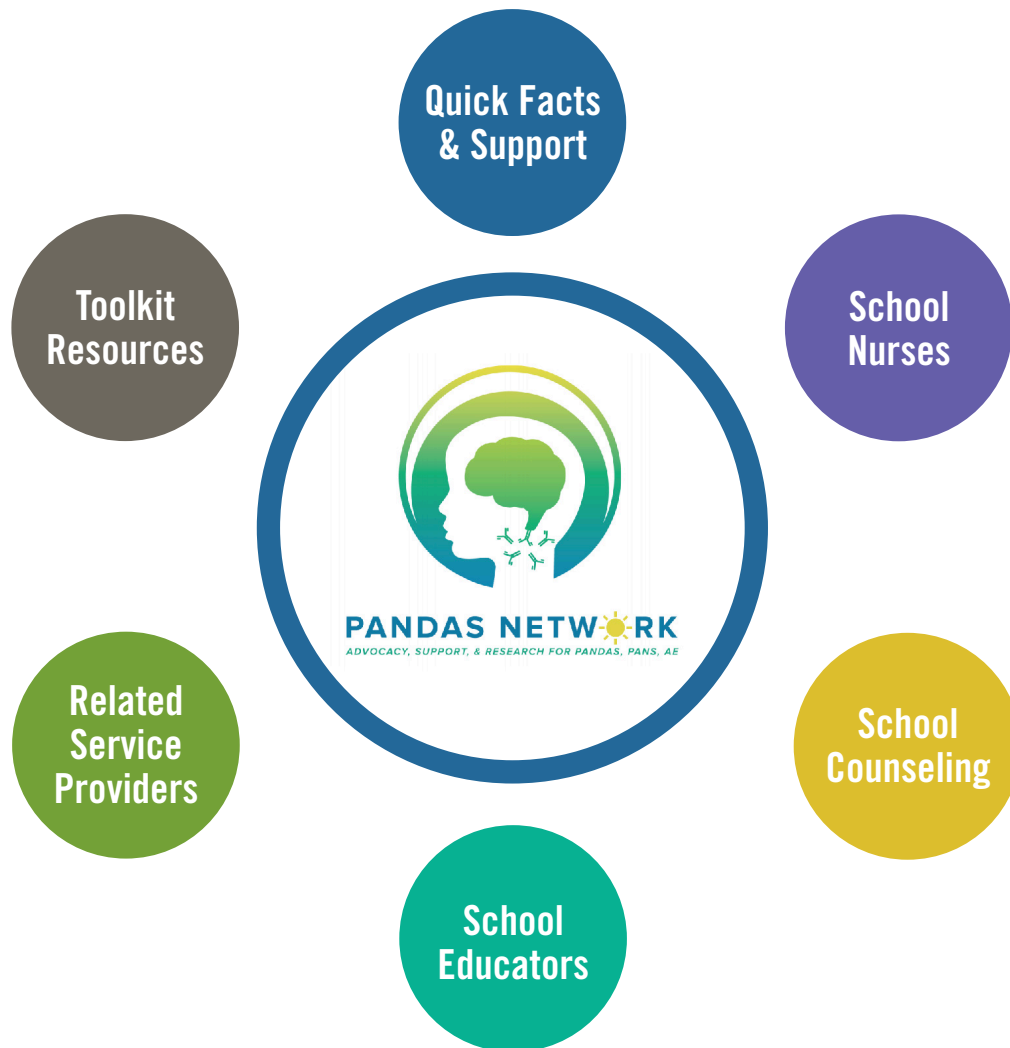


PANDAS, PANS AND RELATED DISORDERS

EDUCATION TOOLKIT



Authors: The PANDAS Network Working Group on Educational Access: Christine L. Amabile, LCSW; Linda C. Avery, PhD; Christine Brown, PhD; Jamie Candelaria-Greene, PhD, BCET; Mary F. Candelaria, PsyD; Amayllis Case, RN; Jodi M. Duke, EdD; Beth A. Economou, MS, CCC-SLP; Emily Klein, M.Ed; H. Nicole Myers, PhD; Patricia Rice Doran, EdD; Catherine Teal, RN; & Janice Tona, PhD, OTR

*Some of the excerpts drawn from "The Critical Importance of School Nurses in the Support of Students with PANS" by J. Candelaria Greene (2016). Special Thanks to Designer: Stephen La Liberte; Angelique LeDoux, PN Board of Director and Diana Pohlman, Founder and Executive Director, PANDAS NETWORK. And to Patricia Rice Doran, Janice Tona, Jamie Candelaria-Greene and Catherine Teal, we are forever grateful for the endless hours of work you dedicated to this desperately needed resource!

