PANDAS/PANS in the School Setting: Supporting Learners with Pediatric Autoimmune Neuropsychiatric Disorders

Parents, teachers, and administrators will learn about PANDAS/PANS, encephalitic syndromes triggered by infections as common as streptococcus (strep throat). Participants will learn the symptoms, progress of disease, and ways to support children and families through the tumultuous behavior changes, school refusal, and educational challenges such as sensory issues and dysgraphia.
PANDAS/PANS

AGGER
Motor Tics

OCD
Anxiety

Scholastic regression

Emotional labiality

Eye Blinking

Separation Anxiety
Eye Rolling

Mood Swings

Fear

Insomnia

Vocal Tics

Memory Loss

Oppositional Defiance

Incontinence

Insomnia
• **Pediatric**-onset (typically sudden) between 18 months and puberty

• **Autoimmune**-antigens against strep attack the brain (particularly the basal ganglia)

• **Neuropsychiatric**-symptoms of OCD and tics, emotional lability, rage

• **Disorder**-normal every day function is impacted

• **Associated with**-caused or correlated with

• **Streptococcus**-a common bacteria that typically causes a “sore throat”

4/28/2017

M. Crombez, M.Ed., C. Crombez, B.S.
PANS is a newer term describing the larger class of acute-onset OCD cases. PANS stands for Pediatric Acute-onset Neuropsychiatric Syndrome and includes all cases of abrupt onset OCD, not just those associated with strep infections.
persevering through the hardships

attacks that can’t be controlled

no one understands you

diagnosing it can be hard

aversions toward things

sometimes you feel like you’re going to explode

4/28/2017 M. Crombez, M.Ed., C. Crombez, B.S.

With her own pen-"B" April 2017
Defining PANDAS/PANS

Auto immune Encephalitis

PANDAS

Strep antigens

Anti-NMDAR

anti-NMDA receptor encephalitis antibodies

PANS

Myco P, TBD, EBV, cocksackie, etc

Treatment is never a straight path!

For the sake of the children, we really need to get a handle on this debilitating, life-altering disorder!

4/28/2017 M. Crombez, M.Ed., C. Crombez, B.S.
Parents say:
My child has changed!
DOCTORS OFTEN OVERLOOK PANDAS AND PANS BECAUSE OF THE ASSUMPTION THAT THE CHILD'S PSYCHIATRIC SYMPTOMS HAVE NO UNDERLYING MEDICAL CAUSE. THIS NEEDS TO CHANGE.

www.thePANDASproject.com
The odyssey that is PANDAS

- J had:
- Early intervention
- OT
- PT
- Behavior Therapy
- ABA
- 3 years of preschool
- Now he is in Kindergarten
The odyssey that is PANDAS

J saw the following medical specialists:

• 2 neurologists
• 2 rheumatologists
• 1 immunologist
• 1 allergist
• 2 psychiatrists
• 6 psychologists
• 3 ENTs
• 12 pediatricians

“When the doctors didn’t know what to they referred “J” to another physician.”
The odyssey that is PANDAS

When J finally found a medical team they tried the following medications:

- Trazodone
- Risperidone
- Guanfacine
- Fluoxetine
- Ritalin
- Prednisone

“None were effective, and most made things worse.”
The odyssey that is PANDAS

“The only thing that ever worked was antibiotics!”
In fact, one family documented their medical odyssey in this way:

https://www.vibby.com/v/XkNw7Yidm

With all of these providers in place for services and treatments it still took three years to find answers and path towards healing!

PANDAS Can Tear The Happy Out Of A Family.

Mason - Age 12
PANDAS since 2009
PANDAS can destroy a picture perfect childhood
Strep, Mycoplasma Pneumonia, and Other Infections can trigger Sudden Onset OCD and other Neuropsychiatric Symptoms.

Symptoms include sudden onset of OCD and/or Severe Anxiety along with at least two other following symptoms:

- Sensory sensitivities
- Separation anxiety
- Sleep difficulties
- Personality changes
- Urinary frequency
- Tics or abnormal movements
- Irritability or aggression
- Inability to concentrate or ADHD
- Deterioration in learning abilities
- Developmental and age regression

PANDAS Network.org
www.PANDASNetwork.org
COULD AN INFECTION BE CAUSING YOUR CHILD’S SYMPTOMS?

