

2019 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

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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 2018, and the advisory council has met four times since November 2018. Final approved minutes from the November 2018 are included in Appendix B. The advisory council subcommittees met three times in 2019. This document summarizes all of the advisory council's activities for 2019.

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 Over the past year, the PANDAS/PANS advisory council developed four draft resources to increase awareness. The council developed 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 draft resources are included in Appendix K.

Status Report on PANDAS/PANS Advisory Council Activities

VDH staff coordinated and facilitated four PANDAS/PANS advisory council meetings and three subcommittee meetings in 2019. Below is a summary of the advisory council's activities in 2019:

March 2019: Four council members of the subcommittee focused on practice guidelines for diagnosis and treatment and one VDH staff met on March 22, 2019. A fifth council member

participated via conference call. The subcommittee worked on revisions to the draft evaluation and treatment algorithm. Two council members of the subcommittee focused on outreach to parents and educators, one VDH staff and one guest were in attendance at the meeting on March 25, 2019. A third council member and one guest participated via conference call. The subcommittee developed a draft FAQs document as an informational resource. Details regarding both subcommittee meetings are included in the meeting minutes (Appendices B and C).

April 2019: Nine council members, two VDH staff and two guests were in attendance for the April 8, 2019 meeting. The council conducted general business and reviewed both the revised draft evaluation and treatment algorithm and the draft FAQs document. Members provided feedback for revisions to both documents. The council also reviewed the Maryland PANDAS legislative report to determine if the report contained any information that might be useful to Virginia. The council did not adopt any of the strategies contained in the report. Meeting minutes are provided in Appendix D.

May 2019: Four council members of the subcommittee focused on outreach to parents and educators and one VDH staff met on May 20, 2019. The subcommittee discussed the feasibility of developing a PANDAS action plan similar to the action plans (e.g. general health care, asthma, life-threatening allergies) that are currently used for students in Virginia's public schools. The subcommittee revised the draft FAQs document. Meeting minutes are included in Appendix E.

June 2019: Ten advisory council members, two VDH staff and two guests attended the June 20, 2019 meeting. Subcommittee members provided updates regarding development of the resource materials. The council reviewed updated versions of the draft evaluation and treatment algorithm and draft parent and school guidance handouts that had been formatted by the VDH communications team. The council also reviewed the revised draft FAQs document. Feedback was provided regarding revisions to the documents. Council members also engaged in discussion regarding a proposed recommendation to educate members of law enforcement and the judicial system. Meeting details are included in the meeting minutes (Appendix F).

August 2019: Each of the nine non-legislative members of the advisory council were reappointed at the expiration of their two-year term. The official appointments were announced on August 16, 2019.

September 2019: Nine advisory council members, two VDH staff and two guests attended the September 23, 2019 meeting. The council reviewed and provided feedback on the updated draft FAQs document, which had been formatted by the VDH communications team. Council members engaged in discussion regarding a proposed recommendation to establish a center of excellence in Virginia. Lack of insurance coverage was also discussed as a barrier to assessment and treatment. The council also reviewed suggested strategies for increasing awareness and education of clinicians and outreach strategies to increase awareness of parents and educators about PANDAS and PANS (Appendix G). The meeting minutes are provided in Appendix H.

November 2019: Ten advisory council members, three VDH staff and two guests attended the September 23, 2019 meeting. One invited guest, Dr. Carl Hoegerl of Liberty University School

of Medicine, participated remotely via Zoom meeting. An invitation had been extended to deans of the six schools of medicine, as well as to designated PANDAS/PANS experts at the schools. Guests were invited to participate in a discussion regarding the proposed recommendation to establish a center of excellence in Virginia to treat PANDAS/PANS and autoimmune encephalopathy (AE).

The first half of the meeting was dedicated to discussing the center of excellence recommendation. Dr. Walker Harris, ex officio council member and Director of the Office of Family Health Services at VDH, led the discussion to obtain feedback from the group. A summary handout of the Arizona and Stanford center models were provided to the group. Dr. Wei Zhao provided a summary explanation of the hybrid model described in the proposal that he developed for the Children's Hospital at VCU. A discussion question handout was used to facilitate group discussion on the recommendation to establish a center and the type of model to implement (Appendix XX). The invited guest and council members engaged in a productive exchange of ideas and information. Council agreed to include the proposed recommendation to establish a center of excellence.

The second half of the meeting focused on general advisory council business. Council members reviewed final drafts of the PANDAS/PANS parent and school handouts and the FAQs resource. The majority of the second half of the meeting was spent reviewing the draft annual report recommendations. Ms. Teresa Champion provided suggested revisions to the recommendations, which the council also reviewed. Council members made final revisions to the draft recommendations. Council voted to approve all of the revised recommendations with the exception of the recommendation to mandate insurance coverage for the treatment of PANDAS/PANS. Ms. Teresa Champion requested that her vote opposing removal of the insurance mandate recommendation be formally noted. The approved recommendations are included below in the Recommendations section of this report.

Summary and Future Plans

The advisory council will continue to develop recommendations on research, diagnosis, treatment and education relating to PANDAS and PANS. Through coordination between VDH and VDSS staff, two subcommittee chairs are scheduled to present at the VDSS Permanency Advisory Council meeting in Charlottesville, Virginia on December 4, 2019. The purpose of the presentation is to educate directors, program managers, supervisors and senior workers in foster care, adoption, or family recruitment from local departments of social services throughout the state about PANDAS and PANS. Council members will be provided potential meeting dates for March and June 2020. Future meeting dates will be confirmed following an official poll of all members.

Recommendations

- 1) The Council recommends the establishment of a center of excellence at a Virginia academic medical center that will:
 - conduct basic, clinical, and translational research for PANDAS/PANS and autoimmune encephalopathy (AE);