PANDAS, PANS AND RELATED DISORDERS:

QUICK FACTS

J. Candelaria Greene Ph.D. | Patricia Rice Doran Ed.D.

In collaboration with the PANDAS Network Working Group on Educational Access

What are PANDAS, PANS?

- Pediatric Autoimmune Neuropsychiatric Disorders Associated with Strep (PANDAS) and Pediatric Acute-Onset Neuropsychiatric Syndrome (PANS) are neuropsychiatric syndromes triggered by a faulty immune system response. Students may experience symptoms after a “strong stimulant” to the immune system (NIMH, 2012) such as strep infection, flu, or even the common cold. In a student with PANDAS or PANS, the immune system is thought to mistakenly react and cause brain inflammation in the basal ganglia region (NIMH, n.d.; Murphy, Girardi, & Parker-Athill, 2014).
- This reaction may cause neurological, psychological, and cognitive symptoms as a result of neurological inflammation (Chang et al, 2015).
- PANDAS and PANS may be treated with anti-inflammatory medications (such as ibuprofen), antibiotics to treat or prevent infection, and immune-modulating therapies (such as steroids, intravenous immunoglobulin (IVIG), and plasmapheresis (PANDAS Network, 2014). Cognitive-behavioral therapy and additional medications may also be important components of a student’s treatment plan.
- More than other conditions, PANDAS, PANS and related conditions can produce sudden, uneven and unusual symptoms.
- PANDAS and PANS may co-occur with other autoimmune disorders, immune deficiency, or other neurological or psychiatric disorders. This can make treatment and management more complex.

COMMON SYMPTOMS



Anxiety, including separation anxiety from familiar people (parents, preferred teacher) or places (home or preferred classroom)



Obsessions and compulsions (e.g., need to sit in a particular spot, inability to tolerate certain activities, unexplained or significant fears)



Tics or involuntary vocalizations or movements may sometimes look like ‘fidgeting’ or hyperactivity



Changes in handwriting and academic performance

Reduced attention span and inability to focus

Changes in personality and behavior

Changes in eating and sleep habits



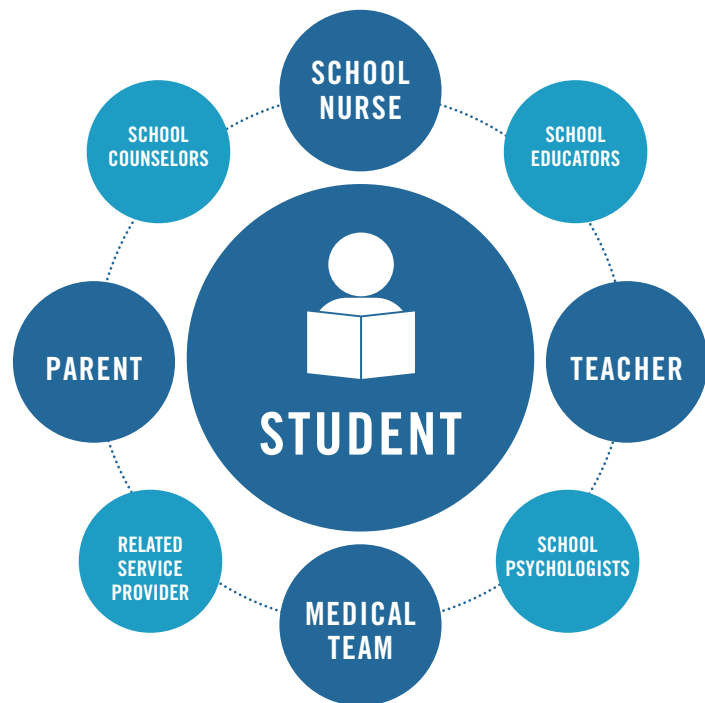
Increased sensory sensitivity

PANDAS, PANS AND RELATED DISORDERS:

SUPPORT

IN SCHOOL

BUILDING YOUR TEAM



KEY CONSIDERATIONS FOR SUPPORT:

Collaborate • Communicate • Assess Impact
Consider Accommodations & Complimentary Services

Build a Supportive & Collaborative Team

that includes parents, teachers, special educators/specialists, the school nurse, school psychologist, administration and other relevant expertise.

