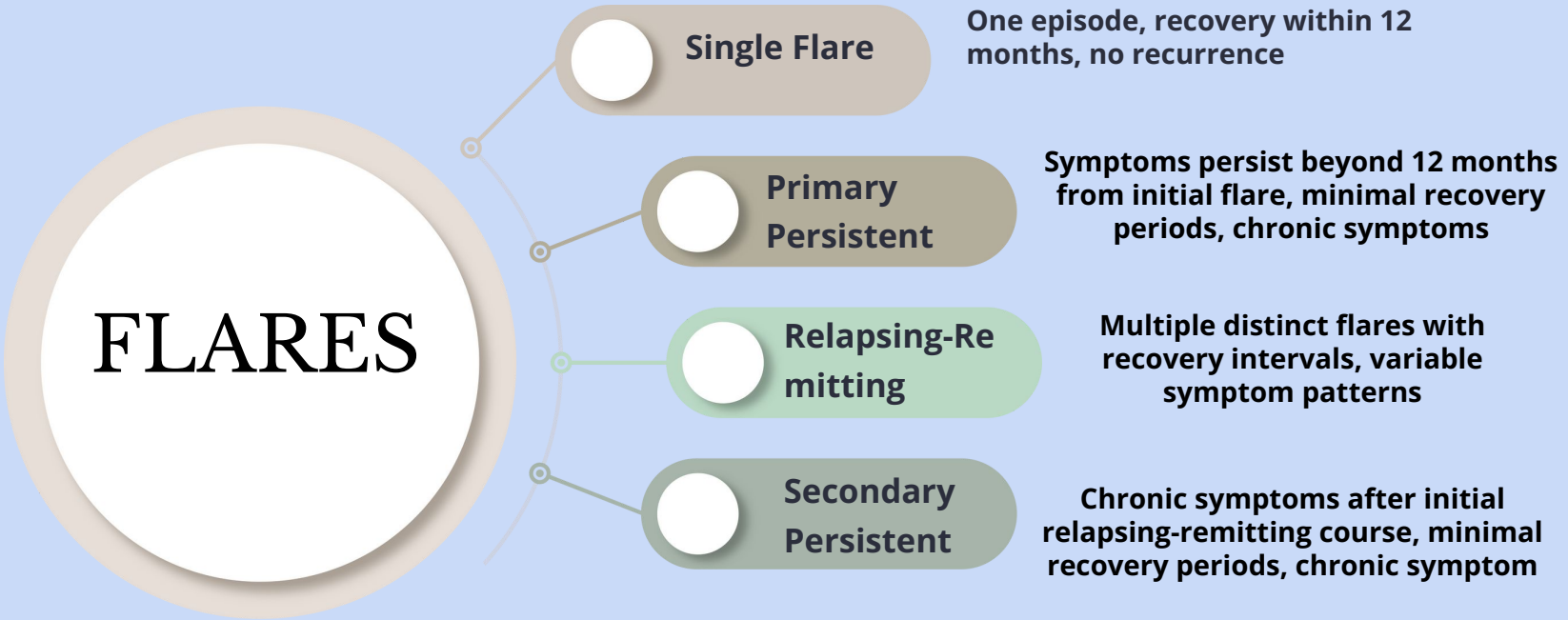
Auto-antibodies- Antibodies that go rogue, become autoantibodies and attack the body's good tissue due to Molecular Mimicry. Once turned into an autoantibody, it starts to knock on the blood brain barrier to go after good tissue like the basal ganglia. Once inside the brain, they bind to tissue such as the basal ganglia and this activates Microglia cells. (E)

Microglia Cells- Immune cells that detect things are "off" and responds by creating more cytokine release.Once the microglia are activated, it responds by releasing more and more cytokines which increase neuro inflammation and dopamine dysfunction.This leads to all kinds of neuropsych responses such as OCD, tics, emotional dysregulation, and cognitive symptoms. (F)



Credit to Angela Henry

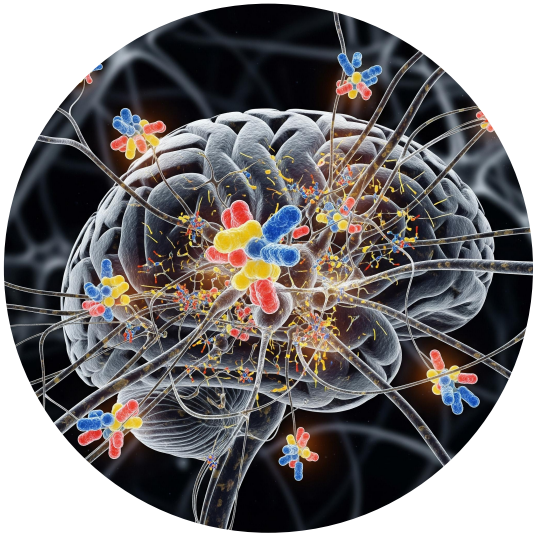
Proposed Phenotypic Classifications of PANS



Masterson, et al, 2025

Immune Response to Infection

- Symptoms result from atypical immune response to a or multiple infectious trigger(s)
- No specific diagnostic or predictive biomarkers exist.
- “Cortico-basal ganglia-thalamo-cortical (CBGTC) circuities become disrupted by poly-reactive antibodies.”
- “These antibodies, which are generated to fight the infectious trigger, cross-react with CNS targets and breach a compromised blood-brain barrier; they then bind to non-neuronal and neuronal cells and neurotransmitter receptors, primarily within the basal ganglia, leading to the resultant symptoms.”



