2021 Report to the Governor and General Assembly

Virginia Department of Health Report on the Pediatric Autoimmune Neuropsychiatric Disorders Associated with Streptococcal Infections and Pediatric Acute-onset Neuropsychiatric Syndrome Advisory Council

Table of Contents

Executive Summary 3

Background 4

PANDAS/PANS in Virginia 5

Status Report on PANDAS/PANS Advisory Council Activities 5

Summary and Future Plans 6

References 7

Appendix A – PANDAS/PANS Advisory Council Member Listing 8

Appendix B – November 13, 2020 Meeting Minutes 9

Appendix C – PANDAS/PANS Resources 12

Executive Summary

The Pediatric Autoimmune Neuropsychiatric Disorders Associated with Streptococcal Infections (PANDAS) and Pediatric Acute-onset Neuropsychiatric Syndrome (PANS) advisory council is established in the Code of Virginia [§32.1-73.9] to advise the Commissioner of Health on research, diagnosis, treatment and education relating to PANDAS and PANS. The advisory council is required to report to the Governor and General Assembly by December 1st of each year recommendations related to the following:

1. Practice guidelines for the diagnosis and treatment of PANDAS and PANS
2. Mechanisms to increase clinical awareness and education
3. Outreach to educators and parents to increase awareness
4. Development of a network of volunteer experts

The last annual report was submitted in December 2020, and the final approved minutes from the November 2020 meeting are included in Appendix B. Restrictions related to the COVID-19 pandemic continued to impact the scheduling of public in-person meetings. The advisory council held two virtual meetings in 2021. This document summarizes the advisory council's activities for 2021. Prior year council activities are included in previous annual reports, which can be accessed on the General Assembly's Legislative Information System website.

What are PANDAS and PANS?

PANDAS is an abbreviation for Pediatric Autoimmune Neuropsychiatric Disorder Associated with Streptococcal Infections. The term was first used in 1998 to describe a subset of children and adolescents who have obsessive compulsive disorder (OCD) and/or tic disorders, and in whom symptoms worsen following strep infections such as strep throat or scarlet fever.[1] The PANDAS subgroup is part of a larger cohort of children whose symptom onset is unusually abrupt and dramatic, or Pediatric Acute-onset Neuropsychiatric Syndrome (PANS).[2] PANS is defined by three clinical criteria:

1) *Abrupt onset of OCD or eating restrictions.*
2) *Concomitant onset of at least two of seven of the following: anxiety (particularly separation anxiety); emotional lability and/or depression; irritability, aggression and/or oppositional behaviors; deterioration in school performance; motor or sensory abnormalities; and somatic signs and symptoms (particularly sleep disturbances, enuresis and urinary urgency or frequency).*
3) *The acute-onset symptoms are not better explained by another neurologic or medical disorder.*

Symptoms of PANS may result from a variety of causes, including post-infectious autoimmunity (e.g. PANDAS) and other autoimmune processes, as well as a diverse array of disorders causing neuroimmune activation.[3]

Background

The PANDAS and PANS advisory council was established during the 2017 General Assembly session as a result of HB2404. The purpose of the advisory council is to make recommendations to the health commissioner on research, diagnosis, treatment and education relating to PANDAS and PANS.

The membership of the council must comply with the specifics set out in the Code of Virginia, Chapter 2 of Title 32.1, Article 16, sections 32.1-73.9, 32.1-73.10, and 32.1-73.11. The advisory council consists of fifteen members and one ex-officio member. The advisory council also consists of both legislative and non-legislative members. The six legislative members include four members from the House of Delegates and two members from the Senate. Nine non-legislative members are citizens of the Commonwealth and include individual representatives from the following medical or healthcare specialty fields: one licensed health care provider with expertise in treating PANDAS/PANS; one pediatrician with experience treating PANDAS/PANS; one child psychiatrist with experience treating PANDAS/PANS; one immunologist with experience treating PANDAS/PANS; one medical researcher with experience conducting research concerning PANDAS/PANS, obsessive compulsive disorder, tic disorder, and other neurological disorders; one representative of a professional organization for school nurses; one representative of an advocacy and support group for individuals affected by PANDAS/PANS; one representative of an advocacy and support group for individuals affected by autism; and one parent of a child who has been diagnosed with PANDAS/PANS. The Commissioner of Health or his/her designee serves as ex officio without voting privileges. Staff

to the advisory council is provided by the Virginia Department of Health (VDH). A list of advisory council members is provided in Appendix A.

The advisory council must prepare and submit an annual report to the Governor and General Assembly by December 1st of each year until HB2404 sunsets in 2020. The council will report on recommendations related to:

- Practice guidelines for diagnosis and treatment of PANDAS and PANS;
- Mechanisms to increase awareness and education regarding PANDAS and PANS among physicians, including pediatricians, school-based health centers and providers of mental health services;
- Outreach to educators and parents to increase awareness of PANDAS and PANS; and
- Development of a network of volunteer experts on the diagnosis and treatment of PANDAS and PANS to assist in the delivery of education and outreach.

PANDAS/PANS in Virginia

The incidence and prevalence of PANDAS/PANS are unknown. A conservative estimate of the prevalence of PANDAS/PANS in the United States is 1 in 200 children.[4] In Virginia, a comprehensive system of care that fully meets the needs of families of individuals with a diagnosis of PANDAS/PANS is lacking. As a result, clinical providers may need additional education and training on how to diagnose and treat PANDAS/PANS. While a variety of treatment options are available to address the range of PANDAS/PANS symptoms and severity,[5] the lack of health insurance coverage for treatment presents a barrier. Additionally, the absence of standardized use of current procedural terminology (CPT) codes among providers when billing for insurance reimbursement for treatment of PANDAS/PANS symptoms can cause barriers to receiving care. Similar to providers, there is a general lack of awareness among Virginia's parents, educators and the public about PANDAS/PANS and available resources.