- ANOREXIA
- ANXIETY
- TICS
- OBSESSIONS
- OCD
- HYPERACTIVITY
- DEPRESSION
- BEHAVIORAL REGRESSION
- IRRITABILITY
- DIFFICULTY CONCENTRATING
- AGGRESSION/RAGE
- BEDWETTING
- SLEEP DISTURBANCES
- SENSORY ABNORMALITIES

Changes in handwriting
PANDAS / PANS affects as many as 1 in 200 children.

Average age of onset is between 4 and 7 years old.

Early intervention of these autoimmune disorders can stop symptoms quickly and save a child from a lifetime of difficulties.
PANDAS

Some doctors say it’s rare, others that it’s just rarely diagnosed, but one fact that worries them all is that, untreated, PANDAS could lead to long-term mental illness in children. Strep is dangerous.

strepmonster.com
COMPARISONS OF MEDICAL CONDITIONS ACQUIRED IN THE FIRST 20 YEARS OF LIFE
COMPARISONS OF MEDICAL CONDITIONS ACQUIRED IN THE FIRST 20 YEARS OF LIFE

Percentage

Juvenile Diabetes
Cancer
Legally Blind
PANDAS/PANS

0
0.1
0.2
0.3
0.4
0.5
0.6
Maybe all the behavior problems your child is having started with a common infection.

“Studies are reinforcing the belief that some psychiatric illnesses can be triggered by ordinary infections and the body’s immune response... the research raises the possibility that some cases of mental illness might be cured by treating the immune system dysfunction” - LA Times

www.StrepMonster.com
Every school in America should alert parents about PANDAS.

PANDAS is a mental disorder in children triggered by STREP bacteria. It can cause sudden OCD, ADHD, tics, rage and anxiety.

According to the MDE
The 2015-16 PUPIL COUNT DATA in Early Childhood classrooms- PK through grade 4 is as follows:

<table>
<thead>
<tr>
<th>Grade</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>PK</td>
<td>48,854</td>
</tr>
<tr>
<td>K</td>
<td>113,304</td>
</tr>
<tr>
<td>1</td>
<td>106,062</td>
</tr>
<tr>
<td>2</td>
<td>107,793</td>
</tr>
<tr>
<td>3</td>
<td>111,558</td>
</tr>
<tr>
<td>4</td>
<td>111,267</td>
</tr>
</tbody>
</table>

Total PK - 4 Pupil Count 598,838

1/200 or .5% = 2994 PANDAS/PANS cases
Schools Should Know...

- PANS/PANDAS affects roughly 1 in 200 kids
- Kids can get better especially with early diagnosis
- Average age of diagnosis is between ages 4-13
- Symptoms are relapsing and remitting
- Not all kids will have all of the symptoms
- Initial and subsequent triggers can be different
- Accommodations will differ from child to child
- It takes a whole team to help the student
- PANS is medical; symptoms are not behavioral

PANS/PANDAS

Know the Signs. Know the Treatments.
PANS/PANDAS & PANS @ School

**Behavioral**
- OCD & Obsessive Thinking
- Eating Issues
- Emotional Lability
- Anxiety & School Refusal
- Aggression
- Age Regression
- ADHD
- Sensory Issues

**Physical**
- Tics (Motor/Vocal)
- Frequent Urination
- Unusual Gait
- Balance Issues
- Chapped Skin
- Trichotillomania

**Academic**
- Loss of Math Skills
- Loss of Handwriting Skills
- Can’t Make Simple Decisions
- Poor Short-Term Memory
- Decline in Creative Work
- Avoidance of High Sensory Environments
- Loss of Focus
- Work Refusal
- Poor Organization Skills
- Perfectionism
- Time Management Issues

PANS/PANDAS is an autoimmune reaction triggered by Strep, Pneumonia, Lyme, Mono, Stress, etc. resulting in an acute onset of neuropsychiatric symptoms that can include: separation anxiety, OCD, tics, age regression, ADHD, sleep difficulties, personality changes, urinary frequency, irritability, rage, sensory sensitivities, deterioration in learning abilities and anorexia.
Strep, Pneumonia, Lyme, Mono
followed by
Sudden Acute Behavior Changes

OCD
Anxiety
Mood Swings
Aggression
ADHD
Age Regression

PANS/PANDAS
Know the Signs. Know the Treatments.