COVID & PANS

- Two pediatric patients who developed acute-onset obsessive-compulsive symptom within two weeks of infection by COVID-19 (Pavone et al., 2021).
- Hypothesized resulted from virus-triggere neuroinflammation (Vanderheiden & Klein 2022).
- Same neuroinflammatory processes are suspected to contribute to the worsening o obsessions and compulsions in COVID-19 affected individuals with preexisting OCD (Davide et al., 2020).
- Observations suggest a link between neuropsychiatric symptoms (including OCD) and post-infectious neuroinflammatory conditions.

CLINICAL ASSESSMENT

What is the Standard of Medical and Psychological Care? Interventions and Management

Infection Control

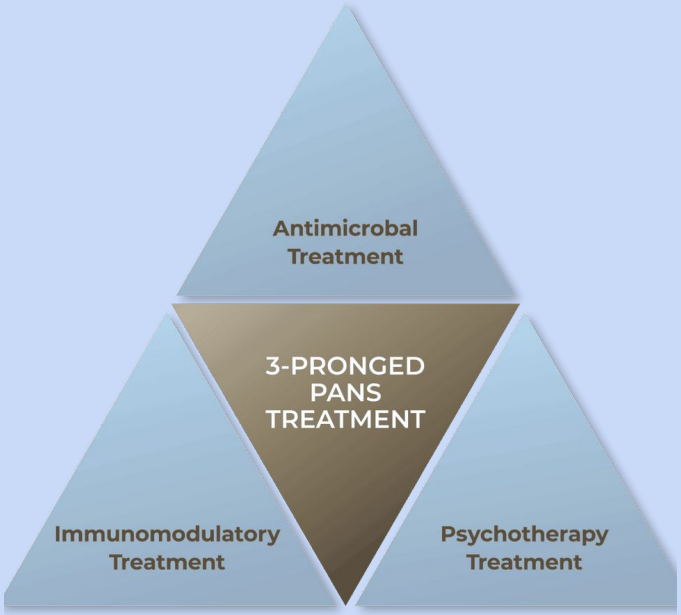
Treat infections, clear Group A strep, prevent recurrence

Anti-inflammatory therapy

NSAIDs first-line, corticosteroids if needed DMARDs for autoimmune conditions, IVIG

Psychiatric Treatment

- CBT, ERP, DBT, SPACE, parent coaching, trauma-informed, EMDR
- SSRIs (low and slow), antipsychotics, guanfacine



Assessing for Autoimmune Encephalitis, PANS, PANDAS

Medical Provider ...

Basic Blood Work

- IgA
- IgM
- IgG (subclass 1, 2, 3, 4)
- CBC
- ANA
- Ferritin (iron)
- B-12
- Vitamin D

Viral/Bacterial Testing

- Strep throat culture, 48-hour culture or perianal culture
- Antistreptolysin O (ASO), group A strep
- Anti DNase B
- Streptozyme
- Mycoplasma Pneumoniae IgA & IgM
- Pneumococcal Antibody Titers
- Lyme disease and co-infections
- Epstein Barr Virus Panel
- Coxsackie A & B Titers
- HHV-6 Titers

Immunology Workup

- CD4: This test measures a generally over-reactive immune response.
- IgG Subclass 1, 2, 3, 4 for total immunoglobulin levels.
- IgA and IgM.

Other Testing

- MRI
- EEG
- PET/CT Scan
- The Cunningham Panel

Advanced Testing

- Brain MRI indicated for specific neurologic symptoms.
- Cerebral spinal fluid evaluation when symptoms present.
- Imaging and fluid tests rule out other conditions.
- Test for focal neurologic symptoms or chorea, impetigo, ecthyma, GAS pharyngitis, peri-anal GAS, vaginal GAS, sinusitis, otitis media, abscesses, ingrown toenails and attempt to clear GAS from the home.
- Studies examining volumetric differences between PANS/PANDAS and control groups are mixed.
    - Factors in the differences are subjects' stage and duration of illness. FLARES

Assessment Scales and Tools

Symptom Assessment Scales for OCD

Yale-Brown Obsessive Compulsive Checklist

- Y–BOCS Checklist (ages 14+)
- Child CY-BOCS (ages 6-14)
- Y-BOCS Self/Parent Report

Symptom Assessment Scales for Tics

Yale-Brown Obsessive Compulsive Checklist

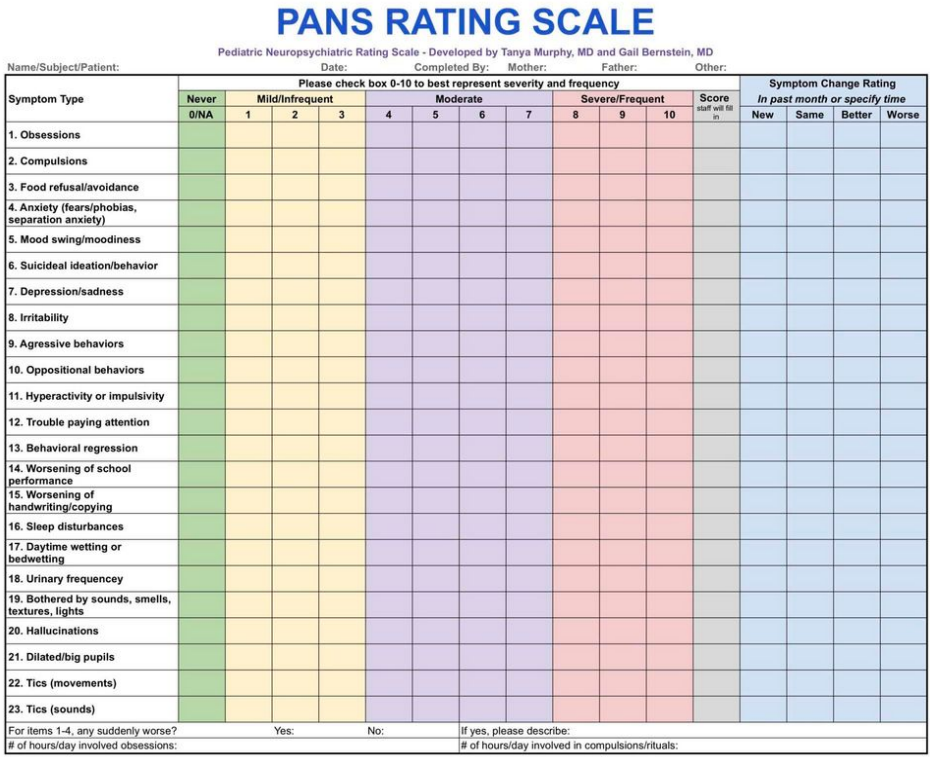
- Yale Global Tic Severity Scale
- Clinician Tic Scale