However, resources are available. The Journal of Child and Adolescent Psychopharmacology published diagnosis and treatment guidelines in 2017.[6] In addition, the PANDAS Physician Network is an online resource that provides information and a directory of physicians specializing in PANDAS/PANS.[7] In 2019, the PANDAS/PANS advisory council developed four resources to increase awareness–an evaluation and treatment algorithm for clinicians; an informational handout for parents; an informational handout for school systems; and a frequently asked questions (FAQs) resource. The final approved resources are included in Appendix C and are available on the VDH PANDAS webpage.

Status Report on PANDAS/PANS Advisory Council Activities

VDH staff coordinated and facilitated two PANDAS/PANS advisory council meetings in 2021. Below is a summary of the advisory council's activities:

May 2021: The May 14, 2021 meeting was held via virtual format as allowed in accordance with a provision of the 2020 Appropriation Act and the Governor's emergency declaration. Twelve council members, one guest and one VDH staff were present virtually. The council

voted to approve the November 2020 meeting minutes. Members shared updates and announcements, including the formal resignation of Ms. Jessica Gavin from the advisory council effective May 31, 2021. Information was shared regarding the appointment application process through the Office of the Secretary of the Commonwealth for members wanting to recommend a replacement for Ms. Gavin. Council members voted to approve that the Chair, Senator Suetterlein, send a letter to the State Health Commissioner informing him of proposed language to be added to the federal appropriations bill for the National Institute of Health (NIH) and encouraging the Virginia Congressional delegation to support inclusion of language that supports cross-disciplinary research by the NIH on Childhood Post-Infectious Neuroimmune Disorders (CPINDs). Council members revisited the discussion regarding the recommendation to establish a Center of Excellence in Virginia. Ms. Buskey provided an update regarding VDH outreach efforts to disseminate the PANDAS/PANS resources through targeted stakeholder organizations outlined in the 2019 annual report recommendations.

Senator Suetterlein sent a letter dated May 19, 2021 to the State Health Commissioner, informing him of the proposed federal appropriations legislation and requesting support of the Virginia Congressional delegation.

On May 21, 2021, Ms. Stacey Link resigned from the advisory council due to increase work commitments.

July 2021: Seven of the nine non-legislative members of the advisory council were reappointed at the expiration of their term, and two new members were appointed to the advisory council. The official appointments were announced on July 23, 2021. In addition, the state health commissioner designated VDH staff to serve as ex officio member to the advisory council. The full roster of council members is included in Appendix A.

October 2021: The October 15, 2021 meeting was held via virtual format. Pursuant to Chapter 1, Enactment 17 of the 2021 Special Session II, the advisory board is allowed to meet virtually as long as no formal votes or recommendations were made. Fourteen members, three guests, and two VDH staff, including the ex officio member, were present virtually. One council member participated via phone. Two representatives from the Bureau of Insurance presented an overview of the insurance mandate process in Virginia and responded to inquiries from council members. Council members engaged in a discussion regarding the Joint Legislative Audit and Review Commission's report on Oversight of Mental Health Parity. The council discussed options for educating clinicians through a webinar and disseminating the PANDAS/PANS resources throughout the state. Council members revisited the 2019 recommendation for the State Health Commissioner to disseminate the PANDAS/PANS resources through a clinician's letter. Based on the consensus of the council, Senator Suetterlein agreed to send a letter to the State Health Commissioner to follow up on the previous recommendation.

Summary and Future Plans

The advisory council will continue to develop recommendations on research, diagnosis, treatment and education relating to PANDAS and PANS. The next council meeting is tentatively set for March 2022.

References

[1] Swedo SE, et al. Pediatric autoimmune neuropsychiatric disorder associated with streptococcal infections: clinical description of the first 50 cases. *Am J Psychiatry* 1998. 155(2):264-71.

[2] Swedo S, Leckman J, Rose N. From research subgroup to clinical syndrome: modifying the PANDAS criteria to describe PANS (Pediatric Acute-onset Neuropsychiatric Syndrome). *Pediatr Therapeut* 2012. 2:113. doi: 10. 4172/2161-0665.1000113

[3] Chang K, et al. Clinical evaluation of youth with pediatric acute-onset neuropsychiatric syndrome (PANS): recommendations from the 2013 PANS Consensus Conference. *J Child Adolescent Psychopharmacology* 2015. 25(1):3–13.