PANS/PANDAS is an autoimmune reaction triggered by Strep, Pneumonia, Lyme, Mono, Stress, etc. resulting in an acute onset of neuropsychiatric symptoms that can include: separation anxiety, OCD, tics, age regression, ADHD, sleep difficulties, personality changes, urinary frequency, irritability, rage, sensory sensitivities, deterioration in learning abilities and anorexia.
KB was an easy going 5 year old who loved going to Kindergarten and excitedly joined her friends at school each day.

KB suddenly became obsessive and rebellious. Cried, refused to go to school, held the door knobs to resist leaving, refused to ride in the car due to fear of running out of gas, afraid of elevators, 2 yrs, 14 doctors, and 19 strep throat infections later, KB was diagnosed with PANDAS.

<table>
<thead>
<tr>
<th>Before PANS</th>
<th>After PANS</th>
</tr>
</thead>
<tbody>
<tr>
<td>“A 4 year old with <strong>attention and behavior difficulties.</strong> Initial testing in June revealed mild visual perceptual and fine motor issues, <strong>but no sensory processing problems.</strong> He began occupational therapy in September.”</td>
<td>“[Later], Luis’ mother reported that he refused to don his socks and complained that the waistband of his pants hurt. In occupational therapy, Luis <strong>demonstrated regression in drawing</strong> and was no longer able to write the letters of his name legibly.”</td>
</tr>
</tbody>
</table>
# Before & After PANS

<table>
<thead>
<tr>
<th>Before PANS</th>
<th>After PANS</th>
</tr>
</thead>
<tbody>
<tr>
<td>“A bright, well-adjusted third-grade girl... The school psychologist ruled out the possibility of recent trauma, reporting that the ‘intact family was wonderfully close and supportive.’ School friendships were numerous, with no identified social problems. The girl rated her teacher as a ‘favorite’ and was <em>not overwhelmed</em> by missed schoolwork, which she described as ‘easy.’”</td>
<td>“who returned to school after a strep infection suddenly appeared acutely school phobic. Yet morning after morning the child became <em>intensely anxious</em>, refused to get on the school bus, and had to be driven to school. She crouched in the car, sobbing and clinging to the seat. No amount of coaxing or prodding seemed to alleviate her <em>severe yet unspecified anxiety.</em>”</td>
</tr>
<tr>
<td>“A second-grade student.... This boy, previously studious and industrious in the classroom,”</td>
<td>“The child had contracted strep during a family vacation [and] became so <em>hyperactive</em> and <em>disorganized</em> that his teacher became quite alarmed. His <em>inability to remain seated</em>, resist calling out, and complete even simple tasks by himself were beyond comprehension.”</td>
</tr>
</tbody>
</table>

PANDAS in the School Setting by Kathy O'Rourke, MA (School Nurse News-2003)
Progression

Behavioral Symptoms

- Anxiety
- Separation Anxiety
- Panic Attacks
- Fight or Flight Response
- School Refusal

- Anxiety may present as
  - Hyperventilating
  - Rocking
  - Pacing
- Anxiety may also present as:
  - Unpredictable bouts of irritability, anger, or rage
  - Nit-picking
  - Sensitivity to disarray, perceived chaos, or change of any kind
  - Fast talking, stuttering, stumbling over words
  - Selective mutism
  - Sitting rigid, staring off, appearing “zoning out”

Accommodations/Interventions

- Do not make eye contact
- Minimize talking
  - Do not speak to the child
  - Do not speak about the child in his/her presence
- Keep the child safe
  - Policies and procedures for safety of students should be planned, practiced, and prepared in advance
  - Complete a functional behavior assessment (realizing much of the function of the behavior may be internal)
  - Develop a Behavior Plan
- Minimize stimulation
  - Dim lights
  - Decrease volume of sounds in the environment
What you might see at school

