

**2018 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 1<sup>st</sup> 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 first report was submitted in 2017 and the advisory council has met three times since then. The advisory council established subcommittees, which also met three times in 2018. This document summarizes all of the advisory council's activities for 2018.

## **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.<sup>1</sup> 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).<sup>2</sup> 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.<sup>3</sup>

## **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 includes 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 1<sup>st</sup> 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.

### **Status Report on PANDAS/PANS Advisory Council Activities**

VDH staff coordinated and facilitated three PANDAS/PANS advisory council meetings and three subcommittee meetings between November 2017 and October 2018. Below is a summary of the advisory council's activities over the past year:

**November 2017:** Thirteen advisory council members and four VDH staff were in attendance for the November 27, 2017 meeting. Staff developed and distributed the September meeting minutes, the draft 2017 Report to the General Assembly, and a revised one-year work plan in advance of the meeting. The following is a list of key points discussed at the November meeting:

- Review and approval of September meeting minutes
- Review and approval of Arizona's PANDAS Treatment Model
- Review and comment on the Draft 2017 General Assembly Report
- Revisions to the first year work plan
- Establishment of three council subcommittees to further develop work on three focus areas: practice guidelines for diagnosis and treatment; mechanisms to increase clinical awareness; and outreach to educators and parents (Appendix A)
- Review of remote meeting policy

Full meeting details are included in the November 2017 meeting minutes (Appendix B).

**January 2018:** The first meeting of the subcommittees was held January 16, 2018. Council members of the three subcommittees agreed to meet conjointly. Six subcommittee members and one VDH staff were in attendance; one subcommittee member participated via phone conference call. Committee members deliberated approaches to simplifying the PANDAS and PANS diagnosis and treatment guidelines into a pocket guide. The group then explored ways that the pocket guide, once developed, could be distributed to the large academic universities for feedback. The final product would be disseminated to physicians and clinicians for practice use.

The group discussed the development of a resource for parents and school educators. Full meeting details are included in the meeting minutes (Appendix C).

**April 2018:** Eleven council members and two VDH staff were in attendance for the April 9, 2018 meeting. The council engaged in a planning process to bring external stakeholders to a future advisory council meeting. The purpose of the stakeholder invitation was to inform them of the purpose of the advisory council and to solicit advice and suggestions from various experts to inform the work of the council. The council also reviewed the initial draft of the PANDAS diagnosis and treatment flow chart and provided feedback for revisions. Full meeting details are included in the meeting minutes (Appendix D)

**June 2018:** Thirteen advisory council members, three VDH staff and eight external stakeholders attended the June 18, 2018 meeting. Invited guests were representatives of the following groups or organizations: a parent advocate, Children’s Hospital of Richmond at VCU; Department of Behavioral Health and Developmental Services; UVA Children’s Hospital; Virginia Premier; Department of Medical Assistance Services; Loudoun Community Services Board; and Virginia Department of Education.

The first half of the meeting was dedicated to engaging the invited stakeholders. Dr. Susan Swedo, council member and principal investigator for the National Institute on Mental Health, provided a presentation of an overview of PANS and PANDAS. Dr. Walker Harris, ex officio council member and Director of the Office of Family Health Services at VDH, led a group discussion to obtain feedback on the following points related to PANS and PANDAS recommendations: diagnosis and treatment guidelines currently used; mechanisms for disseminating resources in practice/clinic settings; recommended tools and resources that will provide the greatest reach to increase awareness and education; evidence-based practices for educators and parents; and structuring a network of volunteer experts. A discussion question handout was provided to the group to facilitate the discussion on the four focus areas (Appendix E). Invited guests and council members engaged in productive exchange of ideas and information.

The second half of the meeting focused on general advisory council business. Subcommittee members provided status updates regarding the development of the PANS and PANDAS diagnosis and treatment algorithm (formerly referred to as a flow chart) and parent and school guidance documents. Full details regarding the meeting are included in the meeting minutes (Appendix F).

