

PANS/PANDAS IN THE SCHOOL

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 **University at Buffalo** The State University of New York



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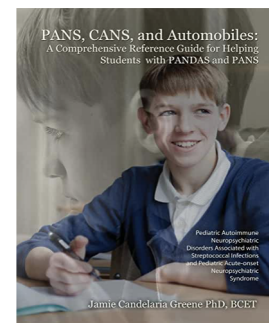
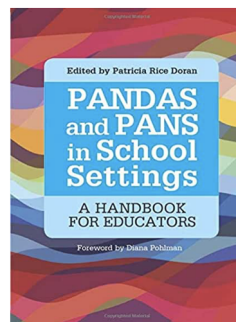
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Objectives

- Symptoms of PANS/PANDAS
- Impact on home and school performance
- Educational Team and intervention
- Accommodations/504 and IEP
- PANS/PANDAS resources

Potential Conflict of Interest:

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Welcome – PANDAS Network



Diana Pohlman

Executive Director

PANDAS network

www.Pandasnetwork.org




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PART I:

Diagnosis and Symptoms





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Part I:

Diagnosis and Symptoms

Christine Brown, PhD,
Neuroscience

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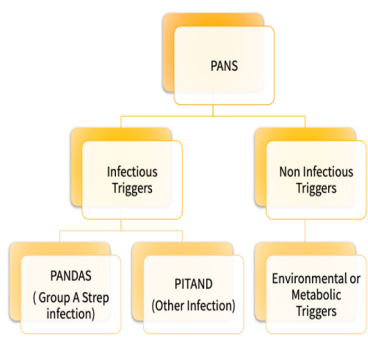

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What are PANS/PANDAS?

PANS (2012)

Pediatric Acute-Onset Neuropsychiatric Syndrome

Swedo, Leckman & Rose, 2012




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PANDAS (1998)


Pediatric Autoimmune Neuropsychiatric Disorder Associated with Strep

Swedo, et. al. 1998



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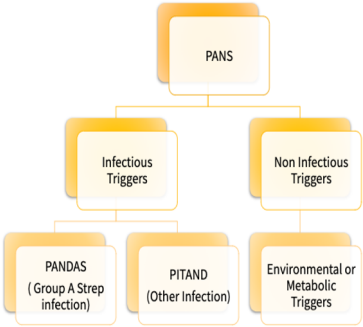

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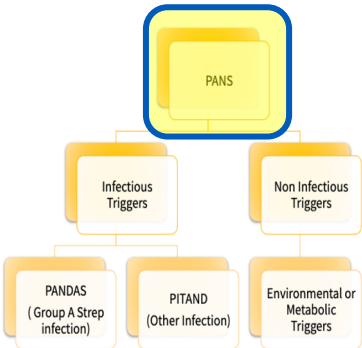

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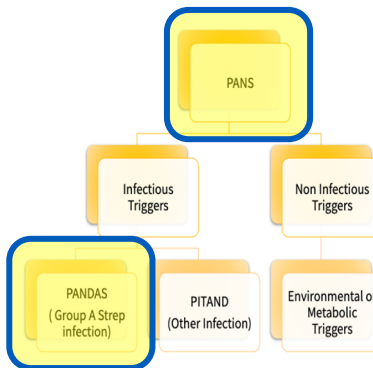
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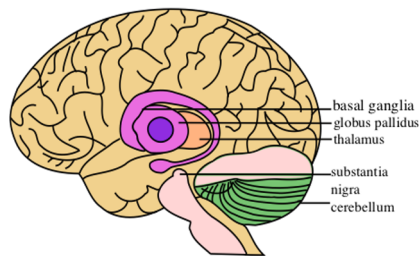
Swedo, et. al. 1998



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Theoretical Changes

1. Genetic predisposition
2. Creation of autoantibody
3. Breach in blood-brain barrier
4. Immune system interacts with neuron in Basal Ganglia and other areas



1. OCD
2. Anxiety
3. Restricted Eating
4. Motor tics
5. Urinary Frequency
6. Sensory defensiveness
7. Mood lability
8. Handwriting deterioration
9. Math dysfunction