[4] PANDAS Network. Statistics. Retrieved from http://pandasnetwork.org/statistics/

[5] Journal of Child and Adolescent Psychopharmacology. Revised diagnosis and treatment guidelines for pediatric acute-onset neuropsychiatric syndrome (PANS/PANDAS). Retrieved from https://home.liebertpub.com/news/revised-treatment-guidelines-released-for-pediatric-acute-onset-neuropsychiatric-syndrome-pans-pandas/2223

[6] PANDAS Physician Network. https://www.pandasppn.org/

[7] PANDAS Physician Network. PANS/PANDAS Treatment Options. Retrieved from https://www.pandasppn.org/treatment/

Appendix A

PANDAS/PANS Advisory Council Members

Legislative Council Members:
Senator George Barker
Delegate Joshua Cole
Delegate Roxann Robinson
Delegate Danica Roem
Delegate Shelly Simonds
Senator David Suetterlein

Non-Legislative Council Members:
Ms. Teresa Champion, Autism Support Group
Ms. Christina Teague, Pediatric Research & Advocacy Initiative
Dr. David Jaffe, Children's Hospital of Richmond at VCU
Ms. Stefanie Levensalor, Parent Advocate
Ms. Megan Bonfili, Virginia Association of School Nurses
Dr. Melissa Nelson, Pediatric Associates of Richmond
Dr. Bela Sood, Children's Hospital of Richmond at VCU
Dr. Susan Swedo, National Institute of Mental Health
Dr. Wei Zhao, Children's Hospital of Richmond at VCU

Ex Officio Member:
Ms. Heather Board, Acting Director, Office of Family Health Services, VDH

Appendix B

PANDAS/PANS Advisory Council Meeting
Friday, November 13, 2020
1:00 – 4:00 p.m.

GoToWebinar Virtual Meeting
https://attendee.gotowebinar.com/register/611586161476949260

Meeting Minutes

Members Present: Senator George Barker, Ms. Teresa Champion, Delegate Joshua Cole, Ms. Jessica Gavin, Dr. David Jaffe, Ms. Stefanie Levensalor, Ms. Stacey Link, Delegate Danica Roem, Delegate Shelly Simonds, Dr. Bela Sood, Senator David Suetterlein, Dr. Wei Zhao

Members Absent: Dr. Melissa Nelson, Delegate Roxann Robinson, Dr. Susan Swedo

VDH Staff Present: Ms. Heather Board, Ms. Robin Buskey

Guests Signed onto Webinar: Arin Barker, Cristy Corbin, Kylee Kindred, Valentina Vega

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Call to Order

Senator David Suetterlein called the meeting to order at 1:02 p.m.

Welcome and Introduction of New Members

Senator Suetterlein welcomed new members appointed to the council: Del. Joshua Cole, Del. Danica Roem and Del. Shelly Simonds. Senator Suetterlein opened the floor to council and staff member introductions.

Agenda Overview

Council members were asked to review the agenda, which was displayed via webinar screen and provided via email attachment. Council members adopted the meeting agenda.

Election of Chair and Vice Chair

Senator Suetterlein acknowledged that Speaker Eileen Filler-Corn is no longer serving in the capacity as Chair of the advisory council.

Delegate Roem made a motion to elect Senator David Suetterlein as Chair of the PANDAS/PANS Advisory Council. The motion was seconded. Senator Suetterlein was elected as Chair by unanimous vote.

Senator Barker made a motion to elect Delegate Danica Roem as Vice Chair of the PANDAS/PANS Advisory Council. The motion was seconded. Delegate Roem was elected as Vice Chair by unanimous vote.

Review and approval of November 2019 meeting minutes

Ms. Teresa Champion moved to adopt the November 2019 meeting minutes. The motion was seconded. The advisory council approved the meeting minutes.

Overview of PANDAS Advisory Council

Senator Suetterlein directed new members to HB2404, which established the advisory council during the 2017 General Assembly session. Senator Suetterlein outlined the purpose of the advisory council, which is to provide recommendations to the state health commissioner regarding:

- Practice guidelines for diagnosis and treatment
- Mechanisms to increase clinical awareness and education
- Outreach to educators and parents
- Development of a network of volunteer experts

Advisory Council Updates

Ms. Teresa Champion and Ms. Jessica Gavin provided a summary update of the presentation provided to the Department of Social Services Permanency Advisory Council at the December 4, 2019 meeting. Representatives from local departments of social services from around the state were in attendance. Ms. Champion and Ms. Gavin shared that the information was well-received and thought that it would be beneficial to present information about PANDAS/PANS at more of these types of events.

Ms. Champion and Ms. Gavin also followed up on the announcement that there is now an available ICD-10 code that can be used for PANDAS/PANS. The announcement had previously been sent via email by Ms. Champion.

Public comment period

Senator Suetterlein opened the floor to receive public comment. Ms. Cristy Corbin provided general comments and expressed an interest to learn more about PANDAS/PANS and other mental health disorders.

Review of 2019 report recommendations and discussion of two-year work plan

Council members reviewed recommendations from the 2019 PANDAS Advisory Council Report to the General Assembly and identified the following as potential priority areas on which to focus over the next two years:

- Disseminate the PANDAS resources through VDH to stakeholder organizations as outlined in the 2019 report recommendations; expand to other entities as appropriate.
- Educate other state agencies and law enforcement about PANDAS/PANS; disseminate resource materials to law enforcement agencies.
- Continue previous discussions to push for insurance coverage for treatment of PANDAS/PANS.
    - Address the issue of insurance as it relates to essential health benefits in Virginia in order to gain widespread coverage
- Reach out to PANDAS/PANS organizations external to Virginia (Arizona, California) to have experts provide education in Virginia.

- Propose PANDAS/PANS as a requirement for continuing medical education units.
- Promote upcoming PANDAS/PANS conferences throughout the PANDAS advisory council member network; research and develop a list of upcoming conferences and events.
    - The Foundation for Children with Neuroimmune Disorders Conference is May 13-14, 2021.

Council members reviewed two draft letters provided by VDH that relate to some of the 2019 report recommendations with regard to disseminating PANDAS/PANS resources developed by the advisory council. Both letters were displayed on the screen for viewing. The letters were also provided in advance of the meeting. The advisory council approved the letter associated with the resources for medical professionals with no suggested edits. Council members made one revision to the letter associated with the resource for school systems; the revision was displayed on the screen. The advisory council approved the revised letter.