Behavioral Symptoms

- Age Regression
- Immaturity
- Poor impulse control
- Personality changes
- Emotional lability
- Attention Deficit (ADD)
- Hyperactivity (ADHD)
- Defiance
- Tantrums
- Rages
- Elopement

Examples

https://vib.by/v/71xEAwMkYm

The text **PANDAS and PANS in School Settings** edited by Patricia Rice Doran provides these simply guidelines when dealing with a child who exhibits an emotional outburst:

- Do not approach the child
- Do not make eye contact
- Maintain a safe yet nonthreatening distance
- Avoid confrontations with the child
- Become trained in non escalation techniques or call for a colleague who is trained
What you might see at school

Behavioral Symptoms

• Obsessive Compulsive Disorder
• Obsessive Thinking
• Inappropriate Thoughts
• Compulsions
• Eating Issues
  • Limited Menu
  • Fear of Choking
  • Anorexia
• Perfectionism
• Rigid Thinking
• Sensory Issues
• Hair-pulling/skin picking

Examples

• Obsessions are the thoughts-Compulsions are the behaviors completed to appease the thoughts
• Just right OCD requires the child to feel something has been done just right which may require them to zip and re-zip their backpack
• Perfectionism
  – erasing through the paper
  – needing to start over repeatedly
  – Re-writing over and over
What you might see at school

Physical Symptoms

• Motor tics
• Vocal tics
• Dilated pupils
• Vision issues
• Hallucinations
• Weight loss/gain
• Frequent urination
• Unusual gait
• Balance issues
• Chapped hands, lips, mouth

Accommodations/Interventions

• Do not draw attention to tics—attention to tics increases their frequency and duration
• Understand tics and dilated pupils are out of the conscious control of the child—psychologists teach strategies to supplant the tic with a less noticeable action
• Suspend rules for eating and using the bathroom
PANDAS - A Story of Hope and Recovery

It worked! Two days later my sweet boy looked into my eyes again.

Before IVIG

2 days after IVIG
What might you see at school?

• Simple and complex tics
  – Vocal tics such as repetitive sniffling, coughs, cries, barking sounds, throat clearing, words
  – Unexpected voice changes
  – Unexpected movements such as head jerking, constant eye blinking, shoulder shrugs
What might you see at school?

• Other unexpected movements
  – Inability to sustain a steady grip on a utensil (milk maid grasp)
  – Complex coughs (may include a ritual pattern of tapping, coughing, touching a wall, etc)
  – Flailing limbs
  – Choreiform movements

Young boy with shoulder shrug tic followed by more debilitating movements

https://www.youtube.com/watch?v=KetZGIDthxw
https://vib.by/v/XJ4ro80dQ

How can a child participate fully in school when this is happening to their body?
What you might see at school

Changes in Appearance

• Absenteeism
• Change in posture
• Poor skin color
• Poor grooming
• Poor eye contact
• Fatigue
• Increase in cuts/scrapes
• Keeping to oneself/socially isolating
• Reduced or increased neatness of personal space

Accommodations/Interventions

• Modify attendance policy
• Provide regular breaks in the daily class schedule
• Allow and respect student initiated breaks
• Do not require eye contact or insist “look at my eyes”, this will only incite the fight or flight response in a child who is already avoiding eye contact due to internal or external overstimulation
What you might see at school

**Academic Symptoms**

- Difficulty or decline in math skills
- Decline in handwriting skills (dysgraphia)
- Resisting math or writing assignments
- Decline in creative activities ie: art/creative endeavors
- Work refusal
- Avoidance of high sensory environments (art, music, cafeteria, gym, assemblies)
Panel A—Drawing produced during an acute exacerbation of OCD and other symptoms of PANDAS which appears quite messy and immature.

Panel B—Age-appropriate picture drawn after treatment with IVIG and symptomatic improvement.

Figure 2:
Dysgraphia

Top image 10-20-16

Middle image 10-24 16

Bottom image 10-28-16
Neurologic Effect -
Inflammation in the brain tissue only allows the child to create on one side of the circle yet the patient “sees” the clock as drawn correctly.