Cutforth, DeMille, Agalliu & Agalliu, 2016
Kirvan, Swedo, Snider & Cunningham, 2006



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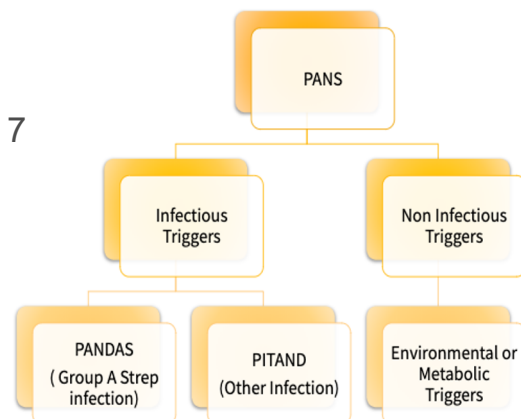
Relation to Other Conditions

- Immune Deficiency
 - One study of 687 families reported 53% of children with PANS were immunocompromised (Calaprice et al 2017)
- Autoimmune Encephalitis
 - Enlarged Basal Ganglia (Dr. Harry Chugani – PET scans)
 - Similar to book / movie “Brain on Fire” (Susan Calahan, 2012)

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Criteria for PANS

- A sudden onset of OCD or restricted eating/Anorexia
- Must present with 2 out of the following 7 symptoms:
 - Anxiety
 - Depression and/or emotional lability
 - Irritability, aggression, and/or severely oppositional behaviors
 - Behavioral regression
 - Deterioration in school performance
 - Sensory or motor abnormalities
 - Somatic signs or symptoms



Swedo, Leckman & Rose, 2012

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Types of OCD in Children

OBSESSIONS

- Contamination
- Harm to Self or Others
- Symmetry Urges (or "Just Right" OCD)
- Doubting
- Numbers
- Scrupulosity
- Sexual Themes

COMPULSIONS

- Washing & Cleaning
- Checking
- Symmetry
- Counting
- Repeating/Redoing
- Hoarding
- Praying

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Obsessive Compulsive Symptoms In School

- Stubborn or oppositional behaviors
- Over-focus on neatness.
- Lining up, or arranging items repeatedly.
- Wanting to complete assignments "perfectly," checking and re-doing.
- Erasing repeatedly
- Reading letters, syllables, words or sentences repeatedly.
- Filling in scantron sheets very carefully;
- Very slow and deliberate work, resulting in incomplete assignments.
- Checking homework, backpack, lockers, pockets, or under the desk and chair repeatedly, ensuring that locks and zippers are fastened.

Modified from: Aureen Pinto Wagner.
http://www.ocfoundation.org/ocdinkids/personnel/ocd_in_school.aspx

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Diagnostic Challenges

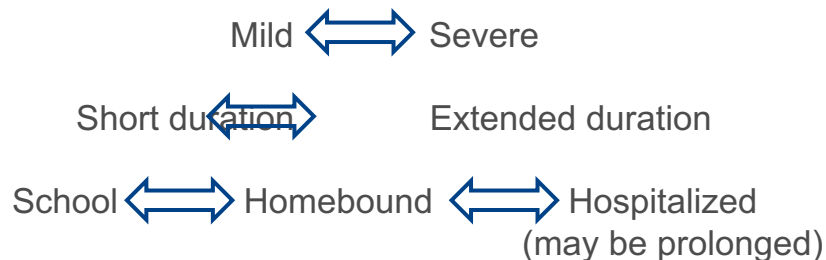
- Comprehensive workup Chang, et. al.,
 - PANS Collaborative Consortium
- Few physicians who specialize in PANS / PANDAS
- Delays from onset to diagnosis may be years

- Common Infectious Triggers:
 - Strep
 - Sinusitis
 - Mycoplasma
 - Colds
 - Lyme Disease and Coinfections
 - Viruses
 - Allergens/Mold
- Environmental Conditions
 - Allergens
 - Mold
- Metabolic Conditions
 - Mitochondrial disorders