- provide assessment and treatment for patients, children and adults, with a diagnosis of PANDAS/PANS and AE; and
 - establish a network of community providers to provide support and education for local delivery of care including the use of all available modalities such as telemedicine.
- 2) The Council recommends that VDH disseminate a PANDAS/PANS diagnosis and treatment algorithm to physicians and clinicians throughout the state. The advisory council has developed a draft evaluation and treatment algorithm to address two focus areas -- practice guidelines for diagnosis and treatment and mechanisms to increase clinical awareness. Once the product is finalized and approved, the resource can be made available to physicians and clinicians for use in daily practice.
 - 3) The Council recommends that VDH work with Virginia American Academy of Pediatrics (AAP), the Medical Society of Virginia (MSV), Virginia College of Emergency Physicians (VACEP) and other relevant stakeholders to promote and increase awareness of and access to the 2015 and 2017 PANS Consortium guidelines to all clinical providers involved in the assessment and treatment of PANDAS/PANS.
 - 4) The Council recommends that VDH work with relevant partners such as the AAP, MSV and VACEP to coordinate dissemination of the PANDAS/PANS evaluation and treatment algorithm to the pediatric providers and through Virginia's six schools of medicine.
 - 5) The Council recommends that the state health commissioner disseminate information about PANDAS/PANS to physicians and clinicians throughout the state via a clinician letter with an attachment of the evaluation and treatment algorithm.
 - 6) The Council recommends that VDH disseminate PANDAS/PANS parent and school guidance documents throughout the state. The advisory council has developed a draft guidance handout for parents and a handout for school staff to address the outreach to parents and educators focus area. Once finalized and approved, the resources can be made available to parents and schools to promote education and awareness.
 - 7) The Council recommends that VDH work with the Virginia Department of Education to coordinate dissemination of the PANDAS/PANS school handout to educational staff and school nurses in all K-12 schools.
 - 8) The Council recommends that VDH educate other state agencies including, but not limited to, the Department of Behavioral Health and Developmental Services, Department of Social Services, Department of Corrections, Department of Juvenile Justice, Commonwealth's Attorneys' Services Council, Department of State Police, Department of Criminal Justice Services including the courts, Office of Children's Services, Health Insurance Reform Commission and Virginia Association of Health Plans on using the PANDAS/PANS informational handouts to promote awareness of PANDAS/PANS.
 - 9) The Council recommends that VDH work with relevant professional associations such as Commonwealth Parenting, Children's Advocacy Center of Virginia, The Arc, statewide Autism Societies, Virginia Autism Project, Virginia Statewide Parent Education Coalition, Virginia Parent Teacher Association and Special Education Parent Teacher Association to coordinate dissemination of the PANDAS/PANS parent informational handout.
 - 10) The Council recommends that VDH disseminate a PANDAS/PANS informational resource throughout the state. The advisory council has developed a draft FAQs document to address the outreach to parents and educators focus area. Once finalized and approved, the resource

can be posted on the Pediatric Research and Advocacy Initiative (PRAI) website,
www.praikids.org.

- 11) The Council recommends that VDH update relevant VDH webpages to include current PANDAS/PANS information and approved resources.
- 12) The Council recommends that VDH work with relevant stakeholder organizations to encourage use of the PANDAS Physicians Network through AAP, MSV, child psychiatrists, neurologists, and immunologists to expand the network of PANDAS/PANS providers for children and adults, including those with disabilities.
- 13) The Council recommends that the General Assembly continue the PANDAS/PANS advisory council for another two years.

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 and Subcommittee Members

Legislative Council Members:

Senator George Barker
Delegate Richard Bell
Delegate Eileen Filler-Corn
Delegate Gordon Helsel
Delegate Roxann Robinson
Senator David Suetterlein

Non-Legislative Council Members:

Ms. Teresa Champion, Autism Support Group
Ms. Jessica Gavin, PANDAS Research & Advocacy Initiative
Dr. David Jaffe, Children's Hospital of Richmond at VCU
Ms. Stefanie Levensalor, Parent Advocate
Ms. Stacey Link, 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:

Dr. Vanessa Walker Harris, Director, Office of Family Health Services, Virginia Department of Health

Subcommittee focus area – practice guidelines for diagnosis and treatment:

Ms. Jessica Gavin
Dr. David Jaffe
Dr. Melissa Nelson
Dr. Bela Sood
Dr. Sue Swedo
Dr. Wei Zhao

Subcommittee focus area – mechanisms to increase clinical awareness:

Ms. Jessica Gavin
Dr. Melissa Nelson
Dr. Bela Sood
Dr. Sue Swedo
Dr. Wei Zhao

Subcommittee focus area – outreach to educators and parents:

Ms. Teresa Champion
Ms. Jessica Gavin
Ms. Stefanie Levensalor
Ms. Stacey Link

Appendix B

PANDAS/PANS Advisory Council Meeting

Libbie Mill Library
Monday, November 26, 2018
1:00 p.m. – 4:00 p.m.

Meeting Minutes

Members Present: Senator George Barker, Ms. Teresa Champion, Del. Eileen Filler-Corn, Ms. Jessica Gavin, Dr. David Jaffe, Ms. Stacey Link, Del. Roxann Robinson, Dr. Bela Sood, Senator David Suetterlein

Ex Officio Member Present: Dr. Vanessa Walker Harris (Commissioner's designee)

VDH Staff Present: Ms. Robin Buskey, Mr. Joe Hilbert

Guests: Ms. Sagé Blaska (Parent), Ms. Arin Barker (Children's Hospital of Richmond at VCU)

Welcome and agenda overview

Delegate Eileen Filler-Corn called the meeting to order at 1:15 p.m. Dr. Vanessa Walker Harris provided an overview of the meeting agenda.

Selection of Chairs for Subcommittees

Chairs were chosen to lead future meetings of the three subcommittees. The following chair assignments were determined:

- Diagnosis and treatment – Dr. David Jaffe
- Clinicians – Jessica Gavin
- Parents and educators – Teresa Champion

Updates and announcements

Advisory committee member shared updates regarding PANS and PANDAS activities and/or events to include the following highlights:

- Ms. Gavin shared that there is increasing clinical awareness of PANDAS/PANS based on caseloads at various health systems and practices. VCU has 80+ patients. Bon Secours St. Mary's does not have as many patients. Dr. Jaffe asked if there are any stats on the number of patients that Bon Secours is treating. Gavin responded that they are treating approximately 25 pediatric patients.
- Ms. Gavin also stated that UVA is making slow progress. They have agreed to complete workups for infections; however, they are not willing to do immune therapy.
- Ms. Gavin shared that the PACE Foundation is funding a multi-center IVIG center to see if it is an effective treatment for PANS.
- Dr. Jaffe inquired if VCU has given any feedback on developing a center. He was told that Dr. Zhao indicated that VCU will not develop a center based on the Arizona model. Dr. Jaffe would

like to talk to someone else about moving forward with developing a center in Virginia. Ms. Gavin responded that there was push for a center but there was no feedback from VCU. The plan is to move forward with working with Bon Secours and UVA.

- Ms. Gavin shared that her organization, PRAI, has developed an online patient registry. The organization will need to determine how they will reach PANS and PANDAS patients. The registry will be parent reported.
- Dr. Jaffe shared that the research from the consortium shows that there is a particular type of blood cell in individuals that meet the criteria for PANS. There is ongoing research related to this.
- Ms. Champion suggested that judges and prosecutors will need to be educated on various mental health issues as more kids age and certain behaviors cause them to come into contact with the judicial system. Education outreach efforts need to target the judicial system.

Review and approval of meeting minutes

Delegate Filler-Corn made a motion to approve the June, August and October 2018 meeting minutes, which were provided to all advisory council members for review in advance of the meeting. The meeting minutes were approved by unanimous vote.