Anxiety Rating Scale

- SCARED Parent Report
- SCARED Child Report
- Spence Children's Anxiety Scale- Child (SCAS-Child)
- Children's Separation Anxiety Scale (CSAS)

Neuropsychiatric Scales

- Pediatric Acute Neuropsychiatric Symptom Scale
- Pediatric Acute Neuropsychiatric Rating Scale



PANS RATING SCALE

Pediatric Neuropsychiatric Rating Scale - Developed by Tanya Murphy, MD and Gail Bernstein, MD

Name/Subject/Patient: Date: Completed By: Mother: Father: Other:

Symptom Type	Please check box 0-10 to best represent severity and frequency											Score staff will fill in	Symptom Change Rating *In past month or specify time*			
	Never	Mild/Infrequent			Moderate				Severe/Frequent				New	Same	Better	Worse
	0/NA	1	2	3	4	5	6	7	8	9	10					
1. Obsessions																
2. Compulsions																
3. Food refusal/avoidance																
4. Anxiety (fears/phobias, separation anxiety)																
5. Mood swing/moodiness																
6. Suicideal ideation/behavior																
7. Depression/sadness																
8. Irritability																
9. Agressive 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 frequencey																
19. Bothered by sounds, smells, textures, 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 obsessions:									# of hours/day involved in compulsions/rituals:							

(Alliance to Solve PANS & Immune-Related Encephalopathies, 2022)

Family Impact of PANS/PANDAS

- PANS/PANDAS significantly impacts families
- Caregivers experience high burden and social strain
- More research is needed on families lived experiences
- Understand family adjustments and specific challenges
- Explore school and health system contributions

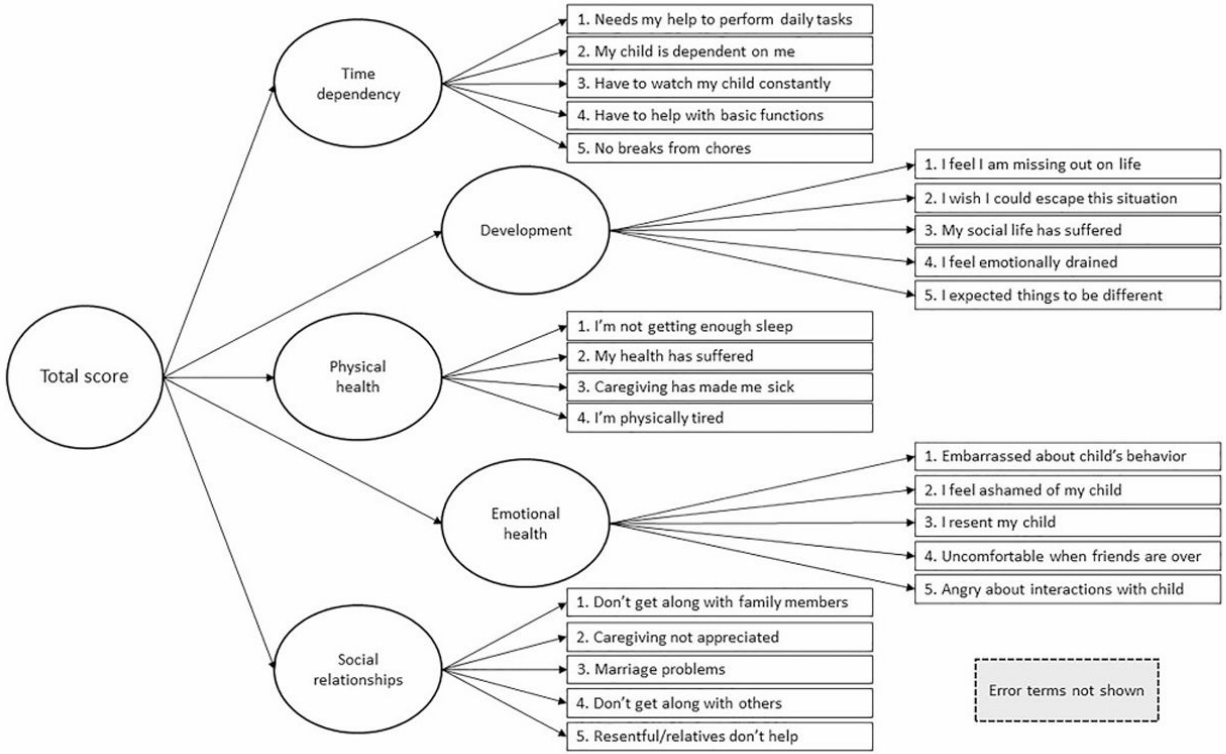


Figure 1. Factor structure of the CBI in the Stanford PANS clinic.

Note. CBI = Caregiver Burden Inventory; PANS = Pediatric Acute-onset Neuropsychiatric Syndrome.