Calaprice, Tona, Parker-Athill & Murphy, 2017
Swedo, Leckman & Rose, 2012

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Range of Symptom Severity and Duration



Calaprice et al., 2017

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Medical Intervention: 3-Pronged Approach

1. Provide symptom relief with behavior therapy and psycho therapeutic drugs

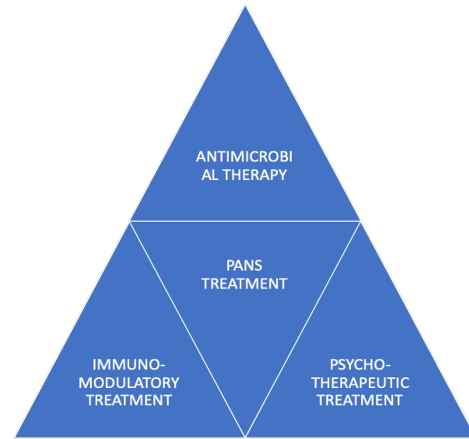
Thienemann, et. al., 2017
Storch & Murphy, 2006
Nadeau, et. al., 2015

2. Treat infections with antibiotics

Cooperstock, et. al., 2017

3. Address inflammation and immune problems with anti inflammatory or immune modulating medications

Frankovich, et. al., 2017

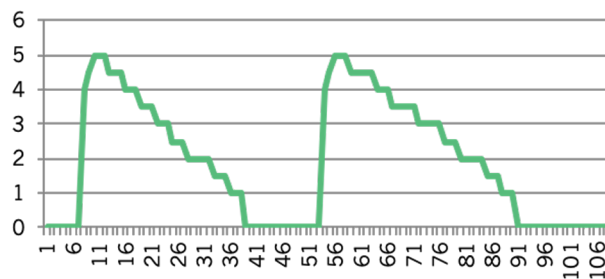


Swedo & Frankovich, 2017

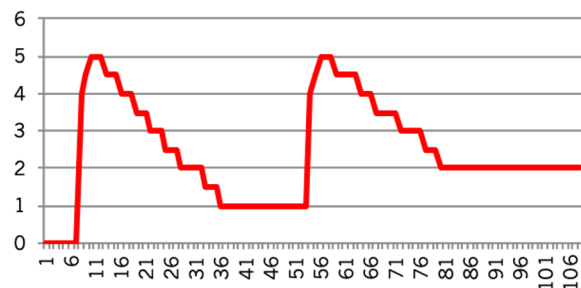
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Saw Tooth Recovery

Saw tooth Recovery - Return to Baseline



Saw tooth Recovery - No Return to Baseline



Calaprice, Tona, Parker-Athill & Murphy, 2017

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Case Study

There has recently been an outbreak of streptococcal infections at a local elementary school, and 7-year-old Josie was diagnosed with strep again. This is her third diagnosis of strep in the past 2 months.

This week, she was sent to the principal's office twice due to aggressive behavior towards other students and an inability to be calmed down after the behaviors.

She also started refusing snacks and lunches, saying she is afraid she will choke. In class, she covers her ears and cries that her classmates are too loud.

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Application Questions

Josie's parents should talk to her doctor about being evaluated for possible:

- a) Metabolic disorders
- b) ADHD
- c) PANDAS
- d) Oppositional-Defiant Disorder

Which of the following symptoms would Josie least likely be experiencing?

- a) OCD-like symptoms
- b) Anxiety
- c) Hirsutism (excessive hair growth)
- d) Urinary Frequency