Review of Draft PANS/PANDAS Algorithm

Advisory council members reviewed the draft algorithm. Dr. Sood suggested that Dr. Swedo prioritize the labs that are “musts” and she noted that the clinical diagnosis must be clearly stated on the final draft. Dr. Jaffe stated that the final algorithm must not contradict existing guidelines. The subcommittee will need to meet again so that the physicians can finalize the algorithm. In the absence of Drs. Swedo, Nelson and Zhao, no additional edits were made to the draft algorithm

Review of Draft Parent and School Guidance Document

Advisory council members reviewed the draft guidance document for parents and schools. Ms. Champion inquired where the document will be housed; who will update it; and who will distribute it?

Dr. Jaffe indicated that Dr. Swedo had discussed a similar topic among the consortium. She envisioned trying to find a way that the various organizations throughout the country will interact with each other, form an umbrella connection, and attain consensus. There is concern that there is a significant amount of difference in how various groups approach this. The documents would be updated by the groups that form the association.

Dr. Sood indicated that the document must have a Virginia flavor. The document should reside in centers and parent groups. Government agencies could also play a role in pushing the information out into the community. The physical hard copy of the document should look like the version that will be posted on the internet.

Ms. Gavin inquired about the next step for the advisory council if the recommendations are not acted upon; how does the council get these recommendations to happen? Senator Barker replied that the council needs to make the recommendations as clear as possible then go to the legislators to determine the best course of action, which will depend on what is happening at the time. The council should start making recommendations now through when the legislation sunsets.

Delegate Robinson inquired about how the guidance document will reach parents. Council members responded that it will likely be disseminated through physicians, school staff and parent groups.

Ms. Link stated that Chesterfield County Public Schools and the Department of Education is ready for the information. The FAQs document is the missing link, as people currently do not know where to go for medical help.

Dr. Sood stated that pediatricians and primary care physicians should be the portal of entry. Dr. Jaffe added that many patients come to him without a referral.

Ms. Gavin stated that 90% of pediatricians do not know about PANS and PANDAS. She would like to figure out a way to direct parents first to the doctors instead of coming through PRAI.

Senator Barker inquired if there is a way to establish a list for pediatricians to inform patients who to contact. Is there a way for specialists to opt in and opt out? Doctors should be able to self-select whether or not they are included on the list. Dr. Jaffe responded that there is an existing list on the PANDAS Physicians Network (PPN) and that it should be included on the algorithm document.

Ms. Champion raised the question of how to get the FAQs document developed. She then made a motion to accept the parent and school guidance document in final draft form and release it to the public to obtain feedback. Ms. Link suggested that the document be revised to remove the second sentence from item 4 on the school guidance. The council approved the motion to release the document for public feedback after the revision is made. Ms. Champion will release the document to parents of PRAI, the Facebook page, and PANDAS parent network.

Dr. Jaffe stated that he has developed a chart for parents to complete a chronological history of the events that occurred with the patient. He would like the council to review his chart and possibly include the chart in the handouts.

Subcommittee members discussed potentially meeting in January to develop the FAQs document for parents and schools, as well as revisions to the algorithm. The chairs will contact Robin to coordinate the respective subcommittee meetings. Dr. Jaffe stated that he would need to include Dr. Swedo and Dr. Nelson in a review of other existing documents. The three main categories for comparison are things in agreement; things in disagreement; and neither. Dr. Sood stated that the algorithm must be clear; in its current form, the clinical diagnosis is missing.

Discussion regarding the need for a Center of Excellence in Virginia

Ms. Champion stated that she wanted to discuss further the need for a center in Virginia. Dr. Jaffe suggested sending out a request to the heads of the pediatrics department at each of the medical schools to offer a meeting to discuss the possibility of a center. It was noted that a leaders of Virginia's medical schools meet regularly through the Medical Society of Virginia. Senator Barker stated that he could check into seeing how council members can get a spot on their agenda to inform the medical schools of where Virginia is on this issue and to request that they keep the PANDAS/PANS documents alive going forward once they are finalized.

Review of the Draft 2018 Annual Report

Advisory council members provided feedback on the draft annual report, which was provided in advance of the meeting for review. Council members agreed to include the following edits to the recommendation section of the report:

- Disseminate a PANS/PANDAS diagnosis and treatment algorithm to physicians and clinicians throughout the state. The advisory council has developed a draft algorithm to address two focus areas -- practice guidelines for diagnosis and treatment and mechanisms to increase clinical awareness. Once the product is finalized and approved, the resource can be made available to physicians and clinicians for use in daily practice.
- Disseminate a PANS/PANDAS parent and school guidance document throughout the state. The advisory council has developed a draft guidance document for parents and school staff to address the outreach to parents and educators focus area. Once finalized and approved, the resource can be made available to parents and schools to promote education and awareness.
- Reach out to the American Academy of Pediatrics (AAP) and the Medical Society of Virginia (MSV) to coordinate dissemination of the PANS/PANDAS diagnosis and treatment algorithm to the pediatric providers and through Virginia's six schools of medicine.
- Update the VDH website to include current PANS/PANDAS information.
- Encourage use of the PANDAS Physicians Network through AAP, MSV, child psychiatrists, neurologists, and immunologists to expand the network of PANS/PANDAS providers.
- Develop a consortium of clinicians model that will work collaboratively with Virginia statewide medical professional groups, community and primary care physicians and other hospital centers to develop areas of excellence, adapting best practices from research centers such as Arizona. Ms. Champion will provide additional clarifying text to include.

Public comment period

No comments were received during the public comment period.

Next steps

Ms. Buskey will make the final edits to the annual report as approved by the advisory council. Ms. Champion will forward additional text to Ms. Buskey to be incorporated in the recommendation to develop a consortium of clinicians model.

Delegate Filler-Corn asked council members to look at the potential 2019 meeting dates that were provided on the agenda. Dr. Jaffe asked if some Thursday and Friday dates could be included. There was also a suggestion to hold a council meeting in September vs. October to accommodate legislative meeting calendars. Ms. Buskey will include some additional dates and send out a Doodle poll to all members.

Subcommittee chairs will contact Ms. Buskey to arrange meeting dates to finalize the algorithm and parent and school guidance documents and to develop the FAQs. Ms. Champion will let Ms. Buskey know if Monday, January 28th is a good date for the parent and educator outreach subcommittee to meet.

Adjournment

Delegate Filler-Corn provided closing remarks and thanked council members and guests for their time and participation. The meeting was adjourned at 4:00 p.m.

Appendix C

PANDAS/PANS Advisory Council – Subcommittee Meeting
Focus Area – Practice guidelines for diagnosis and treatment
Libbie Mill Library – Conference Room
Friday, March 22, 2019
1:00 p.m. – 3:00 p.m.