Council members were also asked to vote on a proposed third letter for dissemination of the parent resource. VDH staff will draft a third letter to include similar language as the two approved letters, with slight variation according to the intended recipients. Council members voted to approve the proposed letter. Ms. Buskey will disseminate the letter to the advisory council via email. Senator Suetterlein advised council members to reply to the email in the affirmative or to state an objection to the letter.

The advisory council requested a status report of activities related to disbursement of the letters and resource dissemination. VDH staff will provide a status update at the next advisory council meeting.

Dr. David Jaffe requested to be placed in contact with the VDH web page manager so that he can discuss suggested edits to the web page. Ms. Buskey agreed to follow up with Dr. Jaffe to discuss the suggested edits.

Next Steps

Senator Suetterlein reviewed the proposed months for the advisory council to meet in 2021: April, June, September and November. Ms. Buskey will send out a Doodle poll with dates for the four months. Senator Suetterlein advised the council that the next meeting will be held virtually if COVID-19 restrictions are still in place. Otherwise, the meeting will be held in person in accordance with advisory council bylaws.

Ms. Buskey reminded the advisory council that an annual report is due December 1, 2020. Ms. Buskey will draft a one-page summary report to include an update regarding the advisory council's continuance through the next biennium and the approved minutes from the last meeting, which occurred November 15, 2019.

Adjournment

The meeting was adjourned at 2:44 p.m.

Appendix C – PANDAS/PANS Resources

PANS/PANDAS Evaluation & Treatment Algorithm

EVALUATION:

History, including assessment of presenting symptoms (behavioral, cognitive, emotional and somatic abnormalities), psychosocial stressors and environmental exposures (including Group A streptococci, mycoplasma and other infections). Family history of autoimmune disorders.

Was symptom onset abrupt or gradual? (Asking the child may reveal a gradual onset that was perceived as sudden by parents because child had been hiding symptoms.) PANS also may occur in children with neurodevelopmental disorders, including autism, and with similarly abrupt onset.

Physical exam, including assessment of throat and perianal region for signs of strep infection.

Laboratory work up should be determined by the child's clinical presentation (e.g., U/A and culture if child has urinary urgency, frequency, enuresis). All children should have a throat culture (rapid strep test can be used, but overnight culture obtained if RS is negative) and perirectal culture/rapid strep.

A diagnosis of PANS is made when the child has:

1. Abrupt onset of obsessive-compulsive symptoms or eating restrictions.
2. Concomitant onset of at least two of the following:
   - anxiety (particularly separation anxiety)
   - emotional lability and/or depression
   - irritability, aggression and/or oppositional behaviors
   - deterioration in school performance
   - sensory or motor abnormalities (e.g. tics, choreiform movements)
   - somatic signs and symptoms (particularly sleep disturbances, enuresis, and urinary urgency or frequency)
3. The acute-onset symptoms are not better explained by other neurological or medical disorders. For Differential Diagnosis, see Chang et al, J Child Adol Psychopharm 2015; 25(1): 3-13. **https://www.ncbi.nlm.nih.gov/pubmed/25325534**

For further information on the PANS/PANDAS history, physical exam and laboratory evaluation, please consult the JCAP guidelines (above) or the "Frequently Asked Questions" section of the NIMH PANS/PANDAS website **(https://www.nimh.nih.gov/health/publications/pandas/index.shtml).**

TREATMENT:

- **Prescribe one month course of antibiotics (JCAP reference):**
  1. Amoxicillin 40mg / kg* rounded up and then divided Q12 hrs
  2. Cephalexin 40mg/kg * rounded up and then divided Q12 hrs
  3. Augmentin 40mg/kg* rounded up and then divided Q12 hrs
  4. Azithromycin 12mg/kg* QD - consider EKG prior to treatment to rule out prolonged QTc.

     * or max dose

Use of probiotics may decrease GI side effects.

- **Refer to child psychiatrist, who may recommend medications, behavioral therapy, and parent skills training.**

- **Schedule follow-up appointment in one to two weeks.**

- **At follow-up evaluation:**

If clinical improvement in all settings:
- Continue current treatment and schedule follow-up appointment 3 - 5 days after end of antibiotic treatment

If minimal or no clinical improvement:
- Continue antibiotic therapy
- Start anti-inflammatory therapy (choice depends on symptom severity, see reference below)
  Ibuprofen 10mg / kg Q8hrs x 5 days **or**
  Prednisone 2mg / kg up to adult dosing QD x 5 days
- Ensure patient is receiving psychiatric/psychological treatment
- Consider referral to specialist (i.e. pediatric immunologist, neurologist, or developmental pediatrician) for further evaluation

- **Follow-up appointment at or around the time of completion of antibiotic (for all children):**

If clinical improvement in all settings:
- Explain that relapses are possible and stress the need for follow up if child has recurrence of symptoms for 3 or more days

If insufficient improvement or child's symptoms have recurred:
- Consider course of a different antibiotic
- If not used previously, start anti-inflammatory therapy with ibuprofen or prednisone
- Ensure child is receiving psychiatric/psychological treatment
- Refer to specialist (i.e. pediatric immunologist, neurologist or developmental pediatrician)

If no clinical improvement:
- Refer to specialist for further evaluation
- Provide support for child and family

For further details on treatment of PANS/PANDAS, please see the Journal of Child & Adolescent Psychopharmacology Special Edition on PANS/PANDAS, 2017.