Assessment Tips for Mental Health Providers

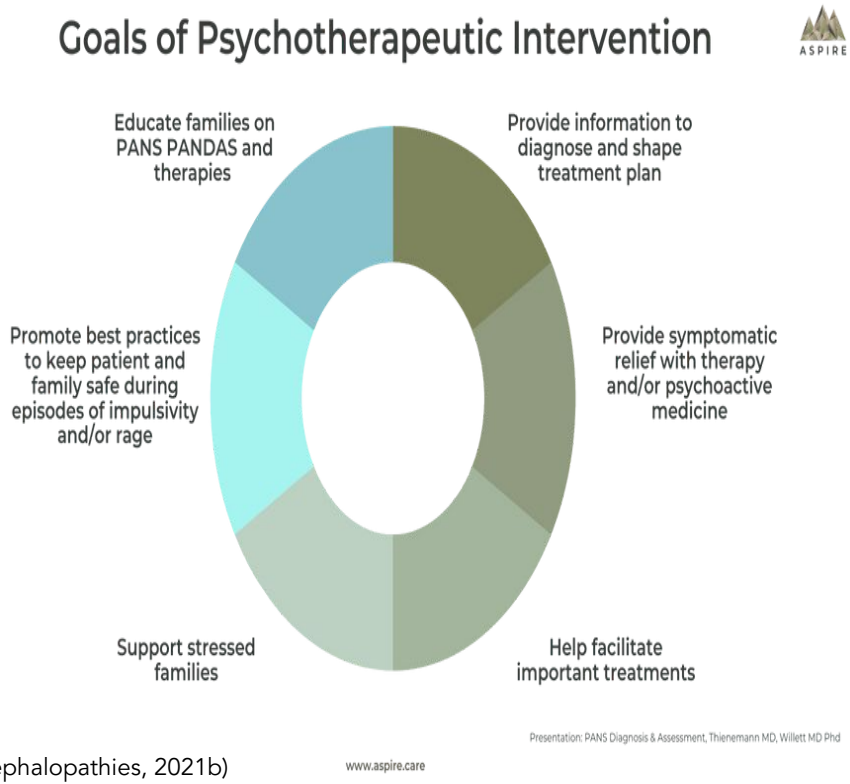
- Collect thorough medical history, assess for ANY recent exposure to strep or illness (PANDAS symptoms often do not appear until several weeks-months after the triggering infection occurs). Parent-given history is often the most important diagnostic tool!
- Collect family history, including any psychiatric and autoimmune disorders
- Assess for acute onset of symptoms, typically so profound that most parents can report an exact date of the first onset!
- Assess for symptoms of anxiety, OCD, or tics (CY-BOCS/Y-BOCS Scales)
- Assess for a sudden academic decline, compare samples of handwriting
- Look for new urinary urge increase/changes, or daytime accidents
- Look for sleep disruptions, nightmares, terrors, need for co-sleeping with a parent
- Look for sudden food restrictions or changes in eating habits
- Assess for suicidal ideation
- Assess for new intrusive thoughts, unusual fears, and ritualistic behaviors
- Look for sudden dramatic changes in personality, emotions, or behaviors
- Assess for neurological abnormalities, choreiform movements, milkmaid handgrip, dilated pupils, hyperalert affect
- Assess for new sensory issues
- Assess for new separation anxiety or school phobia
- Look for symptoms that come and go (emit remit pattern)

PTEC: Symptom Monitoring Tool

- PANS/PANDAS and Related Inflammatory Brain Disorders Treatment Evaluation Checklist (PTEC) designed to assess changes to a patient's symptoms over time
- 101 Questions, 10 subscales: Behavior/Mood, OCD, Anxiety, Food intake, Tics, Cognitive/Developmental, Sensory, Other, Sleep, and Health.
- Structured tool designed to monitor symptoms associated with PANS, PANDAS, and related inflammatory brain conditions.
- The PTEC questionnaire is freely available at neuroimmune.org/PTEC (2025).

Treatment Planning Strategies

- EDUCATE families on PANS PANDAS and therapies
- PLAN for SYMPTOMATIC relief with therapy and/or psychoactive medicine
- Grief/Trauma Support stressed families/SIBLINGS
- PLAN family for safety: episodes of impulsivity and/or rage
- Facilitate communication between medical providers
- SUPPORT academic needs via IEP/504 Plan



(Alliance to Solve PANS & Immune-Related Encephalopathies, 2021b)

Evidence-based INTERVENTIONS

OCD

- Cognitive behavioral therapy (CBT)
- Exposure/response prevention (ERP)
- Parent management techniques (PMT
- selective serotonin reuptake inhibitors (SSRIs).

ANXIETY

- Cognitive behavioral therapy (CBT)
- Exposure/response prevention (ERP)
- Psychoeducation
- Cognitive restructuring
- Relaxation training
- Problem-solving skills

DEPRESSION

- Family supportive therapy
- Individual therapy
- Cognitive behavioral therapy (CBT)
- Interpersonal psychotherapy for adolescents (IPT-A)
- When appropriate, antidepressant medication (SSRIs)

TICS

- Comprehensive behavior therapy for tics (CBIT)
- Habit reversal training (HRT)
- Relaxation techniques and psychoeducation

IRRITABILITY AGGRESSION

- Environmental interventions: reduced stimulation, sleep hygiene
- Low demand parenting strategies for nervous system over activation

ARFID/ RESTRICTIVE EATING

- Cognitive behavior therapy for ARFID (CBT-AR)
- Family-based treatment (FBT-ARFID)
- Exposure therapy (behavioral and sensory desensitization)
- Nutritional and medical support
- Ancillary therapies: OT, ST, Feeding therapies

NEUROPSYCHOLOGICAL ASSESSMENTS

NEUROPSYCH ASSESSMENT

- WHAT ARE WE TESTING?
- REASON FOR REFERRAL?
- ADAPTATIONS DURING A FLARE?
- WHAT IS A BRIEF BATTERY TO TEST?
- HOW DO WE COMMUNICATE TO SCHOOL THAT THESE DECLINES ARE VARIABLE?