Meeting Minutes

Members Present: Ms. Jessica Gavin, Dr. David Jaffe, Dr. Susan Swedo, Dr. Wei Zhao

By Phone: Dr. Melissa Nelson

VDH Staff Present: Ms. Robin Buskey

Welcome and Agenda Overview

Dr. David Jaffe called the meeting to order and informed the group that Dr. Melissa Nelson had previously requested to participate via conference call, as she was unable to attend in person due to her pediatric practice being short-staffed. Dr. Jaffe provided an overview of the meeting agenda. The purpose of the meeting was to finalize revisions to the PANS/PANDAS algorithm.

Revisions to the PANS/PANDAS Diagnosis and Treatment Algorithm

The latest draft version of the PANS/PANDAS Diagnosis and Treatment Algorithm document (dated 8/20/2018) was provided in advance of the meeting. The electronic version of the draft document was placed on the overhead screen and Dr. Jaffe made all edits to the algorithm during the meeting based on feedback and consensus of the group. Key revisions included the following:

- Renamed document title; replaced “diagnosis” with “evaluation”
- Moved autism reference to History section
- Moved the reference to JCAP guidelines to end of Evaluation
- Revised language to more clearly describe a diagnosis of PANS
- Included one additional antibiotic for treatment; revised language to more clearly and accurately describe the prescription for treatment
- Revised language to refer to child psychiatrist
- Revised language to clarify schedule of follow-up appointment in one to two weeks
- Revised language to include note regarding choice of anti-inflammatory therapy
- Revised language regarding follow-up appointment upon antibiotic completion
- Included references and links to the Journal of Child & Adolescent Psychopharmacology overview and treatment guidelines

General language, wording and formatting changes were also made for consistency and clarity. Dr. Jaffe saved all final revisions to the document and emailed it to Ms. Robin Buskey for dissemination to the full council in advance of the April meeting. Dr. Jaffe also asked that Ms. Buskey share the document with the subcommittee scheduled to meet on March 25, 2019 to inform development of the FAQs document for parents and educators, if needed.

Adjournment

The meeting adjourned at 2:20 p.m.

Appendix D

PANDAS/PANS Advisory Council – Subcommittee Meeting
Focus Area – Outreach to parents and educators
Varina Library – Conference Room
Monday, March 25, 2019
1:00 p.m. – 3:00 p.m.

Meeting Minutes

Members Present: Ms. Teresa Champion, Ms. Stefanie Levensalor

By Phone: Ms. Jessica Gavin

VDH Staff Present: Ms. Robin Buskey

Guests: Ms. Sagé Blaska (by phone), Mr. Jason Schiller, Ms. M.J.

Welcome and Agenda Overview

Ms. Teresa Champion, subcommittee chair, called the meeting to order and informed the group that Ms. Jessica Gavin had previously requested to participate via conference call, as she was unable to attend in person. Ms. Champion stated that a parent guest would also participate via conference call. Ms. Champion provided an overview of the agenda; the purpose of the meeting was to develop a FAQs document to supplement the parent and educators guidance document. Ms. Champion stated her preference to forego the scheduled public comment period in lieu of having the participants provide comment throughout the working subcommittee meeting. All members were in favor of the proposed approach.

Ms. Champion provided an update to the subcommittee that the PANS/PANDAS algorithm document would focus on the diagnosis and treatment of PANS, not PANDAS and asked Ms. Gavin to provide an update from the subcommittee that met on Friday, March 22, 2019 to finalize the algorithm. Ms. Gavin stated that due to the past controversy surrounding PANDAS, the algorithm focuses on the overarching umbrella of PANS. Ms. Robin Buskey provided copies of the parent and school guidance and the updated algorithm.

Development of the FAQs document

Ms. Champion provided hard copies of two draft FAQs documents. The first document consisted of a table format that included questions, responses and references for the given responses. The table also included two check columns to indicate if the question was from the perspective of a parent, an educator or both. The second document was a sample format of a FAQ document for parents. Ms. Champion noted that the documents were intended to provide a starting point based on feedback she had received after soliciting parents to determine the type of information they would find most useful.

Ms. Champion made a motion to use the table document as the working document to include all potential questions in one document. Ms. Levensalor seconded the motion. The members voted in favor to develop one comprehensive table during the meeting. The electronic version of the draft FAQs table was placed on the overhead screen and Ms. Champion made all edits to the document based on feedback and consensus of the group. Language, wording and text placement changes were made to the document for consistency and clarity, and reference links were added so that individuals can obtain additional

information on a given topic. In addition, Ms. Levensalor sent a number of reference links via email to Ms. Champion during the meeting for inclusion in the table. Ms. Champion stated that she would incorporate the links into the table and send a clean version to Ms. Buskey for distribution to the full advisory council.

In addition to feedback regarding development of the FAQs document, parent guests noted the following points of consideration:

- There is a need for the advisory council to educate beyond parents and educators. Individuals working within child protective services and foster care at the Virginia Department of Social Services need to be educated on PANS and PANDAS.
- The Department of Behavioral Health and Developmental Services also need to be informed about PANS and PANDAS; the agency provides money for certain in-home services.

Adjournment

The meeting adjourned at 3:06 p.m.

Appendix E

PANDAS/PANS Advisory Council Meeting

Libbie Mill Library
Monday, April 8, 2019
1:00 p.m. – 4:00 p.m.

Meeting Minutes

Members Present: Senator George Barker, Delegate Richard Bell, Ms. Teresa Champion, Del. Eileen Filler-Corn, Ms. Stacey Link, Dr. Melissa Nelson, Dr. Bela Sood, Senator David Suetterlein, Dr. Susan Swedo

Ex Officio Member Present: Dr. Vanessa Walker Harris (Commissioner's designee)

VDH Staff Present: Ms. Robin Buskey

Guests: Ms. Sagé Blaska (Parent), Ms. Arin Barker (Children's Hospital of Richmond at VCU)

Welcome and agenda overview

Delegate Eileen Filler-Corn called the meeting to order at 1:13 p.m. and provided an overview of the meeting agenda. She then asked Ms. Teresa Champion to share an update regarding the Virginia Autism Project. Ms. Champion informed the council that after ten years of advocating to get the age cap lifted, the Virginia Autism Project was successful in getting the age cap lifted off state-regulated plans for all therapy services. She also shared that April is Autism Awareness Month.

Review and approval of meeting minutes

Delegate Filler-Corn made a motion to approve the minutes for the November advisory council meeting and the two March subcommittee meetings. The meeting minutes were approved by unanimous vote.