Overview of treatment of Pediatric Acute-Onset Neuropsychiatric Syndrome.
J Child Adolesc Psychopharmacol (JCAP). 2017: 27:566-573
https://www.ncbi.nlm.nih.gov/pubmed/28722464

Part I-Psychiatric and behavioral interventions. JCAP. 2017: 27:562-565
https://www.ncbi.nlm.nih.gov/pubmed/28722481

Part II – Use of immunomodulatory therapies. JCAP. 2017: 27:566-573
https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5610394/

Part III – Treatment and prevention of infections. JCAP. 2017: 27:594-606
https://www.liebertpub.com/doi/pdf/10.1089/cap.2016.0151

PANDAS/PANS Parent Handout

WHAT ARE PANDAS AND PANS?

PANDAS is an abbreviation for Pediatric Autoimmune Neuropsychiatric Disorder Associated with Streptococcal Infections. The term was first used in 1998 to describe a subset of children and adolescents who have obsessive compulsive disorder (OCD - worries or intrusive, illogical thoughts and/or repetitive behaviors) and/or tic disorders, and in whom symptoms worsen following strep infections such as strep throat or scarlet fever. The PANDAS subgroup is part of a larger cohort of children whose symptom onset is unusually abrupt and dramatic, or Pediatric Acute-onset Neuropsychiatric Syndrome (PANS). PANS is characterized by an unusually abrupt onset of OCD or eating restrictions.

SYMPTOMS:

PANS always involves the abrupt onset of OCD and/or eating restrictions. PANS/PANDAS may occur in children with neurodevelopmental disorders, including autism, and would have similarly abrupt onset. The OCD or restricted eating is accompanied by at least two of the following with the waxing and waning course even with treatment:

1. Anxiety (especially worries about being separated from familiar people or places)
2. Developmental regression (acting much younger than actual age or losing milestones)
3. Extreme mood swings and/or depression (sometimes to the point of suicidal thoughts or attempts)
4. Personality changes, including irritability, aggression or oppositional behaviors
5. Deterioration in school performance due to ADHD-like symptoms of impulsivity, hyperactivity and concentration difficulties; new onset of difficulties with math or reading, deterioration of handwriting or drawing skills, and poor memory
6. Abnormal movements (motor tics, such as eye-blinking, shoulder shrugs, or vocalizations), sensory abnormalities (including new sensitivities to light, sound or textures)
7. Other signs and symptoms, including sleep disturbances, urinary urgency or frequency or new onset of bed-wetting and daytime accidents

SUGGESTIONS FOR PARENTS:

- **Build a team** of medical professionals for your child that you trust. It is common for a symptomatic child to need collaboration from a pediatrician, immunologist, neurologist, and child psychiatrist/child psychologist to manage symptoms. The treatment options and guidelines for care are evolving; research to find specialists through PANDAS Physicians Network.

- **Ask provider to help find a support group such as:** www.praikids.org.

- **Make a medical journal** for your child. Document each and every appointment. Ask for copies of the doctor notes and test results. If possible, go back and request all medical records for your child, including growth charts, since birth – to help document any past illnesses /procedures. Build a timeline for your child and note every major illness or milestone. Bring your journal to every appointment.

- **Be careful and diligent of germs**, especially when traveling or going to the dentist. Avoid water fountains, when possible. If your child is having a dental procedure (other than a regular cleaning), request an antibiotic prior to the procedure. Strep is known as a common trigger, but it is not the only illness that will cause symptoms to re-occur.

- **Be transparent** regarding your concerns with your doctor's and school personnel. Consider reassessing expectations and be patient with your child during this period.

For additional information, please reference the following resources:

PANDAS/PANS School Systems Handout
PANDAS/PANS Frequently Asked Questions (FAQs)

PANDAS/PANS School Systems Handout

WHAT ARE PANDAS AND PANS?

PANDAS is an abbreviation for Pediatric Autoimmune Neuropsychiatric Disorder Associated with Streptococcal Infections. The term was first used in 1998 to describe a subset of children and adolescents who have obsessive compulsive disorder (OCD - worries or intrusive, illogical thoughts and/or repetitive behaviors) and/or tic disorders, and in whom symptoms worsen following strep infections such as strep throat or scarlet fever. The PANDAS subgroup is part of a larger cohort of children whose symptom onset is unusually abrupt and dramatic, or Pediatric Acute-onset Neuropsychiatric Syndrome (PANS). PANS is characterized by an unusually abrupt onset of OCD or eating restrictions.

SYMPTOMS:

Children diagnosed with PANDAS/PANS can have significantly different symptoms – making diagnosis difficult and specialized treatment common. PANS may occur in children with neurodevelopmental disorders, including autism, and would have similarly abrupt onset. These children will have a combination of some of these symptoms:

1. Anxiety (especially worries about being separated from familiar people or places)
2. Developmental regression (acting much younger than actual age or losing milestones)
3. Extreme mood swings and/or depression (sometimes to the point of suicidal thoughts or attempts)
4. Personality changes, including irritability, aggression or oppositional behaviors
5. Deterioration in school performance due to ADHD-like symptoms of impulsivity, hyperactivity and concentration difficulties; new onset of difficulties with math or reading, deterioration of handwriting or drawing skills, and poor memory
6. Abnormal movements (motor tics, such as eye-blinking, shoulder shrugs, or vocalizations), sensory abnormalities (including new sensitivities to light, sound or textures)
7. Other signs and symptoms, including sleep disturbances, urinary urgency or frequency or new onset of bed-wetting and daytime accidents