For reference, the clock was drawn 1/22/2017 (7 yr old) during a huge flare. Negative for Strep, but huge cold sore break out, bilateral foot pain, headache and gritty eyes.
Dysgraphia
Dysgraphia

I have a dream for a better world. First, people should be kind to animals because they were here first. Next, I hope all parents help their children with their homework because they need help sometimes. Last, I hope people have enough food because not all people do. I hope my dream comes true.

baseline

1. Why don’t swarming bees usually sting? 
   - They don’t like any of the bees that live there.

2. Name four common hive raiders: 
   - Bears, wasps, beehive, common hive

3. How many queens can there be in a hive? 
   - Only one

4. Why do beekeepers use smoke? 
   - To calm the bees

3 months later

M. Crombez, M.Ed., C. Crombez, B.S.
Dysgraphia

Before symptom onset

During acute episode

www.pandasnetwork.org
Dysgraphia

Before the infection

During the episode

After treatment
“therapy can be instrumental in negotiating exacerbation, but doing so requires a paradigm shift. Children often lose skills during exacerbation, and traditional remedial intervention may be ineffective. Greater benefit may be found with adaptation and compensation for problems during exacerbation, followed by remediation of ongoing problems during remission.”

*PANDAS: A New Frontier for Occupational Therapy Intervention - Janice Tona & Trudy Posner*
What might you see at school?

Self Care

- Increased requests to use the bathroom
  - Bathroom is a place of respite/a safe place
  - Urinary frequency is a hallmark symptom
    - Urinary frequency may be related to a feeling of wetness that cannot be resolved even if dry
    - Urinary frequency may be a result of serotonin dysregulation (child does not feel he has voided fully)
    - Urinary frequency may be the result of a true increase in urine production
- Increased isolation from peers
- Quizzical looks and comments from peers

Accommodations/Interventions

- Provide access to a “safe” bathroom, often this is a single stall or private bathroom
- Provide a permanent bathroom pass or develop a bathroom policy that allows the child to use the bathroom as needed
- Create a culture of kindness in your classroom ensuring compassion and caring live in your classroom
What you might see at school

**Executive Function**
- Difficulty with short term memory (retaining immediate information), working memory (retaining and holding info briefly), long term memory
- Poor organizational skills
- Time management issues
- Difficulty planning/prioritizing
- Difficulty attending to task
- Difficulty making decisions

**Accommodations/Interventions**
- Poor short–term/working memory may impact testing—provide increased test time
- Provide preferential seating
- Provide special seating such as motion/balance stools, therabands around legs of chairs, bumpy seats

4/28/2017
M. Crombez, M.Ed., C. Crombez, B.S.
Somatic Issues

Somatic Signs
• Disturbed/disrupted sleep
• Restless legs

Accommodations/Interventions
• Allow child to rest at school
• Allow multiple breaks
• Omit tardy policy
Sensory issues

Sensory Triggers

• Light
• Sound
• Touch
• Eye contact
• Talking
• Smell
• Taste

Accommodations/Interventions

• Allow lights to be dimmed
• Allow headphones
• Provide tactile supports as needed (bean bag chair vs hard wooden chair, a soft swatch of fabric to rub between fingers)
• Do not react to child’s clothing choices—they may wear the same clothes every day
• [https://www.vibby.com/v/7Jj5lKjdm](https://www.vibby.com/v/7Jj5lKjdm)

Destructive, clothing sensitivity, mania
School refusal

Possible Triggers

• Anxiety related to moving from room to room
• Anxiety related to noise and commotion
• Anxiety throughout day
• Anxiety associated with workload
• Anxiety related to perfectionism

Accommodations/Interventions

• Allow child to leave room before or after others
• Allow child to enter school after the morning bell/wear headphones
• Safe break space—have at least three options—if the library is assigned as a safe break space and there are students present the space loses its calming capacity, if the principal’s office is already occupied by another student it is no longer safe

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Health and Safety Supports at School

• Handwashing and hygiene practices
• Sanitized work spaces-classroom, specials rooms, lunch room, etc.
• Notifications home regarding incidence of illness in school community
• Excuse participation in known toxic environments-gymnasium, multipurpose rooms, lunch rooms
Continuum of Services