Communicate Frequently & Share Updates with the Team

especially during winter months when flares are common. Discuss current treatment protocols and needs for accommodations and/or modifications.

Assess Impact of Symptoms on School Participation

Consider how symptoms may cause deficits in performance particularly in the areas of: Attendance (due to lack of sleep, fatigue); Cognitive issues affecting behavior, academics—including reading, writing and math; Sensory overwhelm (presenting as motor challenging behavior in overstimulating situations); Fine motor skills (handwriting and task completion); Perceptual and Physical issues (tics and other movements) that affect fine/gross motor skills; Urinary frequency; Ability to eat normally; Social issues with peers and more.

Consider Accommodations and Modifications

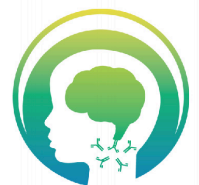
Consider attendance flexibility (shorter days during an uptick in symptoms, Skype classroom attendance during treatments, etc), alternative activities and placements, breaks in the day, testing modifications as needed.

Consider Complementary & Ancillary Services

Services may include Occupational therapy, Physical therapy, and Executive Function & Social skills support. If this is a new condition for your district, it can be helpful to talk with public or nonprofit agencies to see what parameters of services are typically available for students with related conditions such as traumatic brain injury (TBI), Tourette syndrome, and encephalitis or encephalitic conditions, etc.

PANDAS/PANS may impact a student's ability to:

- *Attend and travel to all school related activities*
- *Sustain focused attention & executive functioning*
- *Adapt to transitions and stresses*
- *Understand & remember information*
- *Communicate effectively, both orally and in writing*
- *Behave in age-appropriate ways*
- *Maintain prior level of physical & mental stamina*



PANDAS NETWORK
ADVOCACY, SUPPORT, & RESEARCH FOR PANDAS, PANS, & AF

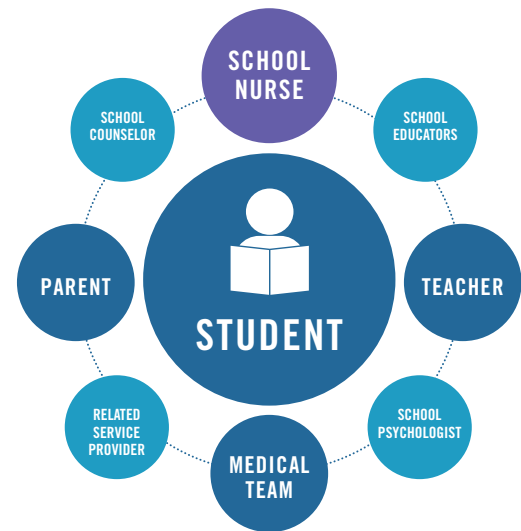
PANDAS, PANS AND RELATED DISORDERS:

IMPACT

FOR SCHOOL NURSES

CASE STUDY: JANE

At a faculty meeting, several teachers mentioned changes in Jane's classroom behavior and academic performance. Earlier that month, Jane's mom commented that her daughter was experiencing tics and OCD-like symptoms which were out of the ordinary for Jane. The School Nurse recalled Jane and several kids in her class tested positive for strep infection a month prior.



Key Considerations for Support

The **School Nurse's** role is vital for the success of students with PANDAS/PANS. As the lead facilitator, you will spearhead collaboration among parents, educators, medical and service providers and the student.

- **Build a supportive and collaborative team** and discuss information about PANDAS/PANS signs and symptoms with faculty and parents
- **Establish best practices prior to the start of school** regarding illness prevention, universal precautions, hygiene, communication with families (i.e. Community Awareness Letter, 'Sick Season' email with flu and strep information, etc.)
- **Share updates with the team** and inform parents of classroom illness especially when flares are common.
- **Consider current treatment protocols** including effectiveness and side effects of medications, etc.