Typical Assessment Battery vs. PANDAS/PANS

Need to identify if there have been any significant declines with functioning after a virus such as adaptive functioning, memory, executive declines, emotional well-being changes.

A PANDAS/PANS interview may require more in depth questions regarding health history and consultation with their doctor or medical records

What are we testing?

- To determine if there were significant declines prior to medical diagnosis
- Has the client developed OCD symptoms/tics
- Gathering medical records, look at timing of onset of symptoms
- Understand emotional/behavioral functioning, pre and post symptoms onset

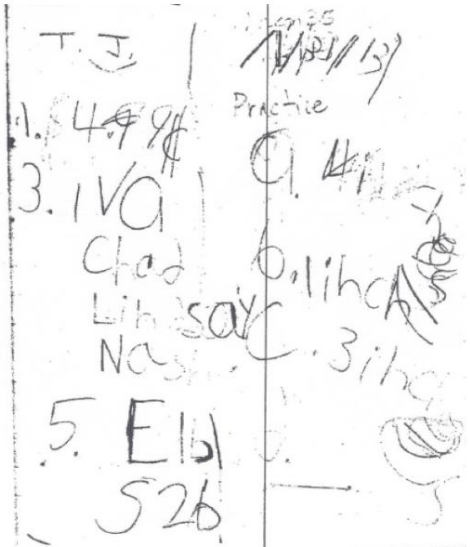
What are we testing?

- Academic skills, changes in math performance, handwriting may be common
- Behavioral concerns, meltdowns, low frustration tolerance
- Memory functioning
- Executive functioning skills
- Adaptive functioning, frequent need to urinate, regression in self help skills
- Cognitive functioning to determine strengths and weaknesses
- Visual-spatial and visual motor skills
- Sensory processing issues, food sensitivities, swallowing issues
- Sleep disturbances

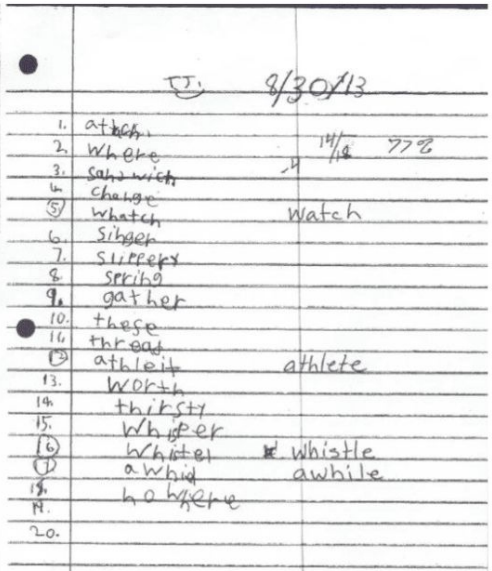
Examples of Changes in Functioning

Handwriting & Fine Motor Skill Deterioration

Age 10- 6 months after symptom onset, prior to any treatment

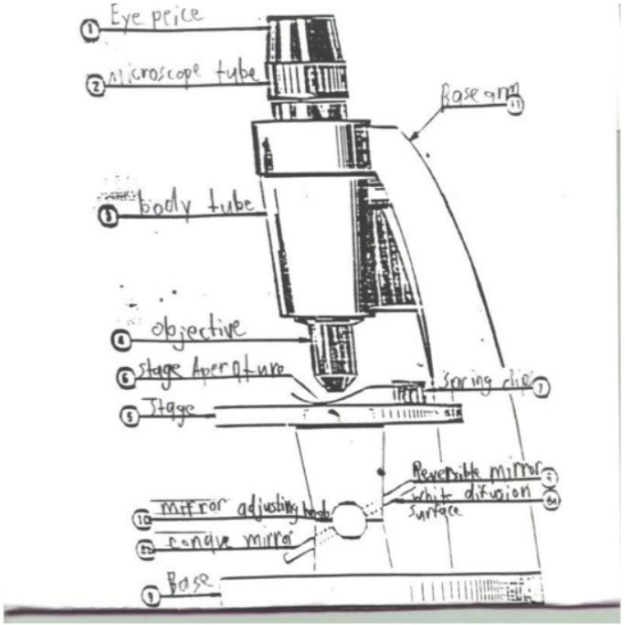


On predinose, weaned from 40 mg -> 20 mg daily over 4 months

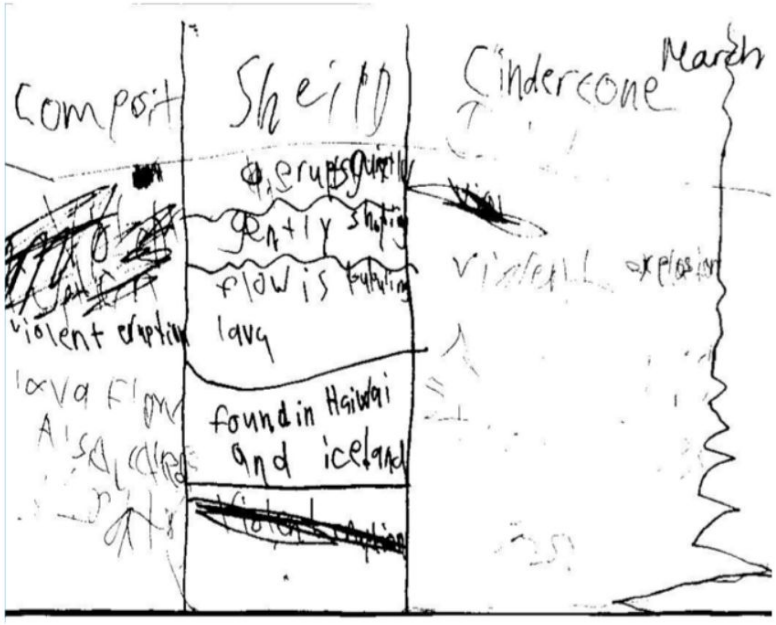


Handwriting & Fine Motor Skill Deterioration

Before Onset



After Onset



Swedo, M.D. Pediatrics & Developmental Neuroscience Branch NIMH, NIH Intramural Program