Updates and announcements

Dr. Vanessa Walker Harris informed the group that VDH has submitted a decision memo to Governor Northam to request reappointment of the nine non-legislative members to the PANDAS advisory council, as the current terms expire June 30, 2019. The decision memo was submitted mid-March; VDH is awaiting a response. Delegate Filler-Corn stated that she would follow up on this request. Advisory committee members shared updates to include the following highlights:

- Dr. Susan Swedo retired from NIH. She now serves as the Chief Science Office for the PANDAS Physicians Network (PPN). She stated that the resource materials developed through the PANDAS advisory council could be disseminated through the PPN.
- Dr. Bela Sood provided an update on the Virginia Mental Health Access Program (VMAP). This project is funded by a small HRSA grant and includes:
 - 24/7 telephone consultation between child psychiatrists and pediatricians
 - Provision of tele-psychiatry when child psychiatric assessment is necessary
 - Education component for pediatricians through an ECHO Lab platform once or twice per month. REACH Fellowship immersion in mental health topics will be available to

pediatricians over a three day period. PANS could be a part of the didactic series. Pediatricians are expected to participate in the series monthly.

- Care coordination office to provide resources and information to families where appropriate

The project will provide these services in five regions of the state. Dr. Sood stated that the materials developed by the PANDAS advisory council could be shared through this initiative.

Contact information for each of the five areas is as follows:

1. Virginia Commonwealth University – Bela Sood, MD
 2. University of Virginia – Roger Burkett, MD; Beth Ellen Davis, MD
 3. Carilion Clinic – Felicity Adam, MD
 4. INOVA/Children’s National Medical Center – Adelaide Robb, MD; Laura Willing, MD
 5. Children’s Hospital of the King’s Daughters – Peter Dozier, MD; Stephanie Osler, LCSW
- Delegate Filler-Corn shared that three states now have mandates for insurance coverage; an insurance mandate for one additional state is currently in progress. There are also twelve advisory councils established to address PANDAS/PANS.

Review of Revised PANS/PANDAS Algorithm

Advisory council members reviewed the revised algorithm. Dr. Swedo stated that members of the subcommittee cleaned up the prior version to make it more succinct so that practitioners will know what to do. The goal is to keep the guidance related to what applies to 75% of PANS cases. Dr. Swedo reviewed edits that were made to page one of the algorithm; Dr. Melissa Nelson reviewed the edits that were made to page two. Council members approved the following additional edits to the algorithm:

- Remove “if exam warrants” from the laboratory work up section
- Include a bulleted list in place of the narrative text under diagnosis item 2
- Remove the comma after “Chang” under diagnosis item 3
- Replace “management” with “skills” in the treatment section
- Remove the entire sentence below “At follow-up evaluation:”
- Include “in all setting” after “If clinical improvement”

VDH will have the communications staff format the algorithm document for a better presentation once the content is final.

Dr. Walker Harris shared that VDH had reached out to the Medical Society of Virginia (MSV) to request that representatives from the PANDAS advisory council be included on an agenda to inform the heads of medical schools about the council’s progress to date. MSV staff responded that the appropriate meeting for this request is the Medical Dean’s Forum. Plans are in progress for the forum; the coordinator will contact Dr. Walker Harris once the date has been determined. Senator George Barker stated that he had also reached out to the Medical Society of Virginia to make the same request. Delegate Filler-Corn stated that she would follow up with MSV about the Medical Dean’s Forum.

Break

The council recessed for a break from 2:15 – 2:30 p.m.

Review of Draft Parent and School FAQs Document

Ms. Champion informed the group that she queried parent groups to obtain feedback on the types of questions they had when they first learned about PANS/PANDAS. She then compiled those questions into a table format, along with appropriate responses and reference sources. The document was provided to subcommittee members to make revisions. She asked advisory council members to review the document and provide input regarding edits or better reference sources needed.

Senator Suetterlein inquired about the sources referenced in the document. Dr. Swedo explained that academic centers with a history of laboratory and clinical trial research into PANDAS are more likely to have contributed information regarding best practices for diagnosis and treatment as opposed to those centers that do not have clinician-scientists researching PANDAS/PANS.

Advisory council members suggested the following edits to the draft FAQs document (noted by page number, as the questions are not numbered):

- p.1 – Dr. Swedo will provide a correct response to the question, as it is incorrect as written.
- p.2 – Remove the age requirement.
- p.3, second question –Replace “has” with “may have”; include the OCD source link.
- p.4 – Dr. Swedo will edit the response.
- p.5 – Revise the question to “What treatments are commonly used for PANS/PANDAS?” or focus the question on why vs. what. Dr. Walker Harris suggested an introductory response such as, “PANS/PANDAS treatment is so complex it often requires collaboration with a multi-disciplinary team”. Dr. Swedo will provide the response; the approach is three-fold.
- p.8 – Dr. Swedo will provide a response.

In addition to the suggested edits to the draft FAQs document, council members discussed the possibility of developing a PANS/PANDAS action plan for use in schools similar to other medical disorder action plans (i.e. asthma action plan) that are currently used. Members also discussed the possibility of developing a standard checklist for pediatricians to use with PANS/PANDAS patients that will help families provide the child’s history.

Council members also revisited the topic about the establishment of a center of excellence in Virginia. Dr. Swedo shared that Dr. Zhao had previously indicated that there had been no progress on this initiative when she spoke with him about it at the March subcommittee meeting.

Review of the Maryland PANDAS Legislative Report

Ms. Champion stated that she had provided the Maryland PANDAS report to the advisory council to determine if any information included in the report could be used in Virginia’s efforts. Many members agreed that communication strategy contained in the report (pp.9-10) might be useful.

Public comment period

Ms. Sagé Blaska thanked the advisory council for the work that they are doing to address PANS/PANDAS. She shared her family’s experience with various providers and human services agencies. She urged the council to inform and educate the Department of Social Services (DSS, child protective services program) and the Department of Behavioral Health and Developmental Services about PANS/PANDAS and the complexities of treating individuals with these disorders. The PANDAS advisory council will make contact with DSS to present progress and activities of the council to date.

Ms. Arin Barker introduced herself as a representative of the Children's Hospital at VCU and Dr. Wei Zhao. Ms. Barker stated that she understood the frustrations of not having an established center in Virginia and would follow up with Dr. Zhao about the status.

Next steps

Delegate Filler-Corn reviewed the scheduled meeting dates of June 20th and September 23rd to determine if those dates were still good for the majority of the council. No changes were made. Delegate Filler-Corn then polled members to see what dates might work for a November meeting; November 11th and 18th were provided as potential meeting dates. Delegate Filler-Corn will check the General Assembly calendar and provide additional dates to consider. Ms. Robin Buskey will poll subcommittee members to determine a meeting date in May to continue developing the FAQs document.

Adjournment

Delegate Filler-Corn provided closing remarks and thanked council members and guests for their time and participation. The meeting was adjourned at 3:53 p.m.