As each child's symptoms can vary greatly, it is important to give specific focus to each individual child's needs. A meeting with the parents/guardians and all teachers, advisors, and school personnel that are able to attend is imperative prior to the school year or as soon as symptoms appear/re-occur. Make a specialized plan (IEP/504) to meet the child's changing academic needs, understanding the child's most common symptoms as described below:

1. **Presence of OCD or tics (motor and verbal):** A child may be scared of vomit/germs/illness. Be cognizant when selecting classmates at the beginning of the school year. Allow students with these symptoms to keep their own water bottle/supplies, if needed. Tics are common; helping these children to find an ideal/safe spot in the classroom is important.
2. **Acute onset and episodic (relapsing/remitting) course:** Be wary of any significant changes in a student and make sure to communicate with the parent/guardian of any noticeable changes in the classroom/school. Children can go through long periods of time with little to no symptoms – but re-occurrence is common and symptoms can appear quickly.
3. **Restrictive eating:** Children who drastically reduce their food intake may need to be watched carefully at lunch and snack times. Since some children will only eat certain foods, it is important to allow that some of these be brought to school when necessary. Do not force a child to eat but do let the parents know what you are observing.

4. **Decline in cognitive function – specifically writing and mathematics and changes in processing speed:** Keeping dated handwriting samples often is important. While symptomatic, it is difficult for a child to focus or improve their work in these areas. Reducing the required homework in these fields during symptomatic times is important, knowing that the parent/teacher can work to make up the lost time/education once symptoms have reduced.
5. **Anxiety, separation anxiety, sleep disturbances, bed wetting, daytime wetting, depression:** Many children have anxiety focused on getting to and staying in school. Their home is usually their 'safe' space and leaving their home/parent to go to school – where many of their fears/symptoms are evident – is overwhelming. Creating a 'safe' space in the school is important. Allow the child to leave the classroom when necessary/safe to do so.

FURTHER SUGGESTIONS:

Making as many individualized preparations as possible will aid in the care of these children while at school, allowing them to stay in school and further their education. Here are further suggestions:

- For the child scared to stay in school, have them make their own daily plan – along with a teacher - to guide themselves through the day and cut the day into smaller increments. Allow them a reward at each increment – a call to a parent at a specific time, a spot next to the teacher, a trip to a safe space, etc., to help them make it to the next milestone.

- A 'safe' space can be created, away from the nurse, (fear of illness can be heightened in the nurse's area where other sick children may be) within the school. This space will allow a child in the midst of their symptoms a space where other students cannot witness their actions.

- A parent/guardian can make a reward box (stickers, notes from home, pictures, art supplies, etc.) to place in a safe space. Depending on the age of the child, they may use the stickers/rewards as an incentive to return to class to pass out the stickers or the teacher can use them to help keep a child in class.

- Reduce the homework load for a child who is symptomatic. If a child can stay at school, their behavior/temperament once they get home can decline rapidly. Homebound instruction may need to be considered.

- The necessary doctor's appointments and therapy appointments can be frequent with times that usually are not flexible in regards to the school day. Work with the parent/guardian on the missed lessons/ schoolwork – usually they, too, are missing work to get their child the care they need.

- When possible, place a sympathetic friend in the child's class. Having a friend nearby to assist the child/teacher/ school personnel is positive and helps to keep the child in school and avoid setbacks.

- Provide extra clothing.

RECOMMENDED EDUCATION BOOKS:

PANDAS and PANS in School Settings: A Handbook for Educators by Patricia Rice Doran
PANS, CANS, and Automobiles: A Comprehensive Reference Guide for Helping Students with PANDAS and PANS by Jamie Candelaria Greene

For additional information, please reference the following resources:

PANDAS/PANS Parent Handout
PANDAS/PANS Frequently Asked Questions (FAQs)

PANDAS/PANS
Frequently Asked Questions (FAQs)

HOW ARE PANS AND PANDAS DEFINED?[1]

PANS (Pediatric Acute-onset Neuropsychiatric Syndrome) is a clinical diagnosis given to children who have an abrupt, dramatic onset of neuropsychiatric symptoms including obsessive-compulsive symptoms and/or eating restrictions. These primary symptoms are accompanied by a variety of behavioral, emotional, cognitive, neurological and physical symptoms, which include separation anxiety, irritability, excessive mood swings, depression (sometimes to the point of suicidality), impulsivity, hyperactivity and developmental regression (acting younger than their age). The children may also develop difficulties with sleep and urinary symptoms, such as urgency, frequency and daytime accidents or bed-wetting. When the symptoms of PANS are triggered by a strep infection (such as strep throat or scarlet fever), then the syndrome can be classified as PANDAS (for Pediatric Autoimmune Neuropsychiatric Disorder Associated with Streptococcal infections). Emerging research suggests that PANDAS is a post infectious autoimmune process.

The cause of the remaining PANS cases is unknown, but likely involves neuroinflammation brought on by a variety of infectious and metabolic factors.

Onset of the illness can be acute and dramatic or episodic. There can also be a pattern of waxing and waning or relapsing and remitting exacerbations of symptoms where at times the symptoms seem to “explode” in severity. Tics can worsen when there is an infection and incapacitate the child to the point of not being able to go to school and/or requiring a visit to the emergency room.