Advocate for Testing & Support as Needed:

- Fine Motor/Visual Motor/Assistive Technology
- Visual Processing (acuity, processing speed, memory)
- Assessments of Functional Behavior and Social/Emotional Development (peer supports/bullying)
- Memory Skills (Visual and Auditory)
- Executive Functioning Skills
- Sensory Integration/Sensory Defensiveness
- Adaptive PE/Gross Motor/Recreational
- Auditory Processing/Language Processing (supports for building social/communicative skills)
- Psychiatric & Neurologic referrals (OCD, anxiety, tics and other)
- Extended time accommodations for testing, assignments and standardized tests, such as the SAT.

PANDAS, PANS AND RELATED DISORDERS: SUPPORT

FOR SCHOOL NURSES

Develop an Individual Health Care Plan (IHCP)
The IHCP will bridge the student's educational and medical needs.

- **Start with Collaboration** - Recognize the need for the school staff, providers, family, and when possible, the student, to provide feedback and work together.
- **Symptom Impact** - Consider interventions that will address symptoms affecting attendance and participation during the school day, to include:
 - **Physical symptoms:** lack of sleep, fatigue/poor stamina, ability to eat normally, urinary frequency, movement issues, tics, etc.
 - **Fine motor skills** (handwriting and task completion)
 - **Behavior and emotions** (separation anxiety, OCD symptoms, etc)
 - **Academics**, including reading, writing and math; poor cognitive stamina
 - **Sensory overload** (this may present as challenging behavior in overstimulating situations)
- **Consider schedule changes, alternative activities and placements, transportation logistics and attendance flexibility.**
- **Consider Occupational Therapy, Physical therapy, and Social Skills Support.**

Develop Safe and Effective Responses to Inappropriate Behaviors

to reduce stimulation and demands on student, redirecting student's attention, and implement Cognitive Behavioral Techniques and/or other therapeutic measures. Regarding behaviors that could be PANS related, how does the school apply federal safeguards regarding inappropriate disciplinary actions/techniques by staff?

Consider aspects of an emergency plan for the diffusion of 'behavioral storms' at school; to include behavioral interventions and immediate support (by parent, staff member, therapist, emergency medical support) and use of specific language and phrases.

Testing and Workload Accommodations and Modifications

will likely include provisions for extra time, distraction free settings, assistive technology, alternate methods of access and completion, prioritization of task completion designed to reflect competence, use of notetakers, reduced academic and/or homework load, rest periods with nurse, adapted PE and home/hospital instruction. Monitor authorized accommodations and modifications, as needed.

Complementary Support/ Services - If this is a new condition for your school or district, it can be helpful to talk with local agencies to understand what services are available for students with related conditions such as traumatic brain injury, Tourettes Syndrome, encephalitic conditions, mental health conditions, etc.

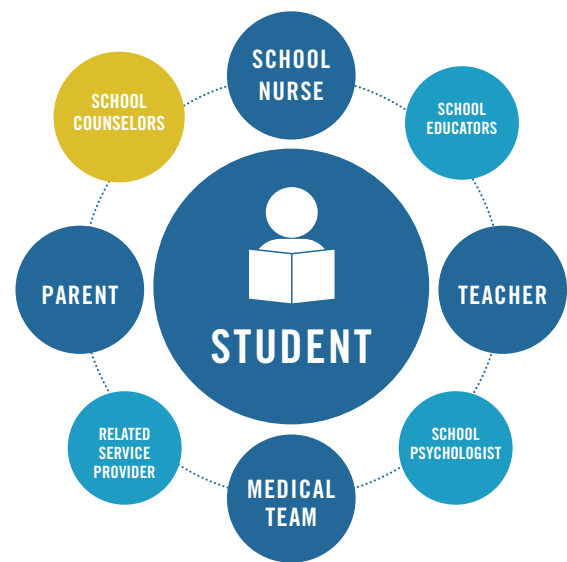
PANDAS, PANS AND RELATED DISORDERS:

IMPACT

FOR SCHOOL COUNSELING PROFESSIONALS

CASE STUDY: JILL

Due to unusual and difficult behaviors that started a week prior, an emergency meeting was called for 4th grader Jill, who returned to school following the flu. Team members report rapid regression across behavioral, emotional, social and academic domains. The counselor noted Jill was easily irritated, frustrated and overwhelmed- in stark contrast to her usual demeanor. She repeatedly wrung her hands and lightly touched objects with multiple taps, indications of possible motor tics and OCD. Jill appeared tired, resisted transitions and repeatedly asked to go home.