Appendix F

PANDAS/PANS Advisory Council – Subcommittee Meeting
Focus Area – Outreach to parents and educators
Libbie Mill Library – Conference Room
Monday, May 20, 2019
1:00 p.m. – 3:00 p.m.

Meeting Minutes

Members Present: Ms. Teresa Champion, Ms. Jessica Gavin, Ms. Stefanie Levensalor, Ms. Stacey Link

VDH Staff Present: Ms. Robin Buskey

Welcome and Agenda Overview

Ms. Teresa Champion, subcommittee chair, called the meeting to order and provided an overview of the agenda; the purpose of the meeting was to revise the FAQs document, which will supplement the parents and educators guidance document

Discussion regarding development of PANDAS action plan for schools

Per Ms. Champion's request, Robin Buskey provided sample action plan documents for subcommittee members to review. The documents were retrieved from the Chesterfield County Public Schools website, and they included action plans for general health care, diabetes, life threatening allergies, and asthma. Members reviewed the documents and asked Ms. Stacey Link to explain how the action plans are used in the school to include who develops the action plan and the role of the school nurse, parents/guardians, pediatrician and teachers in communicating and implementing the plan.

Subcommittee members discussed the need for simple instructions for teachers and school nurses to be included like an "Individualized Healthcare Plan" document or including instructions into an IEP or 504 Plan. The instructions would serve as "Cliff Notes" for teachers and school nurses for what to look for in an individual student if they see changes (such as symptoms of OCD and anxiety) and provide guidance on what supports could be put in place. Subcommittee members see this as more of an "Emergency Action Plan" for this diagnosis rather than a "health plan". The subcommittee recognized that school nurses can go to IEP meetings; that should be encouraged as an option to increase parental awareness. Subcommittee members decided that further research is needed and that the discussion would resume at a later date. The balance of the meeting was devoted to revising the FAQs document.

Revisions to the FAQs document

Ms. Buskey shared an updated electronic version of the FAQs document, which included Dr. Sue Swedo's revisions, with subcommittee members in advance of the meeting. Hard copies were provided at the meeting and the document was projected onto the screen for review. The group discussed Dr. Swedo's revisions and expressed concerns that some of the language may be too technical for parents and lay persons unfamiliar with PANS and PANDAS. Ms. Champion made additional edits to the FAQs document throughout the meeting discussion based on group consensus. Ms. Champion planned to send an electronic version of the revised document to Ms. Buskey for distribution to the full committee.

Adjournment

The meeting adjourned at 3:00 p.m.

Appendix G

PANDAS/PANS Advisory Council Meeting

Libbie Mill Library
Thursday, June 20, 2019
1:00 p.m. – 4:00 p.m.

Meeting Minutes

Members Present: Senator George Barker, Delegate Richard Bell, Ms. Teresa Champion, Del. Eileen Filler-Corn, Ms. Jessica Gavin, Dr. David Jaffe, Ms. Stefanie Levensalor, Ms. Stacey Link, Dr. Melissa Nelson, Senator David Suetterlein

Ex Officio Member Present: Dr. Vanessa Walker Harris (Commissioner's designee)

VDH Staff Present: Ms. Robin Buskey

Guests: Ms. Sagé Blaska (Parent), Ms. Arin Barker (Children's Hospital of Richmond at VCU)

Welcome and agenda overview

Delegate Eileen Filler-Corn called the meeting to order at 1:18 p.m. and provided an overview of the meeting agenda.

Review and approval of meeting minutes

Delegate Filler-Corn made a motion to approve the minutes for the April advisory council meeting and the May subcommittee meeting. The meeting minutes were approved by unanimous vote.

Updates and announcements

The following updates and announcements were shared:

- Ms. Teresa Champion provided an update that the autism insurance legislation was signed into law. She thanked everyone for his or her contributions in getting that accomplished.
- Dr. Melissa Nelson shared some feedback from an ENT meeting that she attended at Georgetown University. Some of the ENT specialists who provide care to children with PANDAS/PANS felt that 1/3 were improved; 1/3 had no change; and 1/3 were worse after treatment.
- Ms. Jessica Gavin stated that there is a publication coming out this summer regarding PANS/PANDAS biomarkers.
- Dr. Vanessa Walker Harris provided an update regarding outreach to the Medical Society of Virginia; MSV still has not set a date for the Dean's Forum but will reconnect with VDH once the date is set. She provided an update regarding outreach to the Department of Social Services; there is a meeting scheduled with Carl Ayers in July to discuss the work of the advisory council. Dr. Walker Harris also provided an update regarding the Virginia Mental Health Access Program (VMAP) and shared that there had been a site visit for the HRSA component of the grant. The major pieces of VMAP include:
 - REACH Fellowship program for pediatricians
 - Telehealth/telepsychiatry consultative services
 - Contracts with five academic centers across the state

- DBHDS expansion to include social workers and psychologists
- Ms. Robin Buskey shared that VDH had not received a response from Secretary Thomasson regarding advisory council member reappointments. Delegate Filler-Corn added that she also had not received a status update.
- Senator David Suetterlein suggested that it might be beneficial to get a mention of PANDAS/PANS in some of the many publications (i.e. NCSL) that he receives, even if the mention is via other states.

Review of PANS/PANDAS Evaluation and Treatment Algorithm

Advisory council members reviewed the revised algorithm document that had been formatted by VDH's communications staff. Council members inquired if the VDH logo should be included on the document. Dr. Vanessa Walker Harris agreed to follow up on the request. No other changes were recommended.

Review of PANS/PANDAS Parent and School Guidance Handouts

Advisory council members reviewed the parent and school guidance documents that had been formatted by VDH's communications staff. Council members recommended edits to include removing all references to "CPAE" in both documents, as well as revisions to the list of symptoms and inclusion of www.praikids.org as a support group reference. Ms. Buskey made edits to the electronic version of the documents, which were displayed on the overhead during the meeting. Edits will be provided to communications staff to revise the documents. Ms. Buskey will send the revised documents to the advisory council for review and feedback.

Dr. David Jaffe inquired about the process for making updates to the documents once the advisory council has completed its work in 2020. Dr. Walker Harris advised that the council could recommend a standard schedule for revising the documents. The council should consider what resources should be in place for future review and revision. Senator George Barker suggested that the council recommend a process for obtaining review and recommendation. Ms. Champion added that references and website links would also need to be verified and updated as needed.

Review of Draft Parent and School FAQs Document

Ms. Champion highlighted the revisions that Dr. Susan Swedo and the subcommittee made to the draft FAQs document following the June advisory council meeting. Council members reviewed the revisions. A few minor edits were suggested to include additional reference sources and deletion of the last question regarding abrupt onset. Ms. Buskey made edits directly onto the document, which was displayed on the overhead during the meeting. Council members requested that VDH communications staff format the FAQs document once all revisions are final.