**August 2018:** Council members of the three subcommittees met conjointly for the August 20, 2018 meeting. Six subcommittee members, one VDH staff and two guests were in attendance; one subcommittee member participated via phone conference call. The purpose of the meeting was to complete final revisions to the draft PANS and PANDAS diagnosis and treatment algorithm and the parent and school guidance documents. The subcommittee completed revisions to the algorithm during the scheduled meeting time. The draft algorithm will be presented to the full council for review and approval. Meeting details are available in the meeting minutes (Appendix G).

**October 2018:** Council members of the subcommittees met conjointly for the October 15, 2018 meeting. Four subcommittee members, two VDH staff and two guests were in attendance. The purpose of the meeting was to complete final revisions to the draft PANS and PANDAS parent and school guidance document. The subcommittee completed revisions within the allotted meeting time. The draft guidance will be presented to the full council for review and approval. Meeting details are available in the meeting minutes (Appendix H).

### **Summary and Future Plans**

The council will continue to develop recommendations on research, diagnosis, treatment and education relating to PANDAS and PANS. The next advisory council meeting is scheduled for Monday, November 26, 2018. Future meeting dates for the 2019 calendar year will be determined at the meeting. Given the timing of the meeting and the status report due date, a summary of the November meeting and the approved minutes will be included in the December 2019 report to the Governor and General Assembly.

### **Recommendations**

- 1) 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.
- 2) 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.
- 3) 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.
- 4) Update the VDH website to include current PANS/PANDAS information.
- 5) Encourage use of the PANDAS Physicians Network through AAP, MSV, child psychiatrists, neurologists, and immunologists to expand the network of PANS/PANDAS providers.
- 6) 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, to:
  - provide treatment for patients with a diagnosis of PANS/PANDAS;
  - disseminate the latest treatment guidelines for clinical care of PANS/PANDAS patients;
  - maintain a network of providers willing to treat patients with a diagnosis of PANS/PANDAS;
  - conduct or oversee clinical research for PANS/PANDAS; and
  - maintain an updated website with outreach to families and other support professionals regarding education and awareness of PANS/PANDAS symptoms, diagnosis and treatment.

### References

<sup>1</sup>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.

<sup>2</sup>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

<sup>3</sup>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.



**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 – November 2017 Meeting Minutes**

PANDAS/PANS Advisory Council Meeting

Libbie Mill Library – Large Meeting Room

Monday, November 27, 2017

1:00 p.m. – 4:00 p.m.

### **Meeting Minutes**

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Legislative Members Present: Del. Eileen Filler-Corn, Del. Roxann Robinson, Senator George Barker, Senator David Suetterlein

Non-Legislative Members Present: Ms. Teresa Champion, Ms. Jessica Gavin, Dr. David Jaffe, Ms. Stefanie Levensalor, Ms. Stacey Link, Dr. Melissa Nelson, Dr. Bela Sood, Dr. Susan Swedo, Dr. Wei Zhao

VDH Staff Present: Ms. Robin Buskey, Mr. Joe Hilbert, Dr. Norman Oliver, Dr. Vanessa Walker Harris

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#### ***Welcome, Introductions and Agenda Overview***

Delegate Eileen Filler-Corn called the meeting to order at 1:11 p.m. Dr. Vanessa Walker Harris provided welcoming remarks and asked that council members re-introduce themselves for the benefit of anyone who did not attend the September council meeting. She then provided an overview of the meeting agenda.

#### ***Review and Approval of September Meeting Minutes***

Delegate Filler-Corn presented a motion to approve the September meeting minutes, which had been provided to all council members for review in advance of the meeting. The meeting minutes were approved by unanimous vote.

#### ***Presentation of Arizona's PANDAS Treatment Model***

Ms. Jessica Gavin provided a presentation on Arizona's clinical model for Children's Postinfectious Autoimmune Encephalopathy (CPAE) disorders. The presentation highlighted estimated statistics regarding PANDAS/PANS prevalence; background information and/or possible explanations for why PANDAS and PANS are not being diagnosed and treated; rationale for why Virginia must act now; and the process and benefits of Arizona's clinical model for CPAE disorders. Ms. Gavin also proposed additional possibilities for the PANDAS advisory council to explore while developing recommendations for the four focus areas.