Role of Neuropsychological Testing in PANS/PANDAS

- Differential diagnosis and treatment planning, understanding acute symptoms
- Assess visual-motor skills
- Memory, executive functioning, attention, processing speed, academic functioning (children and young adults)
- Anxiety, depression, anger and irritability
- Sensory issues, visual changes, handwriting
- Make accommodations/modifications during testing depending on symptom severity

Brief Test Battery

- Clinical interview, developmental history
- Medical records, onset of symptoms
- Work samples, products of behavior, pre and post
- Emotional and behavioral rating scales (BASC, YBOCS/CYBOCS, SCARED, BDI/BAI, CDI)
- Adaptive functioning: Vineland/ABAS

Case Example

6 year old female child presenting for neuropsych assessment due to severe anxiety, OCD symptoms, social problems and sensory reactivity, family suspected PANDAS

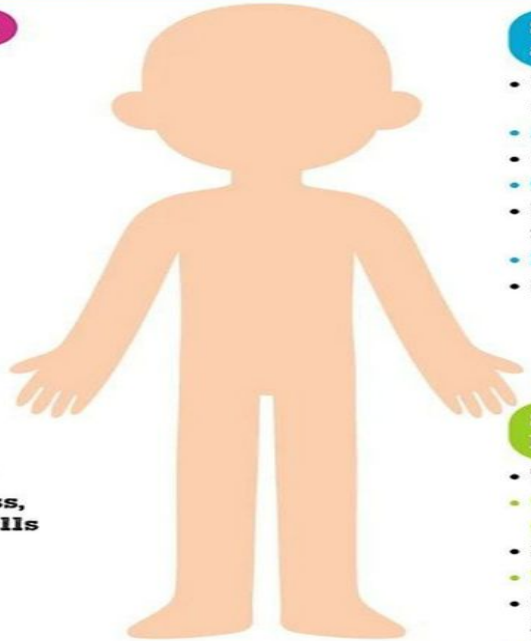
Onset of symptoms predate suspected streptococcus infection and include intense fear of using the toilet, poor eye contact, lack of interest in playing w/ peers, fixation on the movie Cars, opening and closing doors repeatedly

Pediatrician consult does not confirm that child had positive Strep test, but prior concerns for sensory issues and referral to Occupational Therapy and Speech Therapy

Assessment included background interview, WPPSI, NEPSY subtests, CYBOCS, BASC (parent and teacher), ADOS Module 3

Child was diagnosed with Autism Spectrum Disorder

Be PANS and PANDAS Aware
#BrainAwarenessWeek2022



Cognition and Learning

- Dysgraphia
- Dyscalculia
- Sleep issues
- Brain fog
- Visual processing difficulties
- Working memory issues
- Auditory processing difficulties

Social, Emotional and Mental Health

- Emotional and social regression
- Anxiety
- Panic attacks
- OCD
- Issues with regulating emotions
- Self-harm
- Suicidal thoughts

Communication and Interaction

- Regression in language use
- Onset of stuttering
- Regression of coping skills, social awareness, or social language skills
- Trouble with peers
- Reactivity
- Screaming and verbal outbursts
- Tantrums
- Suicidal language

Sensory and Physical Needs

- Tics
- Changes in fine and gross motor skills
- Sensory sensitivities
- Eating disorders
- Enuresis/urinary frequency
- Masking

PANS (Paediatric Acute-onset Neuropsychiatric Syndrome)

This is a neuropsychiatric condition which is triggered by a misdirected immune response.

PANDAS (Paediatric Autoimmune Neuropsychiatric Disorders Associated with Streptococcal Infections)

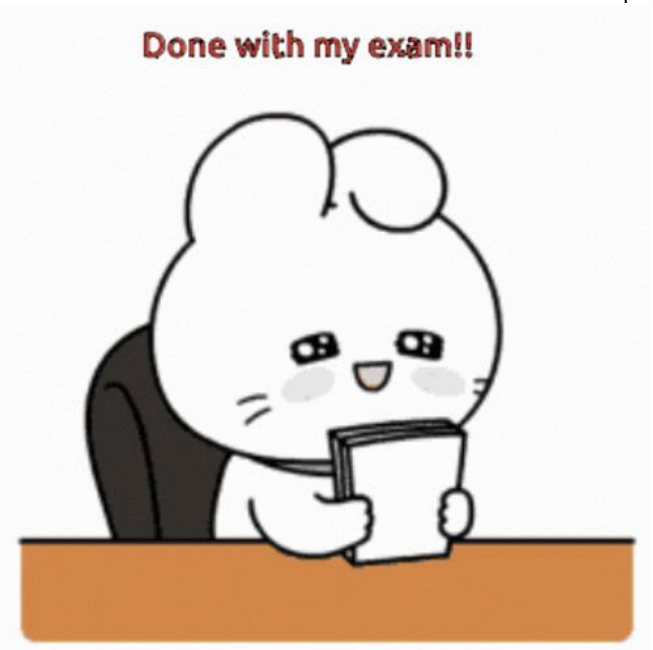
PANDAS is a subset of PANS. Similarly, it is a neuropsychiatric condition which is triggered by a misdirected immune response to a streptococcal infection.