Key Considerations for Evaluation

School Nursing Assessment (to inform a school nursing plan that would support the student’s medical needs)

Fine Motor/Visual Motor/Assistive Technology

(Occupational Therapy referral to also assess motor skills, sensory processing/sensitivities, handwriting, activities of daily living (ADLs), etc.)

Assessments of Functional Behavior and Social/Emotional Development (to include peer supports/bullying)

- Memory Skills (visual and auditory)
- Visual Processing (acuity, tracking, closure, processing speed, memory, etc)
- Executive Functioning Skills (organizing, planning, etc)
- Academics

Adapted PE/ Physical Therapy referrals to assess gross motor skills, team sports and recreation

Speech Therapy Referral to access language and auditory processing (to determine supports for building social / communicative skills)

Psychiatric referrals for diagnosis, ruling out and monitoring of OCD, anxiety, etc. and determine therapeutic supports.

College Considerations, SAT/ACT (IMPACT testing if needed)



To learn more, see PANDASNetwork.org/Education for resources, links and more information.

PANDAS, PANS AND RELATED DISORDERS:

SUPPORT

FOR SCHOOL COUNSELING PROFESSIONALS

Considerations for Intervention

Where is the student in the medical treatment process?

How many hours is the child actually sleeping each night?
(Rule out need for Sleep Study).

Has the student's diet and/or eating changed?

Does the student have sensory overwhelm, sensory amplification, or pain?

Are medications being used and being effective? Note parental awareness of actual and potential side effects.

Are there changes in urinary frequency or bed wetting?

Are additional mental health diagnoses or symptoms present?
Effectiveness of counseling or other therapies offered?

How is this condition affecting the rest of family?

How does this student's condition affect attendance/ logistics/ transportation?

How does the school apply federal safeguards regarding inappropriate disciplinary actions/techniques by staff?

What educational/psychoeducational interventions are needed to support the student?

How will the School Psych evaluation (as well as other provider testing results) inform the IEP team on how this condition affects this student's school functioning?

Are periodic adjustments to interventions due (since symptoms frequently change during the illness)?

How does this affect this student's participation in extracurricular activities (sports, band, field trips, etc.)? What can coaches and other staff do to enable student/family participation?

Considerations for Support

Start with Collaboration - Recognize the need for teacher, special educators, nursing, family, providers (counselors, therapists, etc.), and administration collaboration, and periodic clarification of authorized accommodations and modifications. Share and Discuss information about PANDAS/PANS with every member of your team.

Symptom Impact - Comprehensively consider how symptoms are impacting participation during the school day, particularly in the areas of:

- Attendance
- Physical symptoms: lack of sleep, fatigue/poor stamina, ability to eat normally, urinary frequency
- Fine motor skills (handwriting and task completion)
- Behavior and emotions, separation anxiety, OCD symptoms, mental flexibility
- Academics, including reading, writing and math; poor cognitive stamina
- Sensory overload (this may present as challenging behavior in overstimulating situations)

Consider schedule changes, alternative activities and placements, and attendance flexibility

Consider Occupational Therapy, Physical Therapy and Social Skills Support

Develop Non-Punitive, Safe and Effective Responses to Inappropriate Behaviors

Consider Testing and Workload Accommodations and Modifications

Meet quarterly or once a semester with parents or as needed during flares to provide support for families and student

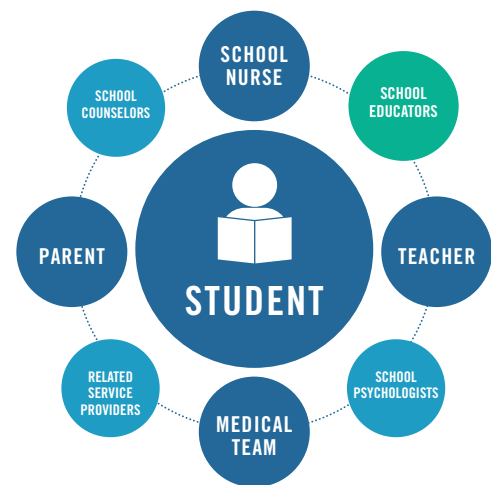
PANDAS, PANS AND RELATED DISORDERS:

IMPACT

FOR EDUCATORS

CASE STUDY: JAKE

Jake, who was recently diagnosed with PANDAS, is back at school after missing school from what appeared to be a sore throat. Once bright, neat and sociable, Jake's teacher notes he's now messy in his grooming and handwriting, and seems indifferent toward his schoolwork and peers. Others comment on Jake's unexpected sounds and strange movements. His worried Mom confides that he now won't go to bed unless she's sitting in his room, refuses to ride in the car and started wetting the bed at age 10.



Key Considerations for Intervention

How does this student's condition affect attendance, transportation and day to day functioning?

How much attention and energy is the student using to cover up symptoms at school?

What interventions are needed to support the student academically, socially or behaviorally?

How does this affect this student's participation in extracurricular activities (e.g. sports, band, field trips, etc..?)

What can coaches and other staff do to enable student/family participation?

Is the student impacted to a mild, moderate, or severe degree during the school day?

How many hours is the child taking to do homework?
How much sleep is the child getting nightly?

Are medications being used and if so, does it appear to be effective? Are side effects noticeable, and if so, are the parents aware of side effects?

Are there changes in urinary frequency during the school day?

Are additional mental health diagnoses or symptoms present?
Effectiveness of counseling or other therapies offered?



To learn more, see PANDASNetwork.org/Education for resources, links and more information.

PANDAS, PANS AND RELATED DISORDERS:

SUPPORT

FOR EDUCATORS

Key Considerations for Support

Start with Collaboration

Recognize the need for teacher, special educators, nursing, family, related service providers (like counselors, therapists) and administration collaboration, and periodic clarification of authorized accommodations and modifications. Share and Discuss information about PANDAS/PANS with every member of your team.

Symptom Impact

Consider how the following symptoms are impacting student participation during the school day, particularly in the areas of:

- Attendance
- Physical symptoms: lack of sleep, fatigue/poor stamina, ability to eat normally a typical diet, urinary frequency
- Fine motor skills (handwriting and task completion)
- Behavior and emotions, separation anxiety, OCD symptoms, mental flexibility
- Academics (including reading, writing and math; poor cognitive stamina)
- Sensory overload (this may present as challenging behavior in overstimulating situations)

More Considerations for Support

Consider schedule changes, alternative activities and placements, and attendance flexibility.

Consider occupational therapy, physical therapy, and social skills support

Testing and workload accommodations and modifications

These may include provisions for extra time, distraction free settings, assistive technology, alternate methods of access and completion, prioritization of task completion designed to reflect competence, use of notetakers, reduced academic and/or homework load, rest periods/ safe zones with nurse, adapted PE and home/hospital instruction.

Develop non-punitive, safe, and effective responses to inappropriate/destructive/reactive behaviors, to include minimizing/reducing stimulation and demands on student, redirecting student's attention to something novel, and implementing Cognitive Behavioral Technique and/ or other therapeutic measures.

Complementary support/ services

If this is a new condition for your school or district, talk with public or nonprofit agencies to see what services are available for students with related conditions such as traumatic brain injury, Tourette syndrome, encephalitic conditions, mental health conditions, etc.

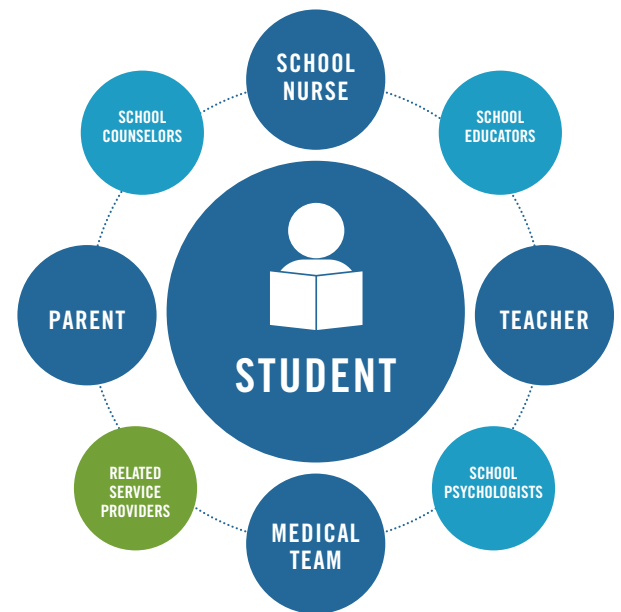
PANDAS, PANS AND RELATED DISORDERS:

IMPACT

RELATED SERVICE PROVIDERS

CASE STUDY: MARCO

Marco, 7, has been struggling in school since returning from break. He has yelled "BE QUIET" at his classmates during free play and refuses to complete his art project. He seems to be less coordinated than usual. His teacher noticed him stammering over his words. His handwriting is suddenly so poor that even he cannot read it. Marco said "I want to be myself again". Marco's mother said she just learned he has PANS and is flaring from a sinus infection he had over break. He is starting on medication now.



Key Considerations for Evaluation

Start with Collaboration

Parents, general and special educators, therapists, nurses, and administration all must collaborate and periodically review accommodations.

Interview family and teachers regarding recent changes in functioning.

Evaluate all school environments (classroom, specials, bus, lunch room, recess, etc.)

Conduct assessments to track function across exacerbation and remission

Sensory Processing - standardized checklists such as the Sensory Profile or Sensory Processing Measure.

Standardized handwriting assessments, such as the Minnesota Handwriting Test, or Test of Handwriting Skills, to document changes in handwriting which may help to understand exacerbation and remission

Visual-motor integration tests such as the Beery VMI can help to understand underlying difficulties.

Fine motor and gross motor tests- such as the Peabody Developmental Motor Scales II or the Bruininks-Oseretsky Test of Motor Proficiency II.

Assistive Technology evaluation.

Evaluate for altered speech patterns such as stuttering, dysfluency, decreased use of language/selective mutism, and simplified language structures.

Check for reading dysfluency.

PANDAS, PANS AND RELATED DISORDERS: SUPPORT

RELATED SERVICE PROVIDERS

Consider accommodations to support the child's function during an exacerbation. Switch to a rehabilitative approach as the child moves out of the exacerbation.

The child and family may be dealing with:

- Where is the student in the medical treatment process?
- Does the family report the child receiving Cognitive Behavioral Therapy (CBT) with Exposure and Response Prevention (ERP) or other interventions you could reinforce?
- Would the child/family benefit from outpatient or home-based PT/OT/SLP/counseling?
- How can you reduce the risk of spreading infection during intervention?
- How might this condition affect the rest of family?
- What is daily life like at home; What parts of the day are challenging?

Restrictive eating is common due to oral hypersensitivity or fears about choking or contamination.

Bladder management issues are common during exacerbation, which may be due to a loss of sphincter control.

Bathing and handwashing may become atypically more frequent or less frequent.

Sleep issues may include difficulty separating from parents, falling and staying asleep.