Council members provided feedback and posed questions following the presentation. Some highlights of the discussion include:

- Illinois is currently the only state that requires insurance coverage for PANDAS; Arizona provides restricted coverage with documentation of need.
- Per Ms. Gavin, under the Arizona model, the primary care physician completes a work-up but is not necessarily making the patient diagnosis. The patient is referred to the clinic and that is where the diagnosis is made. This process can take three weeks to one month.

- Dr. Melissa Nelson shared concerns from a pediatrician's perspective as it relates to protocol, time management and ordering the required tests when providing services to patients who present with symptoms of PANDAS and PANS.
- Dr. Bela Sood acknowledged the issues raised by Dr. Nelson as very good points. She advised that more collaborative care is needed between the primary care physician and the specialist.
- Dr. Walker Harris shared that the Project ECHO model is currently being used in Virginia to address substance abuse and is also used in other areas of the country to address other health issues.
- Dr. Susan Swedo stated that the current protocols/guidelines are not bulleted into a pocket guide but this needs to be done.
- A recommendation to request the creation of billing codes (CPT, ICD) specific to PANDAS/PANS was presented. The pros and cons of making the request at this time was discussed at length. Delegate Robinson advised that revising billing codes is above the council's authority.
- Members discussed the importance of collecting data to differentiate between which patients have PANDAS/PANS and which do not.
- Senator George Barker suggested that the All Payer Claims Database may be used to obtain information on the numbers related to symptoms associated with PANDAS/PANS cases.
- Mr. Joe Hilbert reminded council members about the suggestion to invite various stakeholder groups to come in and share their perspective on the various topics. He also said that it might be beneficial to invite some of the provider groups.
- Dr. Wei Zhao suggested that a PANDAS/PANS summary page is needed. He asked if that should be developed by the PANDAS advisory council or the consortium.
- Council members decided it would be best to form council subcommittees to work on the four focus areas.

### ***Review and Comment on the Draft December Report***

Delegate Filler-Corn asked Dr. Walker Harris to lead the discussion on the draft December report, which was provided to all council members in advance of the meeting. Dr. Walker Harris provided a summary outline of the report and its contents. Council members were asked to provide feedback.

Senator Suetterlein recommended that the final report include the approved council bylaws. Dr. Jaffe recommended that the language in the introductory section of the report, which provides a definition of PANDAS and PANS, be revised to reflect a more comprehensive characterization of the disorders. Dr. Swedo agreed to provide the expanded definition to include a true definition of PANS. Revisions were made to the text of the report during the meeting and presented to the council for approval. Dr. Swedo advised that she would forward the corresponding references for the text revisions to Robin for inclusion in the report. Report revisions to include the council bylaws and the expanded definition were approved by unanimous vote.

### ***Revisions to First Year Work Plan***

Dr. Walker Harris asked council members if there were any recommendations of groups to engage in upcoming council meetings related to the four focus areas.

Ms. Teresa Champion recommended that council members go back to the exploratory list that Ms. Gavin proposed to determine how those action items can fit into the work plan. She also suggested assigning subcommittees to each of the focus areas; subcommittees can then develop agendas with respect to the assigned focus area.

Dr. Swedo reminded everyone that subcommittees of three or more members must have public meeting notices. She also suggested keeping the April meeting as a full council meeting with reserved time for subcommittees.

Council members agreed to form subcommittees for the first three focus areas. The council will resume discussion regarding development of the fourth focus area at a later time. Council members volunteered to form the following subcommittees:

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

Focus area – mechanisms to increase clinical awareness:

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

Focus area – outreach to educators and parents:

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

The motion to accept the work plan with edits related to the subcommittees was approved unanimously.

***Review of Remote Meeting Policy***

Mr. Hilbert reviewed the draft *PANDAS/PANS Advisory Council Remote Meeting Participation Policy*, which was provided in advance of the meeting. He informed the council that the policy was adopted from the remote meeting policy that was drafted for the Virginia Foundation for Healthy Youth.

Mr. Hilbert advised that the subcommittees can develop guidance/questions that can be provided to other agencies and organizations prior to inviting them to the council meetings. He also advised that subcommittees will need to be polled for meeting availability prior to securing a meeting location. A public notice will have to be posted. The motion to approve the council's remote meeting policy was approved unanimously.