WHAT ARE SOME SIGNS AND SYMPTOMS OF PANS/ PANDAS OTHER THAN OCD AND TICS?[2]

Diagnostic criteria for PANS:

1. An abrupt, acute, dramatic onset of obsessive-compulsive disorder or severely restricted food intake.
2. Concurrent presence of additional neuropsychiatric symptoms with similarly severe and acute onset from at least 2 of the following categories:
   - anxiety
   - Emotional Lability and/or Depression
   - Irritability, Aggression, and/or Severe Oppositional Behaviors
   - Behavioral (Developmental) Regression
   - Sudden Deterioration in School Performance
   - Motor or Sensory Abnormalities
   - Somatic Signs and Symptoms, including Sleep Disturbances, Enuresis, or Urinary Frequency (such as urgency, frequency and daytime accidents or bed-wetting)
3. Symptoms are not better explained by a known neurologic or medical disorder

Diagnostic Criteria for PANDAS:

1. Presence of OCD and/or tics, particularly multiple, complex or unusual tics
2. Age Requirement (Symptoms of the disorder first become evident between 3 years of age and puberty)
3. Acute onset and episodic (relapsing-remitting) course
4. Association with Group A Streptococcal (GAS) infection
5. Association with Neurological Abnormalities, such as tics, choreiform movements, motoric hyperactivity, and sleep disturbances

WHAT ARE SOME COMMON OCD PRESENTATIONS IN PANDAS/PANS?[3]

As with other forms of obsessive compulsive disorder (OCD), individuals with PANDAS/ PANS have intrusive thoughts surrounding obsessions and compulsions. These can be about fears of contamination, losing control, concern with exactness or perfection, religious compulsion, unwanted sexual thoughts.

Compulsiveness can be around washing and cleaning, checking things, repeatedly drawing or writing the same things over and over. OCD is diagnosed when obsessions and compulsions interfere with daily functioning and cause distress requiring a visit to the emergency room.

HOW DO CHILDREN GET PANS/PANDAS? IS PANDAS CONTAGIOUS? HOW DO I AVOID GETTING PANDAS?[4]

"The current belief is that children who develop PANS or PANDAS have a genetic predisposition for these syndromes, which are triggered by an environmental stressor, often an infection. With PANS, that trigger is unknown. PANDAS is thought to be triggered by a Streptococcal infection. Blood tests conducted on children with PANS may show signs of inflammation."

"PANS isn't contagious, so kids can't catch it from a classmate. If a contagious infection (like strep throat) triggered someone's PANS, that illness can be passed from one person to another. But in general, you don't have to worry about your child developing PANS. Almost all school-age kids get infections and almost all recover with no complications."

HOW IS A CHILD DIAGNOSED WITH PANS/PANDAS?[5]

As a clinical syndrome, PANS is a diagnosis that describes a set of symptoms which frequently appear together. A clinical diagnosis means that it is based on the signs, symptoms, and medical history of the patient rather than on laboratory tests or medical imaging. Thus, the diagnosis can be made on the basis of the child's symptom presentation. However, that does not determine the cause of the symptoms, nor does it determine an appropriate course of treatment. To do that, clinicians must perform a physical examination and order laboratory studies to rule-out other known causes of neuropsychiatric symptoms.

To make a diagnosis of PANDAS, it is necessary to document a close exposure to/or infection with Group A streptococcal bacteria (the bacteria that causes strep throat and scarlet fever.) This can be done by obtaining a throat swab and sending it for overnight culture and/or by a blood test which will demonstrate a rise in anti-streptococcal titers (ASO and anti-DNase B). Rapid strep tests can be inconclusive, ask for a strep culture if the rapid strep is negative. Because the strep that causes PANDAS often is "silent" and produces few or no symptoms of a sore throat, ask for a throat culture. Perianal culture may also be appropriate. Additional tests will be determined by the child's presenting symptoms (for example, if a child has a persistent cough, tests for mycoplasma pneumonia might be done.) Guidelines to the complete PANS/PANDAS work-up can be found in the Journal of Child and Adolescent Psychopharmacology Jan/Feb 2015.

If the rapid strep is negative, ask for a strep culture. If any of these tests are positive, the child needs to be put on antibiotics for strep. If strep is negative, the child should have blood tests for strep. If the child has had or been exposed to an illness with prolonged coughing, then your pediatrician may consider testing for a bacteria called mycoplasma."

WHAT TREATMENTS ARE COMMONLY USED FOR PANS/PANDAS?[6]

Treatment of PANS/PANDAS is three-fold:

- Remove the SOURCE of the symptoms by using antibiotics to eradicate infection
- Return the immune SYSTEM to normal functioning with immunomodulatory therapies, such as non-steroidal anti-inflammatory medications (e.g., ibuprofen, naproxen), steroids, IVIG or in extremely severe cases, plasmapheresis
- Reduce the child's SYMPTOMS with standard psychological treatments, such as antidepressants, anti-anxiety medications or SSRIs and behavioral therapy for OCD symptoms

The choice of treatments depends on the severity of the child's symptom and the degree of dysfunction the child is experiencing. The PANDA Physicians Network provides summary guidelines for treatment of "mild", "moderate" and "severe" illness. Ideally, these treatments would be administered by a multi-disciplinary team with experience in management of inflammatory brain diseases.

PANS/PANDAS treatment is so complex it often requires collaboration with a multi-disciplinary team.