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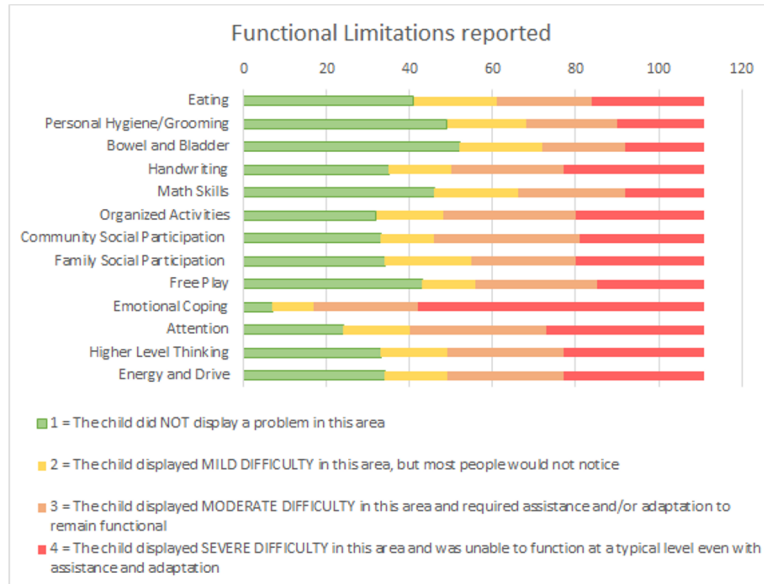
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PART II:

Impact on Home and School
Performance



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Tona, Bhattacharjya & Calprice, 2017

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Impact on Social Participation, Leisure, and Family Quality of Life

Children move from:

- Socialization → Isolation
- Exploration → Separation anxiety

Families Characteristics:

1. "Life suddenly turned upside down"
2. "My Child is not crazy"
3. "Emotional distress within the family"
4. "Major Life Alterations"
5. "School drastically influences Family QOL"



Demchick, Ehler, Marramar, Mills & Nuneviller, 2019
Tona, Bhattacharjya & Calprice, 2017

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Tona, Bhattacharjya & Calaprice, 2017

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Demchick, Ehler, Marramar, Mills & Nuneviller, 2019
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Demchick, Ehler, Marramar, Mills & Nuneviller, 2019
Tona, Bhattacharjya & Calaprice, 2017

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Impact on School Performance

23% can function in a school setting without accommodations (Calaprice et al. 2017)

PANS/PANDAS leads to significant deterioration in school functioning.

Including:

- Handwriting ability
- Social interactions
- Social anxiety
- Low endurance
- Emotional lability
- Separation Anxiety
- Restrictions on diet



Rice Doran, 2017
Tona, Bhattacharjya & Calaprice, 2017

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Application Question

Josie's family asked the pediatrician about PANS and he suggested they keep a journal of unusual or regressive behaviors at home and school for one week.

Which of the following would NOT be indications of PANDAS/PANS? (select all that apply)

- a) Recently refusing to eat a variety of foods
- b) High blood sugar
- c) Having to urinate frequently
- d) Sadness/Depression
- e) Handwriting deterioration
- f) Low levels of calcium in the blood

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PART III:

Educational Team




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Part III:

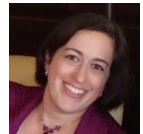
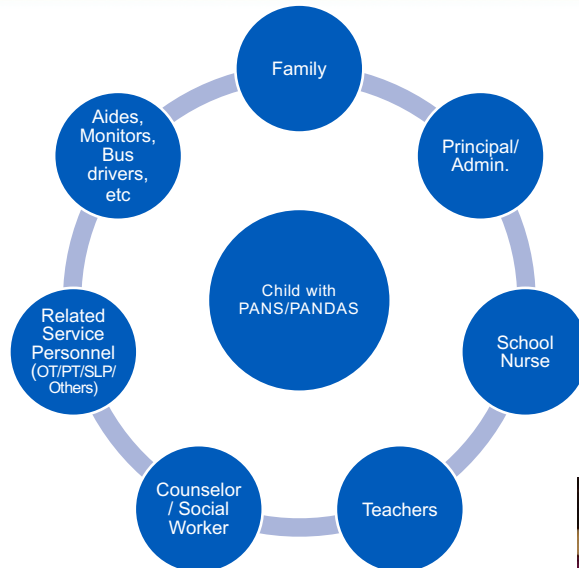
Educational Team

Jodi Duke, EdD
Associate Professor, George Mason University
College of Education and Human Development



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Educational Team

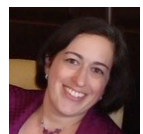


Candelaria Greene & Rice Doran, 2019

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Principle and Other Administrators