***Public Comment Period***

No members of the general public were present for comment.

***Proposed Future Meeting Dates***

Council members discussed the proposed 2018 meeting months included in the work plan. Council members agreed that it would be best to schedule meetings for dates after the 2018 General Assembly session ends. However, subcommittees can schedule meetings prior to the April meeting date as long as public notice is given. The next full advisory council meeting will be scheduled for a date in April 2018.

***Next Steps***

Dr. Swedo will forward references for inclusion in the December report to Robin Buskey. Robin will make final revisions to the report, including appendices, as approved by the council. The final report will be submitted by the December 1, 2017 due date.

Robin will poll subcommittee members for availability to meet in early 2018, prior to the April 2018 full council meeting. A separate meeting poll will also be sent out to council members for June, September and November 2018 meeting dates. Meeting notices will be disseminated and posted based on poll results.

Subcommittees will develop agendas and work plans for their respective focus areas for upcoming meetings. All information will be disseminated to the full committee through designated VDH staff.

Ms. Champion inquired if there is guidance pertaining to the use of social media to disseminate information regarding council meetings, posting pictures of council meetings, etc. among existing networks.

Mr. Hilbert advised that VDH has a Communications Director who provides guidance on all communication for the agency. Ms. Champion stated that she would like to share information about PANDAS. She also recommended that council members provide status updates on any PANDAS/PANS news either at the beginning or end of each meeting in the future.

***Adjournment***

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

## Appendix C – January Meeting Minutes

PANDAS/PANS Advisory Council  
Meeting of the Subcommittees

Libbie Mill Library – Large Meeting Room  
Tuesday, January 16, 2018  
1:00 p.m. – 4:00 p.m.

### Meeting Minutes

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Subcommittee Members Present: Ms. Teresa Champion, Dr. David Jaffe, Ms. Stefanie Levensalor, Ms. Stacey Link, Dr. Melissa Nelson, Dr. Susan Swedo

Ms. Jessica Gavin participated via telephone conference.

VDH Staff Present: Ms. Robin Buskey

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#### *Welcome and Agenda Overview*

Robin Buskey called the meeting to order and informed the group that Ms. Jessica Gavin had called that morning to inform her that she would not be able to attend the meeting in-person due to illness and requested to participate via telephone conference. Ms. Gavin was conferenced into the meeting. Ms. Buskey provided an overview of the meeting agenda. Committee members agreed to meet in the order of the prepared agenda versus meeting concurrently by subcommittee topic area so that all members could participate in the full discussion of each topic.

#### *Focus Areas: Practice guidelines for diagnosis and treatment*

Committee members discussed possible approaches to systematizing and simplifying the guidelines into pocket guides that can then be distributed among providers. Dr. Susan Swedo suggested that VDH could help with development of the pocket guidelines. Dr. Melissa Nelson volunteered to make a checklist and create a flowchart of the discussion for the pocket guide. Key points raised by committee members included the following:

- Which tests will be ordered as standard?
- In addition to *what* tests to order, determine what is low, what is high and what is expected on the test results.
- What are the most relevant history questions (lab results do not make or exclude the diagnosis)?
- Target the top three symptoms for treatment.
- What defines abrupt onset?
- How does one know when he/she should continue to consider PANS?
- What antibiotics are prescribed? What dosage and for how long?
- When is follow up after the start of treatment?
- What happens if there is a relapse?
- What other tests, such as EKG, are performed?
- Use of antidepressants and cognitive behavioral therapy as treatment options
- What is the biology of the family?

- Can development of the pocket guide be considered creating a standard of care? Committee members think there needs to be legal approval so that they are not liable.

Dr. Swedo and Dr. David Jaffe described the Arizona model, of which Dr. Nelson drew a diagram on the white board. Dr. Jaffe stated that he has a whole PowerPoint presentation on the Arizona model that can be shared with the full council. Dr. Swedo stated that she visited Arizona four times; they are well coordinated and have the ability to call in whomever (pediatrician, psychiatrist, etc.) they need for service provision. The goal is to have all services in place once the child is at the center. Dr. Swedo stated that the cystic fibrosis model was the source used for other models.