HOW DOES PANS AND PANDAS AFFECT A CHILD'S SCHOOL PERFORMANCE?[7]

If you suspect or have a diagnosis of PANS/PANDAS, begin to gather samples of handwriting and school performance with dates cross-referenced to dates of illness. You may see a decline in math and/or reading kills, handwriting regression, school refusal, executive function problems, processing delays, and short-term memory issues.
If a decline in school performance is a problem, then you may need to consider an Individualized Education Plan ("IEP") or a "504 plan" to ensure your child is provided necessary accommodations so that they can access an appropriate education. Both plans are provided under Federal US Department of education regulations, 34 C.F.R. Part 104. For these accommodations, you will need to approach your child's teacher and school administration to request a meeting to discuss educational accommodations for your child in the classroom setting.

It is possible to have a decline in cognitive function – specifically writing and mathematics and changes in processing speed. Keeping dated handwriting samples often is important. While symptomatic, it is difficult for a child to focus or improve their work in these areas. Reducing the required homework in these fields during symptomatic times is important while knowing that the parent/teacher can work to make up the lost time/education once symptoms have reduced.

HOW DO I ADJUST MY EXPECTATIONS OF MY CHILD'S BEHAVIORS/SCHOOL PERFORMANCE?[8]

A. Medical and Longer-Term Expectations:

1. PANS OCD has a relapsing remitting course. Most children will experience at least one recurrence of symptom onset due to a PANS trigger. Parents need to understand there is no "quick fix".
2. With PANS OCD, the course is relapsing-remitting, with dramatic, abrupt exacerbations of OCD and ancillary PANS symptoms.
3. Unlike traditional OCD, some studies have shown improvement in neuropsychiatric symptoms in patients with PANDAS after 2–6 weeks of antibiotic treatment. It is unclear if these improvements are from treatment of a latent infection or from some other non-microbial effects.
4. Residual OCD may persist despite any treatment of infection, inflammation, CBT, or medications. In the 1999 study using aggressive immunomodulatory treatment, patients improved on average 45%. Cognitive-behavior therapy (specifically exposure with response prevention) can be helpful in eradicating symptoms of PANS. Anti-obsessional medications can also be used in combination with CBT but studies indicate to "start low and go slow."

B. Home and School Expectations:

1. PANS OCD is OCD. Family education and support is critical, particularly in the early stages of illness. Providing material on treating and managing childhood OCD is an important step.
2. Communication with the school will help alleviate stress and establish a better understanding between faculty and student. Parents may request to be informed of documented strep within the classroom and ensure that teachers are following good hygiene practices. Clinicians and parents might also volunteer to provide an informative lecture to class, parents, and teachers, and/or request a 504 Plan, IEP, or Student Success Team ("SST").

C. Suggestions for parents:

1. Build a team of medical professionals for your child that you trust. It is common for a symptomatic child to need collaboration from a pediatrician, immunologist, neurologist, and child psychiatrist/child psychologist to manage symptoms. The treatment options and guidelines for care are evolving; research to find specialists through Pandas Network/PPN or through online support groups if necessary.
2. Find a support group, along with accepting help from family and friends. There are many online support groups across the country for families and caregivers.
3. Make a medical journal for your child. Document each and every appointment. Ask for copies of the doctor notes and test results. If possible, go back and request all medical records for your child, including growth charts and dental procedures, since birth. It can help to document any past illnesses /procedures. Build a timeline for your child and note every major illness or milestone. Bring your journal to every appointment.
4. Be careful and diligent of germs, especially when traveling or going to the dentist. Avoid water fountains, when possible. If your child is having a dental procedure (other than a regular cleaning), request an antibiotic prior to the procedure. Strep is known as a common trigger, but it is not the only illness that will cause symptoms to re-occur.
5. Be transparent regarding your concerns with your doctor's, school personnel and your employer. Consider reassessing expectations and be patient with your child (and yourself) during this period.

SOURCES:

[1] PANDAS Physicians Network Diagnostic Guidelines
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https://www.pandasppn.org/ppn-pans-diagnostic-guidelines/

Stanford Medicine
https://med.stanford.edu/pans.html

Stanford Children's Health
https://healthier.stanfordchildrens.org/en/q-sudden-symptoms-first-sign-pans-pandas/

Southeastern PANS/PANDAS Association
www.sepans.org
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[2] PANDAS Physicians Network
https://www.pandasppn.org/ppn-pans-diagnostic-guidelines/
https://www.pandasppn.org/ppn-pandas-diagnostic-guidelines/

[3] International OCD Foundation
https://iocdf.org/about-ocd/

Beyond OCD
http://beyondocd.org/information-for-parents
http://beyondocd.org/ocd-facts/what-is-ocd

[4] Stanford Children's Health
https://healthier.stanfordchildrens.org/en/q-sudden-symptoms-first-sign-pans-pandas/

KidsHealth from Nemours
https://kidshealth.org/en/parents/pandas.html

[5] Susan E. Swedo, M.D., Scientist Emerita, National Institute of Mental Health, National Institutes of Health Intramural Research Program

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Clinical Management of Pediatric Acute-Onset Neuropsychiatric Syndrome: Part III—Treatment and Prevention of Infections
https://www.liebertpub.com/doi/full/10.1089/cap.2016.0151

[7] Wright's Law Special Education Advocacy Site
https://www.wrightslaw.com/

Immune Deficiency Foundation
https://primaryimmune.org/wp-content/uploads/2015/01/IDF-School-Guide-3rd-Edition-2015-FINAL.pdf

[8] PANDAS Physicians Network
https://www.pandasppn.org/seeingyourfirstchild/

For additional information, please reference the following resources:

PANDAS/PANS Parent Handout
PANDAS/PANS School Systems Handout