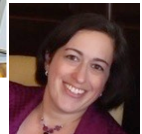
- Coordinate and deploy the team
- Understand parents' perspectives
- Manage school-wide policies



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Educators

- Teachers lead the team
 - Spearhead support from specialists
 - Orchestrate classroom accommodations
- Teachers and Aides have the most contact with the students
 - Record symptoms and behaviors
 - Understand child's anxiety and possible triggers
 - Facilitate interaction with peers
 - Communicate regularly with family
 - Practice good infection control in the classroom

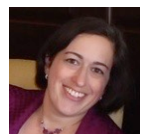


Candelaria Greene & Rice Doran, 2019

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School Psychologists

- Support Families
- Identify exacerbations and flares before psychological testing
- Recognize changes in neuropsychological function in exacerbation
- Stay abreast of the literature

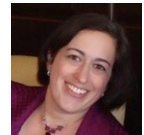


Gamucci, et. al., 2019

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School Counselors & Social Workers

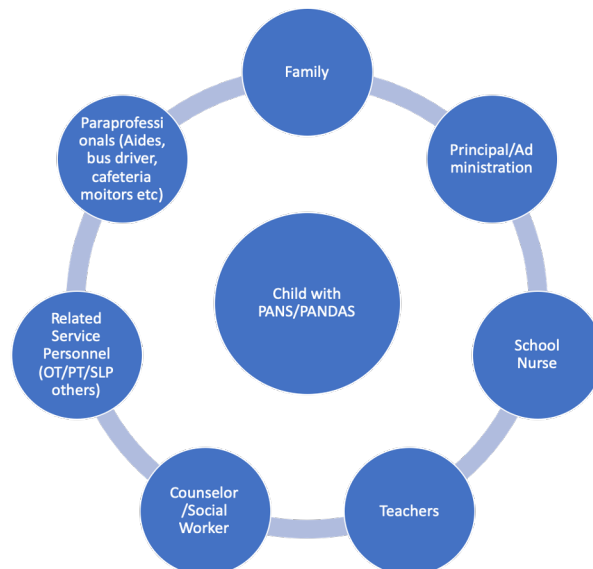
- Be aware of frequent PANS/PANDAS symptoms and educate other team members
- Work with the team to determine the best accommodations for the child
- Provide a safe space for the child
- Support child and family during exacerbations, especially regarding emotional coping.
- When the child is willing and able, use Cognitive Behavioral Therapy with Exposure and Response Prevention (CBT with ERP) – or guide family to find a qualified practitioner for this type of intervention to help child develop skills to modulate OCD symptoms.
- Support siblings during exacerbation



Storch, et. al., 2006

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Educational Team



Candelaria Greene & Rice Doran, 2019

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Candelaria Greene & Rice Doran, 2019

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School Nurses

- Initiate a support team for the child
- Learn about PANS/ PANDAS and help team members to understand the diagnosis
- Work with team to establish good infection control routines in classrooms and throughout school
- Track frequency of strep and other illnesses among students
- Consider patient treatment protocols and support continuation of treatment during school hours
- Advocate for further testing and accommodations
- Recognize patterns of urinary frequency or frequent accidents



Candelaria Greene & Rice Doran, 2019

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Occupational Therapists

- Sensory assessment
- Handwriting assessments
- Energy conservation and work simplification techniques
- Accommodation during exacerbation
- Classroom consultation



Swedo, Leckman & Rose, 2012
Tona, Bhattacharjya & Calaprice, 2017

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Physical Therapists

- Deterioration in motor function
- Decreased strength and endurance
- Changes in muscle tone
- Decreased endurance
- Gait changes
- Difficult to navigate in the school and participate in physical education and other activities.