- Individual Health Care Plan
- General education with embedded supports
- Response to Intervention (TRI) / Multi-Tiered System of Support (MTSS)
- 504 Plan – accommodations/modifications
- FBA/BIP-when behavioral issues are present
- IEP- accommodations/modifications/services
- Transition plans-when setting is prone to change from school to homebound and back

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IEP Eligibility

• PANDAS/PANS qualifies as OHI
• In the absence of a medical diagnosis of PANDAS/PANS the MET team may determine other relevant special education eligibilities:
  – ECDD
  – SLI
  – ASD
  – EI
  – SLD
We Inform

We inform families and the medical community of the most current information on PANDAS/PANS by offering:

- Provider referrals
- Research and case studies
- Online newsletters
- Tools that support diagnosis, treatment, coping and ultimately healing

We Connect

We connect people with one another and open lines of communication. We achieve this by providing:

- Support groups
- Professional networking opportunities
- Presentations and surveys that create snapshots of the PANDAS/PANS community

We Advocate

We advocate for increased awareness, acceptance and treatment through affiliations and partnerships with:

- National Institute of Mental Health
- National Organization for Rare Disorders
- AARDA – National Coalition of Autoimmune Patient Groups

To learn more or support our work, visit [www.PANDASnetwork.org](http://www.PANDASnetwork.org)
Together, PANDAS Physician Network and Pandas Network are developing Nationwide PANDAS Centers of Excellence. Our hope is that soon Michigan will host a comprehensive center of excellence to better serve the children and families in our state living with this disorder.
Questions?

Contact information:  
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PANS/PANDAS  
Acute-Onset  
Neuropsychiatric Syndromes

*It can change a child’s a world.*
Universal Design for Learning

Drs. Fewster and Rice-Doran highlight these examples of UDL in the classroom relative to PANDAS/PANS:

- Understand how a child learns; their strongest modality
- Manage the environment/physical setting
- Engage in purposeful decision-making before and during the school year
- Create an emotionally warm and safe space for learning
- Promote student engagement
- Provide movement and exercise
- Ensure hydration and rest
- Facilitate engagement with high interest topics and choices
- Provide time management skill development opportunities
- Build breaks into the daily schedule (ideally every 10 minutes)
Universal Design for Learning

Drs. Fewster and Rice-Doran highlight these examples of UDL brain friendly classroom strategies relative to PANDAS/PANS:

- Ensure each modality is addressed in each lesson
- Begin each lesson with a different modality to increase interest and motivation
- Provide ample time and opportunities for auditory learners to talk about the lesson
- Ensure kinesthetic learners are provided various reasons to move about the learning space
- Be aware of the language young learners use relative to their learning modalities (visual learners say “There it is, I see it”, auditory learners say “I heard that”, and kinesthetic learners say “I did it!”)
- Make observations about how your students learn best

4/28/2017 M. Crombez, M.Ed., C. Crombez, B.S.
**PANS** is defined by the following criteria:

Abrupt, dramatic onset of OCD or severely restricted food intake; symptoms are not better explained by a known neurologic or medical disorder; and the addition of at least 2 of the “accompanying” symptoms:

- Anxiety
- Emotional lability and/or depression
- Irritability, aggression and/or severely oppositional behaviors
- Behavioral (developmental) regression
- Deterioration in school performance
- Sensory or motor abnormalities
- Somatic signs including sleep disturbances, enuresis or urinary frequency

The onset of PANS may start with infectious agents other than strep. It also includes onset from environmental triggers or immune dysfunction.

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**PANDAS** is defined by the following criteria:

Clinical diagnosis of PANDAS includes 5 criteria:

- Presence of significant obsessions, compulsions and/or tics
- Abrupt onset of symptoms or a relapsing-remitting course of symptom severity
- Prepubertal onset
- Association with streptococcal infection
- Association with other neuropsychiatric symptoms (includes any of the PANS “accompanying” symptoms)
General Supports

• Health supports (IHCP)
• Establish health alerts
• Create PANS awareness
• Include teachers, parents, staff, school nurse