Dr. Jaffe inquired where the FAQs document would be kept. Dr. Walker Harris responded that the document could potentially be maintained within VDH's Division of Child and Family Health as PANS/PANDAS could fit with either the Early Childhood or Children with Special Health Care Needs program.

Dr. Jaffe inquired if the government would provide funding for ongoing expert consultation to update the PANS/PANDAS documents that the council has developed. Dr. Walker Harris stated that council members could recommend that general funds be appropriated to support payment of any consultants. Sen. Suetterlein and Barker then stated that a more likely successful strategy would be for the agency to forward a budget proposal.

Ms. Gavin inquired if it would be acceptable for the FAQs document to be posted on her organization's website, www.praikids.org. Council members agreed that the site would be appropriate. Dr. Walker Harris shared that VDH routinely shares information and FAQs on the agency's website.

Discussion regarding recommendations for educating the judicial system

Ms. Champion informed the group that she asked to include this topic on the agenda because she had become aware of more incidents involving adults who have been diagnosed with PANDAS/PANS coming into contact with law enforcement. She stated that there is a need for education throughout the judicial system. Delegate Filler-Corn described the bill that she introduced in 2018 that would have addressed law enforcement's ability to deal with individuals on the spectrum. The bill did not advance because the Department of Criminal Justice Services (DCJS) had indicated that this work was already in progress. Delegate Filler-Corn stated that she would follow up with DCJS and provide a status update to the advisory council.

Senator Barker described the recent changes that have been implemented for the transport of individuals with temporary detention orders. The state has now contracted with a private contractor to provide transportation services. Drivers that have been trained on how to handle and manage situations involving persons with mental illness will transport them. Law enforcement will be contacted for assistance if needed.

Public comment period

Ms. Sagé Blaska shared her personal experience with law enforcement and the manner in which they treated her son. She stated that she did not think that law enforcement should be transporting or handling children who have a mental illness. Ms. Blaska stated that her recommendation would be for emergency medical transportation (EMT) personnel to transport individuals in those situations. Ms. Blaska also stated that there are silos regarding medical treatment to treat PANDAS/PANS and she thinks it would be beneficial to have the perspective of an immunologist and gastrointestinal specialist on the advisory council. Ms. Blaska also described her family's traumatic experience in dealing with the Department of Social Services (DSS) and the foster care system. She stated that it is important that DCJS and DSS be informed about the disorders that cause certain behaviors.

Next steps

Delegate Filler-Corn asked council members if the scheduled September 23rd meeting date worked for everyone. No changes were made to the meeting date. She then asked council members to suggest a November meeting date. Delegate Filler-Corn asked Ms. Buskey to send out a Doodle poll to determine member availability for November 13th and 18th.

Adjournment

The meeting was adjourned at 3:29 p.m.

Appendix H

PANDAS/PANS Advisory Council Meeting

Glen Allen Library – Large Meeting Room
10501 Staples Mill Road
Glen Allen, VA 23060
Monday, September 23, 2019
12:00 p.m. – 2:30 p.m.

Meeting Minutes

Members Present: Delegate Richard Bell, Ms. Teresa Champion, Del. Eileen Filler-Corn, Dr. David Jaffe, Ms. Stefanie Levensalor, Dr. Melissa Nelson, Dr. Bela Sood, Senator David Suetterlein, Dr. Wei Zhao

Ex Officio Member Present: Dr. Vanessa Walker Harris (Commissioner's designee)

VDH Staff Present: Ms. Robin Buskey

Guests: Ms. Sagé Blaska (Parent), Ms. Arin Barker (Children's Hospital of Richmond at VCU)

Welcome and agenda overview

Delegate Eileen Filler-Corn called the meeting to order at 12:13 p.m. and provided an overview of the meeting agenda.

Review and approval of meeting minutes

Delegate Filler-Corn made a motion to approve the minutes for the June 2019 advisory council meeting. The meeting minutes were approved by unanimous vote.

Updates and announcements

The following updates and announcements were shared:

- Ms. Teresa Champion briefly discussed the article (Journal of AutismOne, 2012) that she forwarded via email to the full council through Ms. Robin Buskey. Ms. Champion distributed copies of the *School Guide for Students with Primary Immunodeficiency Diseases*.
- Dr. Vanessa Walker Harris provided updates:
 - The Governor reappointed all members to the advisory council; Ms. Buskey forwarded the announcement via email 8/19/19.
 - The Medical Society of Virginia informed VDH that due to scheduling difficulties, they had to push the Dean's Forum back to October to take place during the annual conference. Due to the nature of the meeting's agenda, they are unable to invite outside guests to the meeting. They will keep VDH posted regarding the next meeting that will be held in the first half of 2020. They also offered to send out any electronic materials. Dr. Walker Harris shared that VDH applied to have a vendor table at the October meeting; this may be an option for the council to disseminate information in the future.
 - The Virginia Department of Social Services Permanency Advisory Council meeting will be held Wednesday, December 4, 2019 from 10:00 – 3:00 at the Albemarle County

Office Building in Charlottesville. DSS will allot an hour for members of the advisory council to present on PANDAS/PANS. Robin previously reached out to chairs of the three subcommittees to inquire if they would like to present at the meeting. Ms. Champion and Ms. Jessica Gavin confirmed they would like to present at the December meeting. Ms. Buskey was asked to inquire if the meeting will be open to the public.

Review of FAQs layout

Advisory council members reviewed the FAQs document that had been formatted by VDH's communications staff. Senator David Suetterlein suggested that the document text include footnotes and that the sources be placed at the end of the document. Council members agreed that each of the handouts should be cross-referenced. No other changes were recommended.

Discussion of council recommendations for 2019 General Assembly report

Dr. Walker Harris suggested that the council discuss recommendations to include in the 2019 report to the General Assembly to include revisiting the suggestion to establish a Center of Excellence, as well as plans to make the resource materials (algorithm, handouts, FAQs) durable and sustainable over time.

Establish Center of Excellence

Dr. Melissa Nelson expressed concerns regarding the lack of a patient registry and clinical trials and stated that she would like data regarding the number of patients being treated and which treatments are effective. Dr. Nelson suggested that the council invite representatives from UVA, VCU and the Children's Hospital of the King's Daughters to the next advisory committee meeting to include them in a discussion regarding establishing a center in Virginia. After some discussion, the council agreed to invite the deans of the schools of medicine and/or their appropriate designee who is an expert in PANS/PANDAS. Delegate Filler-Corn made a motion to move forward with inviting representatives from the school of medicine to the next meeting. The motion was seconded.

Dr. Walker Harris inquired if anyone knew how much money is required for the maintenance of a center. Dr. Jaffe responded that the Arizona center is self-supporting; he would need to follow up with Dr. Frankovich at the Stanford center to inquire. He added that the proposed Virginia center would be more patient center-oriented and less costly than the centers that are research-based.