Tona, Bhattacharjya & Calaprice, 2017

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Speech Language Pathologists

- Disfluencies and stuttering are common during exacerbation
- Some children may experience loss of speech or selective mutism
- Evaluate for auditory processing problems
- Use assistive technology for communication
- Consider audiobooks for reading fluency and visual attention
- Implement visual schedules for auditory processing problems



Potock, 2015

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Application Question

It has been two months since Josie was diagnosed with strep and she just had an appointment with a PANS/PANDAS specialist last week, who diagnosed her with PANDAS and started her on medication yesterday. Over the past two weeks the teacher has noticed that Josie no longer plays with her peers during recess and when she does try to play with her peers, she is unable to keep up. She also has been frequently missing school and when she is present she tends to leave early because she constantly misses her mom or has to go to the bathroom often. Her handwriting is nearly impossible to read, and she keeps falling in physical education. On top of that, she has started to stutter. The educational team has now set a meeting to discuss the recent changes in Josie.

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Application Question

Who is likely to be included on Josie's educational team?

- a) Her teacher
- b) The school nurse
- c) The school counselor
- d) The occupational therapist
- e) The physical therapist
- f) A and B only
- g) All of the above

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PART IV:

Educational Intervention



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Part IV:


Educational Intervention

Patricia Rice Doran, EdD
 Assistant Professor, Towson University
 Editor: PANDAS and PANS in the school Setting: A Handbook for Educators



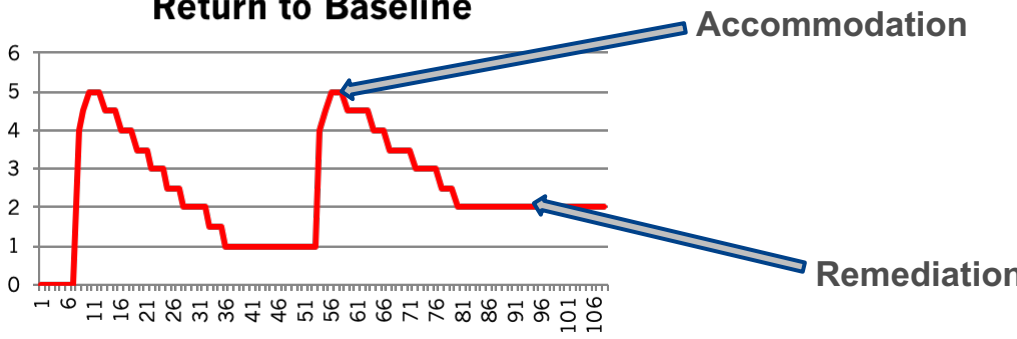


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Intervention Approaches

Saw tooth Recovery - No Return to Baseline



Accommodation

Remediation



Tona, Bhattacharjya & Calaprice, 2017

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Accommodations

- Increase likelihood of child attending school
- Provided during exacerbation
- Removed as exacerbation subsides



Mazur, 2017

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School Accommodations: Fatigue

- Children may experience fatigue throughout the day
 - Offer them breaks to allow for time to rest
- Following low energy activities offer an activity to help excite the child
- Following a high stress times or sedentary times give the child a sensory stimulating exercise
- Energy conservation techniques
- Educate parents on sleep hygiene for child



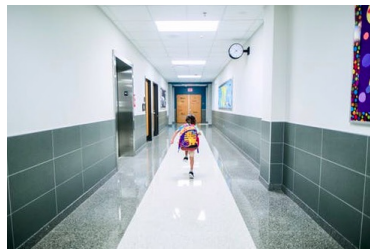
Tona, 2016

Tona & Posner, 2011

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School Accommodations: Classroom Environment

- Changing the classroom environment
- Incorporating movement into the day
- Special seating arrangements
- Providing different handouts
- Universal precautions to prevent infection



- Look into testing and workload accommodations and modifications
 - Extra time
 - Alternate methods of access and completion
 - Distraction free setting
 - Assistive tech
 - Note taker



Tona, 2016
Tona & Posner, 2011

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School Accommodations: Modify Class Activities

Visual Perception

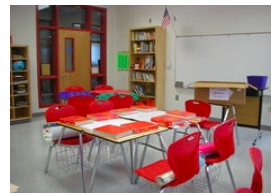
- Visual Cues
- Large Margins
- Bold Print