Comprehensive Assessment: Neuropsychological Batteries/Tools CHILDREN

- Beery-Buktenica Developmental Test of Visual-Motor Integration Sixth Edition
- Cognitive/IQ assessment (WISC/KABC)
- DKEFS/ NEPSY
- CTMT, TRAILS X
- SCARED, CES-D
- MIGDAS, Sensory Profile 2
- BASC, Conners 4

Suggested Neuropsychological Batteries/Tools Continued

- CVLT
- Woodcock Johnson Tests of Achievement, KTEA
- FAW and FAM
- TOWL-4
- CYBOCS
- ABAS/Vineland
- PPVT/EVT, OWLS-2, SLDT, OPUS
- Cross disciplinary and consultation with OT, PT, speech, audiologist and medical



Comprehensive Assessment: Neuropsychological Batteries/Tools ADULT

- Test of Visual-Motor Skills-3 (TVMS-3), Grooved Peg Board
- Cognitive/IQ assessment (WAIS-V/WJ-COG-5)
- DKEFS
- CTMT, TRAILS X
- PHQ-9/GAD-7; personality assessment PAI/MMPI
- MIGDAS/Sensory Processing Measure
- CVLT/RBANS
- ABAS/Vineland
- PPVT/EVT
- Cross disciplinary consultation with OT, PT, speech, audiologist and medical

Accommodations During Testing

- Break up assessment over multiple sessions
- Take frequent breaks
- Allow client to have parent or partner/friend in room at start of the assessment and check in with them as needed
- Use relaxation strategies and emotional coping strategies
- Let client stand up or move around examination room as needed
- Within standardization requirements provide support, reassurance and encouragement
- For children use structured reinforcement system and rewards

Support Team for PANS/PANDAS at School

- 504 accommodation plan
- IEP likely under umbrella of OHI
- Hospital/Homebound program
- Virtual options and hybrid models
- (issues connected to attendance)
- Support of school nurse
- School psychologist, counselor, social worker
- Good communication and flexibility
- May need occupational therapy evaluation

School Needs

Communication

- Letting school know about diagnosis
- Sharing any evaluations with school
- May need to inform them on PANS/PANDAS

Accommodations/Services

- May need 504 Plan
- Work with school nurse
- May need to work with school counselor/school psychologist
- May require educational accommodations
- Permission to have breaks during the day
- Behavior plans
- Check in/check out with a staff member
- Reduced course load/hospital homebound

School Needs Continued

Communication

- Crisis Planning
- Rage
- Contact Person at school
- Not blame parents, it is hard enough

Accommodations/Services

- Support for parents
- Support Group
- Low demand
- Attendance concerns
- Try not to overwhelm school staff

Accommodations for HS to College Transition School Needs

Communication

- Letting school know about diagnosis
- Sharing any evaluations with school
- May need to inform them on PANS/PANDAS

Accommodations/Services

- May require educational accommodations
- Reduced course load/online classes
- Note taking support
- Priority registration for classes
- Single door room
- Priority housing -close to campus
- Counseling services
- Peer mentor
- Academic coach/tutoring
- Establish health care team close to college

PANS/PANDAS ADULTS

- ADA accommodations at work/college
- Virtual and/or hybrid work/school options
- Specialized support groups: https://aspire.care/resources/aspire-chitchat/

  https://neuroimmune.org/patient-and-family-resources/

- Use of adaptive technology: talk to text, AI note takers, calculators, excel
- EFMLA/FMLA

PANS/PANDAS ADULT WORK ACCOMMODATIONS

- Flexible scheduling - late start or flexible work hours
- Breaks during workday
- Quiet workspace to reduce sensory overload
- Noise canceling headphones
- Working from home during flare ups
- Written instructions or checklists
- Regular check-ins from manager
- Digital calendars with reminders
- Allowing time to engage in calming routines
- Space for movement if tics require space
- Allowing time off for medical appointments

TREATMENT PLANNING

Treatment Plan Components

Medical Management

- Treatment plans by the medical team
- Different therapies being offered and the medical regimen for the client

Psychological Interventions

- Different types of therapies that will be utilized (note when, why, and adaptability measures)
- Specific treatment during flares

Family Supports

- Types of modalities will be used to support the family (caregivers and siblings)

Academic Interventions/Supports

- 504 Plans/IEP- What types of supports will the client need
- Plan to work with the academic setting (homeschool, unschool, public or private)

Adaptations during Flare Up

- <u>For students:</u>
- Reduced workload at school
- Working with therapist or medical team
- Work with school psychologist or school counselor
- Extended time on submitting assignments
- <u>For adults:</u>
- Work from home or hybrid options
- Flexible start times
- Flexible deadlines
- Permission to attend therapy sessions during work hours

Legal Support: American with Disabilities Act (ADA) & Family and Medical Leave Act (FMLA)

Case Examples

- What you did different?
- Adaptations to the testing battery? Ex. crying and emotional dysregulation
- Vineland to assess their adaptive functioning
- Ways to communicate with school about fluctuations in abilities
- Impact of Lyme Disease on memory and other neuropsych functioning and executive functioning
- Tailored recommendations
- Communicating with parents and different sort of recommendations and outcomes and follow-up testing
- Autoimmune Disorders in parents? Hashimoto?
- Any practical feedback to psychologists? Parents already face doubt and confusion how do we help?