Dr. Jaffe asked Dr. Zhao to provide a status update regarding the plans to establish a center following past discussions with Paul Ryan with the PACE Foundation, which helped establish the center in Arizona. Dr. Zhao stated that he worked with others to develop a proposal for a Center of Excellence. He shared that there were plans to meet with leadership of the Children's Hospital of Richmond at VCU but the meeting never occurred. Leadership did not see view the center as a priority. Dr. Zhao stated that it might be a possibility to move the proposal forward through the Children's Hospital Foundation. Dr. Zhao agreed to share the proposal with the council.

Council members discussed the need for a statewide patient registry. Currently, various entities are collecting information but there is not statewide registry. Dr. Jaffe expressed concerns that information is not being shared. He stated that the PANS/PANDAS Consortium is developing a registry. As he recalled, the information will be provided by parents and edited by the providers.

Dr. Bela Sood suggested that the Virginia Mental Health Access Program (VMAP) model could be incorporated in to the proposed Center of Excellence for treating patients with PANS/PANDAS.

Marketing Plan for Resource Materials

Dr. Walker Harris asked the council to review the marketing plan that was provided to the council in the meeting packet. The plan includes suggested strategies for increasing awareness and education of clinicians and for increasing awareness of parents and educators about PANS/PANDAS.

Other Recommendations

Ms. Champion suggested that the council invite representatives from the insurance industry to the next council meeting. Senator Suetterlein expressed concern that about the potential suggestion to push for an insurance mandate, which was specifically precluded from original discussions about the intended work of the advisory council. Ms. Champion stated that she would like to include an insurance recommendation in the report if there is research to support requesting insurance coverage. Delegate Filler-Corn reminded the group that the council is still in the early stages of educating stakeholders about what PANS and PANDAS is.

Public comment period

Ms. Sagé Blaska shared her personal experience in trying to address the Legionella bacteria issue with Chesterfield County Public Schools and her inability to get answers. She also suggested that there needs to be representation of a gastroenterologist on the advisory council to lend expertise to the association between gut bacteria and brain disorders.

Next steps

Delegate Filler-Corn inquired if the November 13th meeting date was still good for everyone. A couple of the members requested to meet on Friday, November 15th instead due to scheduled clinics. Senator Suetterlein requested that the meeting be held at a location near capitol square. Ms. Buskey will send out a Doodle poll for the date change.

Ms. Buskey will follow up with VDSS to inquire if the Permanency Advisory Council meeting will be open to the public.

Ms. Buskey will work with the VDH communications team to incorporate the suggested changes to the FAQs document and to cross reference all documents.

Dr. Zhao will forward the proposal for the Center of Excellence Ms. Buskey to share with the full council.

VDH will send an invitation to deans of the medical schools to attend the next meeting for a discussion on establishing a Center of Excellence.

Ms. Buskey will begin drafting the 2019 report. The draft report will be disseminated to council members prior to the next meeting for review. Council members will edit and finalize recommendations at the next meeting.

Ms. Buskey will research which states have mandated insurance coverage for the treatment of PANS/PANDAS.

Adjournment

The meeting was adjourned at 2:30 p.m.

Appendix I

Suggestions for Marketing PANDAS/PANS Resources

General

- Update VDH web page branding
- Add handouts and FAQs to the web page
- All advisory council members add the web page link to email signatures
- Share materials via email blast with all stakeholders
 - Ask stakeholders to re-share via email blast
- Share information via the agency's social media
- Request that partner agencies (DBHDS, DOE, DSS) include a link to the web page

Algorithm

- Reach out to professional organizations (i.e. Medical Society of Virginia, Virginia Nurses Association, AAP Virginia Chapter, etc.) to request that PANDAS/PANS advisory council host a table or booth to share materials
- Request to speak at scheduled professional organization meetings or conferences
- Request that information about PANDAS/PANS be included in a clinician's letter with the algorithm attachment
- Offer PANDAS/PANS training as part of CME units/professional development for physicians
- Offer PANDAS/PANS training as part of CE units/professional development for nurses

School Handout

- Reach out to professional organizations (i.e. Virginia Association of School Nurses, Virginia Education Association, Virginia Head Start, etc.) to request that PANDAS/PANS advisory council host a table or booth to share materials
- Request to speak at scheduled professional association meetings or conferences
- Include PANDAS/PANS training as part of school nurses' CE units/professional development

Parent Handout

- Reach out to professional associations (i.e. Commonwealth Parenting, Children's Advocacy Center of Virginia, Virginia Statewide Parent Education Coalition, etc.) to request that PANDAS/PANS advisory council host a table or booth to share materials
- Request to speak at scheduled professional association meetings or conferences
- Reach out to other relevant partner agencies (i.e. DSS, DJJ, DBHDS/CSBs, etc.) to request that PANDAS/PANS advisory council speak before stakeholder groups

Appendix J

Discussion Questions re: Proposal to Establish Virginia PANDAS Center of Excellence

1. Should the advisory council recommend establishing a center of excellence at an academic health system? If yes, which model should the council recommend?
 - a. Arizona center of excellence
 - b. Arizona CPAE clinic
 - c. Stanford center/PANS clinic
 - d. VCU hybrid model

2. Is the recommendation to establish a) a statewide hub to receive referrals of all cases from across the state or b) regional centers of excellence as an approach to provide equitable access to specialty care for PANDA/PANS?

3. Who (i.e. academic centers, primary care providers, others) should participate in administering the center of excellence?

4. Should the advisory council recommend general funds be appropriated to support establishing and operating the center? If yes, what amount?

Appendix K – 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 skills, 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

<https://www.pandasppn.org/ppn-pandas-diagnostic-guidelines/>

<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

<https://www.sepans.org/education-packets>

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

Clinical Evaluation of Youth with Pediatric Acute Onset Neuropsychiatric Syndrome (PANS): Recommendations from the 2013 PANS Consensus Conference

<https://www.liebertpub.com/doi/full/10.1089/cap.2014.0084>

⁶ Susan E. Swedo, M.D., Scientist Emerita, National Institute of Mental Health, National Institutes of Health Intramural Research Program

Overview of Treatment of Pediatric Acute-Onset Neuropsychiatric Syndrome

<https://www.liebertpub.com/doi/full/10.1089/cap.2017.0042>

Clinical Management of PANS: Part I—Psychiatric and Behavioral Interventions

<https://www.liebertpub.com/doi/full/10.1089/cap.2016.0145>

Clinical Management of Pediatric Acute-Onset Neuropsychiatric Syndrome: Part II—Use of Immunomodulatory Therapies

<https://www.liebertpub.com/doi/full/10.1089/cap.2016.0148>

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