Alternative Responses

- Visuals or pointing

Modify Sequence

- Incorporate movement breaks
- Alternate positions for work
- Stress ball or fidgets



Tona, 2016
Tona & Posner, 2011

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School Accommodations: Sensory Functions

- Most experience sensory defensiveness
- Modify school environment
 - Decrease sensory input via headphones, use of gloves for sticky activities, quiet space in the room, standing in the back of the line
- Consider SOS feeding program if sensory problems interfere with nutrition
- Increase calming sensations
 - Work with OT to develop individualized sensory diet to increase calming sensations, such as deep pressure and muscle resistance



Tona, 2016
Tona & Posner,

57

School Accommodations: Physical Education

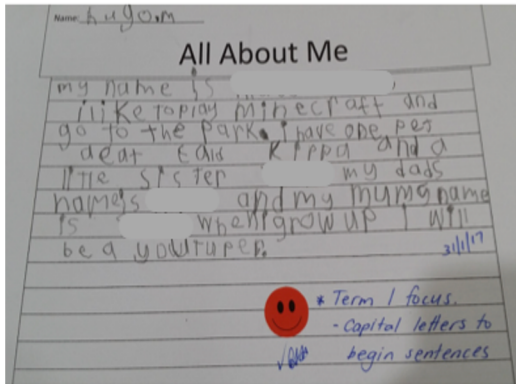
- Children with PANS/PANDAS may experience:
 - Low endurance
 - Social isolation
- Solutions:
 - Rest breaks
 - Accommodating lesson plans



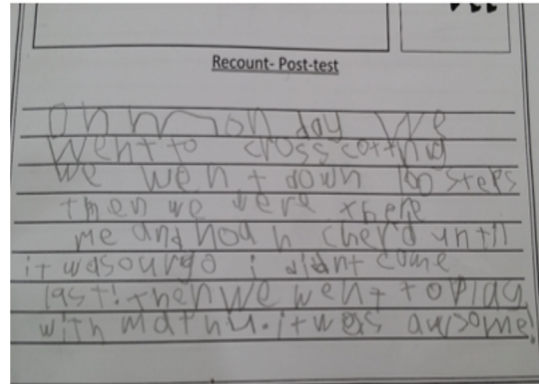
Tona, 2016
Tona & Posner,

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7 Year Old Boy Before and During Exacerbation



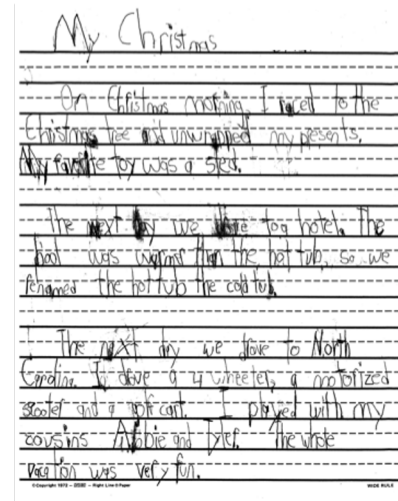
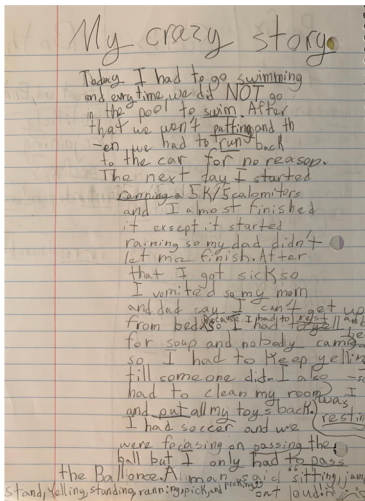
Before