Case Example

- 13 year old female

- Kawasaki Disease in 2013 at 2 years old and 2018 -Hospitalized both times due to high fever
- What is Kawasaki Disease: It causes swelling, inflammation in walls of blood vessels that carry blood throughout the body. Most often affects the heart arteries of children. It also causes swelling in glands (lymph nodes) and membranes inside the mouth, nose, eyes, and throat
- Side effects: high fever,swollen hands and feet, skin peeling, red eyes, and tongue.
- Cause of Kawasaki disease is unknown but not spread from person to person and some evidence it occurs after a bacterial or viral infection, linked to factors in environment and some genes may make someone more incline to develop it

Case Example Continued

- After first diagnosis, difficult to determine which behavior changes were related to age or symptoms, which included crying and changes in mood

- After 2018 diagnosis - she missed a month of school during recovery - took months to fully recover

- Had physical damage to her heart, as two aneurysms were identified. Her family noticed significant changes in her personality, energy levels, attention, and school performance following this episode. She showed increased moodiness, sound sensitivities, and had difficulty completing schoolwork. Additionally, she started displaying motor tics when anxious or fatigued.

Case Example

- A previous Antimitochondrial Antibody (AMA) test revealed elevated levels of the antimitochondrial antibodies. Lira is seen on yearly basis to check her heart and takes Aspirin daily.
- Has to have her heart checked yearly

Therapist:

At home, engages in minimal school-related activities and has limited motivation, which further impacts her sense of accomplishment and autonomy. Emotional meltdowns can last for hours and disrupt the entire day, presenting ongoing challenges for the family. Concerns with memory.

She continues to struggle with all current treatment goals:

- Emotional regulation remains poor
- Adaptability to change has not improved significantly
- Social engagement and self-confidence are extremely limited

Case Example

- Testing Battery: WISC-V, D-KEFS, CVLT-3, NEPSY-II, OPUS, Trails-X, Grooved Pegboard, WCST, SLDT-A:NU, FAM, BASC-3, MIDGAS-2, SRS-2, ABAS-3, MASC, PAI-A.
- Testing: Completed over 2 session; very easily frustrated immediately, crying/tearing up frequently especially during 1st session
- She had sensory sensitivities, rigid behaviors, compulsions, obsessive thoughts, anxiety,
- very concerned about her health status, distress, tension, clinically significant levels of anxiety, irritability, cognitive, affective, and physiological symptoms of depression. Feelings of hopelessness, worthlessness, lack of self-confidence, distress, and lack of interest in activities once enjoyed. She also endorsed feeling socially isolated and detached. She may have difficulty interpreting the social nuances of behaviors. Difficulty with self-expression and communication. She has difficulty making decisions and handling unexpected situations. Phobic behaviors that interfere in her life significantly.
- Adaptive skills were average to above average on ABAS
- SLDT: Below average - making inferences & interpreting social lang

Case Example

- Testing memory concerns - auditory & visual
- Executive functioning testing all average except trails -x
- Slow processing speed
- Anxiety & depression reported

- Diagnosis: Generalized Anxiety Disorder, Persistent Depressive Disorder, OCD, and ASD.
- Suspected PANS and referred for medical evaluation

Resources for Parents and Clinicians

Podcasts

- PANS PANDAS-Hope
- PANS/PANDAS STORIES
- TAMF Podcast
- Mom & Doc Talk: Healing PANS/PANDAS
- PAN and PANDAS- Body Talk Radio Podcast
- Surviving the Flares
- Demystifying PANS/PANDAS

Support Groups/Information

- PANDAS Network
- PANDAS Physicians Network
- ASPIRE
- Neuroimmune Foundation
- The Alex Manfull Fund

Facebook Groups

- PANS/PANDAS Support Group
- PANDAS Parents
- PANDAS PANS Support Groups
- Aspire PANS PANDAS Group
- PANS/PANDAS Therapists Collective
- PANDAS/PANS Parent Stress Relief Group
- Adult PANDAS/PANS/Lyme/Tick-Borne Diseases
- Holistic Guide to PANS/PANDAS
- Pans Pandas-Hope

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Assessment Abbreviations Guide

Adaptive Behavior Assessment System, Third Edition (ABAS-3)
Behavior Assessment System for Children, Third Edition (BASC-3)
California Verbal Learning Test, Third Edition (CVLT-3)
California Verbal Learning Test-Children's Version (CVLT-C)
Center for Epidemiological Studies Depression Scale (CES-D)
Conners 4th Edition (Conners 4)
Comprehensive Trail Making Test-Second Edition (CTMT-2)
Delis-Kaplan Executive Function System (DKEFS)
Expressive Vocabulary Test, Third Edition (EVT-3)
Feifer Assessment of Math (FAM)
Feifer Assessment of Writing (FAW)
Kaufman Test of Educational Achievement-3rd Edition(KTEA-3)
Monteiro Interview Guidelines for Diagnosing the Autism Spectrum, Second Edition (MIGDAS-2)
NEPSY-II: A Developmental Test of Neuropsychological Assessment (NEPSY-II)
Oral and Written Language Scale-2nd Edition (OWLS-2)
Oral Passage Understanding Scale (OPUS)
Peabody Picture Vocabulary Test, Fifth Edition (PPVT-5)
Personality Assessment Inventory, Plus (PAI-Plus)
Repeatable Battery for the Assessment of Neuropsychological Status (RBANS)
Screen for Child Anxiety Related Disorders (SCARED)
Social Language Developmental Test (SLDT)
Test of Written Language-4th Edition (TOWL-4)

Assessment Abbreviations Guide (continued)

Trails X: A Test of Executive Planning (Trails X)
Woodcock Johnson Tests of Achievement-5th Edition (WJ ACH-5)
Woodcock Johnson Tests of Cognitive Abilities-5th Edition *(WJ COG-5)*
Wechsler Adult Intelligence Scale-Fifth Edition (WAIS-5)
Wechsler Intelligence Scale for Children-Fifth Edition (WISC-V)
Wechsler Memory Scale-Fourth Edition (WMS-IV)
Wechsler Preschool and Primary Scale of Intelligence-Fourth Edition (WPPSI-IV)
Yale-Brown Obsessive-Compulsive Scale (YBOCS)

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