Key Considerations for Support in School

ISSUE	BEHAVIOR	RECOMMENDATION
<p>Anxiety, especially separation anxiety.</p> <p>Attention span reduced, hyperactivity, and inability to focus.</p> <p>Obsessions (recurring thoughts, often fears) and Compulsions (behaviors performed to relieve obsessions).</p> <p>Cognitive and executive function problems – especially organizing, planning, memory, and math.</p>	<p>Child may have difficulty understanding and remembering information. Completing assignments, organizing materials, and keeping track of schedule may be challenging.</p> <p>Child may go home without knowing assignment, may have left important materials at school, may not have complete directions at home for assignment, or may forget to bring assignment back to class.</p>	<ul style="list-style-type: none"> • Teachers check child’s assignment book before dismissal • Have child use smart phone to take pictures of assignments on board • Provide supports including multiplication charts, word banks, visual schedules, and reteaching • Use cloud storage to upload assignment instructions to view at home and to allow child to upload completed assignments from home (e.g.: school IT or Google docs) • Communicate with families in advance about larger projects/break it into manageable chunks
<p>Handwriting deterioration</p>	<p>Messy papers, frequently with margin drift, poor spacing, general illegibility. Difficulty communicating in writing- child may shorten written responses to decrease handwriting.</p>	<ul style="list-style-type: none"> • Keyboarding, Dragon Dictation, other dictation programs • Use graph paper or place a paper with dark vertical lines beneath the standard horizontal lined paper (vertical line template) to help with spacing • Try pencil grips or “Twist ‘N Write” pencil
<p>Personality / behavior changes & regression; Mood variability (depression, irritability, opposition)</p>	<p>May have difficulty adapting to transitions & stresses; Regression in interactions with peers & other behaviors</p>	<ul style="list-style-type: none"> • Support social and emotional learning (e.g. the Incredible 5 Point Scale; Zones of Regulation) • Provide opportunities to briefly touch base with a trusted adult during the school day or on a routine basis at beginning and end of day • Offer lunch bunches or other peer groups led by to develop and reinforce social skills
<p>Sensory Processing Changes - frequently decreased tolerance to sensory input</p>	<p>Difficulty tolerating and managing sensory input; Becoming upset or refusing to participate in activities with high levels of visual, auditory, tactile, olfactory, gustatory, kinesthetic or vestibular input; Decreased tolerance to auditory input and deterioration in auditory processing may result in academic distractions</p>	<ul style="list-style-type: none"> • Consider ALL of the stimulation in the classroom/work with teacher to decrease stimulation • Consider deep pressure/proprioceptive activities if evaluation warrants • Use assistive technology such as noise-reducing headphones, gloves during sticky art projects, and moving to less-crowded areas to reduce light touch during the school day

Key Considerations for Support in School

ISSUE	BEHAVIOR	RECOMMENDATION
Speech issues including Selective Mutism or issues with speech fluency (e.g., stuttering, baby talk)	Child may develop sudden-onset changes in speech patterns (stuttering, dysfluency), decreased use of language (selective mutism), as well as simplified language structures. These may be further impacted by auditory processing deterioration. Dysfluency may include reading dysfluency.	<ul style="list-style-type: none">• Provide professional development to staff/peers to implement fluency strategies and support• Provide Alternative/adapted communication as needed such as communication devices, visual schedules, reduced reliance on auditory information• Offer audiobooks for reading dysfluency
Motor Incoordination	May have difficulty in physical education or extracurricular sports. May see difficulty with fine motor skills including handwriting, cutting, and tying shoes.	<ul style="list-style-type: none">• Modify PE/sports to maintain physical activity while decreasing coordination demands• Provide accommodations to support individual fine motor needs
Tics (vocal or motor) or involuntary movements	Child may appear to be fidgeting or may appear to be clearing throat or making noises. Tics may be distracting in the classroom and to the child.	<ul style="list-style-type: none">• Allow opportunities for movement to relieve tics (walk, bathroom, etc.)• Educate peers and teachers re: difference between tics and willfully distracting behavior
Community participation withdrawal	Child may stop attending extracurricular activities; Social isolation; Reduced play dates and time spent with friends outside of class	<ul style="list-style-type: none">• Encourage simple interactions among peers• Modify extracurricular activities to allow child to participate when in exacerbation





PANDAS NETWORK EDUCATION TOOLKIT RESOURCES

PUBLICATION CREDITS

AUTHORS:

The PANDAS Network Working Group on Educational Access
Christine L. Amabile, LCSW; Linda C. Avery, PhD; Christine Brown, PhD; Jamie Candelaria-Greene, PhD, BCET; Mary F. Candelaria, PsyD; Amaryllis Case, RN; Jodi M. Duke, EdD; Beth A. Economou, MS, CCC-SLP; Emily Klein, M.Ed; H. Nicole Myers, PhD; Patricia Rice Doran, EdD; Catherine Teal, RN; & Janice Tona, PhD, OTR

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Stephen la Liberte; Angelique LeDoux, PN Board of Director and Diana Pohlman, Founder & Executive Director, PANDAS NETWORK

WEBSITES:

International OCD Foundation PANDAS Page:
www.kids.iocdf.org/what-is-ocd/pandas
National Institutes of Mental Health PANDAS Facts:
www.nimh.nih.gov/health/publications/pandas/index.shtml
PANDASNetwork.org:
www.pandasnetwork.org
School Info:
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PANDAS Physician's Network:
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To learn more, see PANDASNetwork.org/Education for resources, links and more information.