During

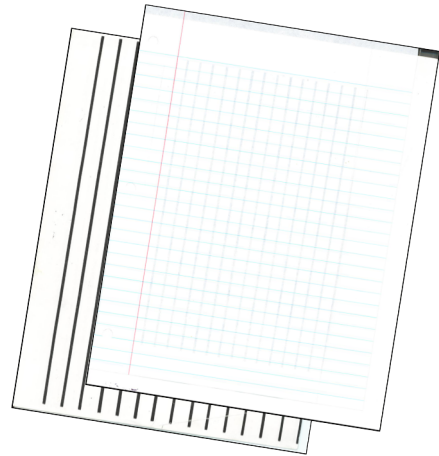
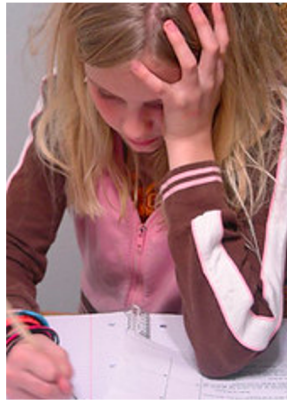
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Margin Drift and OCD Writing with Exacerbation



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Suggestions for Handwriting



Tona & Posner,
2011

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School Accommodations: Math

- Regression in math skills
- Solutions:
 - Calculator
 - Opportunity to redo work
 - Reduce visual stimulation
 - Reduce homework problems
 - Rest breaks
 - Frequent check-ins



Tona, 2016
Tona & Posner,

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Accommodation Question

Based on what you have learned, which of the following accommodations are appropriate for Josie?

- a) Use a vertical line template behind her paper
- b) Provide rest breaks throughout the day
- c) Add 10 points to all of her papers to ensure her grades do not suffer
- d) Laminated a bathroom pass to use as needed
- e) Recommend that she eat lunch in the nurse's office
- f) Create a behavior chart so that she can earn television time when she gets home if she does not use the bathroom more than twice per day


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Accommodation Question

Based on what you have learned, which of the following accommodations are appropriate for Josie?

- a) **Use a vertical line template behind her paper**
- b) **Provide rest breaks throughout the day**
- c) Add 10 points to all of her papers to ensure her grades do not suffer
- d) **Laminated a bathroom pass to use as needed**
- e) **Recommend that she eat lunch in the nurse's office**
- f) Create a behavior chart so that she can earn television time when she gets home if she does not use the bathroom more than twice per day

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**University at Buffalo** The State University of New York


Part V:

Educational Plans

Jamie Candelaria-Greene, PhD, BCET
Learning Specialist
Author: PANS, CANS and Automobiles:
A Comprehensive Reference Guide for
Helping Students with PANDAS and
PANS






**University at Buffalo** The State University of New York

Education Plans

Individualized Education Program (IEP)	504 Plan	Individual Health Plan (IHP)
<ul style="list-style-type: none">• Child has identified disability• Requires specialized instructor• Includes accommodations, modifications and support services• Includes plans for transitioning to post secondary settings for students ages 14-16 years.• Part of federal Individuals with Disabilities Education Act (IDEA)	<ul style="list-style-type: none">• Civil rights law to prevent discrimination• Students must meet criteria for a disabling condition that interferes with major life activity• Provides accommodations, modifications, and supports for student to participate in school• Covers students at any age including postsecondary	<ul style="list-style-type: none">• Considers how to manage issues that may arise in school due to child's health condition.• Based on a comprehensive nursing assessment including: description of the current medical condition; impact on student performance; review of medications & health history; baseline status.• Addresses medical issues that do not directly impact the student's learning.• May include medication routine, notification to the family of strep or other illnesses, and collaboration with medical providers and others with family consent• Identifies responsibilities of the nurse and other personnel in carrying out IHP interventions

Candelaria Greene, 2016
Rice Doran, 2017

drcandelariagreene.com

Education Plans

Diagnostic Category

- Otherwise Health Impaired

Accommodations:

- Medical absences
- Home school / Plan to Transition to return

Transition :

- Postsecondary education
- Employment



Candelaria Greene, 2016
Rice Doran, 2017

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For More Information

To access the citations for all References for this presentation and to access a list of school-related PANS resources to help you, go to:

<https://tinyurl.com/pansinschool>

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Thank you

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Diana Pohlman, Executive Director, Pandas Network

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Before we part...

Please take a few minutes to complete this online survey to provide feedback and help us to continue to improve our training.

<https://www.surveymonkey.com/r/PANS2021pilot>

Thank You!

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