***Focus Areas: Mechanisms to increase clinical awareness***

Ms. Teresa Champion stated that there must be a systematic education of physicians in the five regions of the state. Other members agreed that it would be necessary to have the large education universities on board this process. Once the pocket guide is developed, it will need to be shared with the universities to get their feedback; that feedback should be incorporated into final development of the guide.

Ms. Champion shared information gathered from her research on the *UpToDate* resource used by physicians. She stated the importance of ensuring that the resource is updated with all of the most recent studies related to PANS and PANDAS because physicians reference that resource when providing an explanation about them not being valid disorders. Based on her research, she found that there are one or two people running *UpToDate*. Dr. Swedo stated that NIMH would look into providing updates to the resource.

***Focus Areas: Outreach to educators and parents***

Ms. Stefanie Levensalor shared her family's personal experience in dealing with PANDAS. She volunteered to draft an outline of an action plan that describes what helped them navigate through the school. Committee members thought that would be helpful. Dr. Swedo stated that schools need a comparable pocket guide. Committee members discussed the disparities that exist across and within school divisions; many schools lack adequate resources and some have nursing staff that are available less on a part-time basis only, if that.

Ms. Nelson inquired about implementation of the pocket guide. She stated that she had previously asked Mr. Joe Hilbert if in fact the council can implement this and would like more clarification. Ms. Buskey stated that the role of the advisory council is to advise the health commissioner on the council's recommendations regarding the four focus areas. Ms. Buskey also stated that she would follow up with Mr. Hilbert regarding implementation.

***Public Comment Period***

No members of the public were present for the subcommittee meetings.

Committee members discussed efforts around developing a Center of Excellence in Virginia. Ms. Gavin stated she would initiate an invitation for someone to come speak to the advisory council to provide an update on this initiative. Members conferred about what is needed to move this effort forward. There is some cost information available through the PANDAS Network. There is also money available through the General Assembly for the Virginia Neuroscience Initiative, which encourages hospitals to work together.

Ms. Champion asked if any of the committee members were aware of Governor Northam's position on PANDAS and PANS. Members discussed the possibility of sending an introductory letter from the advisory council through VDH.

Dr. Nelson stated that she would send the draft checklist/flow chart of the pocket guide to Ms. Buskey to disseminate to the full council.

***Adjournment***

Ms. Buskey provided closing remarks and thanked the committee members for their time. Committee members agreed that it had been a productive meeting. The meeting adjourned at 4:00 p.m.



## Appendix D – April 2018 Meeting Minutes

### PANDAS/PANS Advisory Council Meeting

Varina Library – Large Meeting Room  
Monday, April 9, 2018  
1:00 p.m. – 4:00 p.m.

### Meeting Minutes

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Legislative Members Present: Del. Eileen Filler-Corn, Senator George Barker, Senator David Suetterlein,

Ex Officio Member Present: Dr. Vanessa Walker Harris

Non-Legislative Members Present: Ms. Teresa Champion, Ms. Jessica Gavin, Dr. David Jaffe, Ms. Stefanie Levensalor, Dr. Melissa Nelson, Dr. Bela Sood, Dr. Susan Swedo, Dr. Wei Zhao

VDH Staff Present: Ms. Robin Buskey

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#### *Welcome and agenda overview*

Delegate Eileen Filler-Corn called the meeting to order at 1:15 p.m. Dr. Vanessa Walker Harris provided welcoming remarks and an overview of the meeting agenda. Dr. Swedo introduced Jessica Vaughan, NIMH clinician, who accompanied her to the meeting.

#### *PANDAS/PANS updates and announcements*

Council members provided updates regarding recent PANDAS/PANS activities and events. Some members shared highlights from the conference, *Common Threads among Post-Infectious Autoimmune Diseases of the Brain*, which was held in March 2018 at Columbia University Medical Center. Dr. Susan Swedo presented at the conference. There are YouTube videos of some of the conference presentations available online.

Dr. David Jaffe shared an update regarding a study that is currently in progress. The use of PET scans will show where the brain is most and least active. Members discussed PANDAS and PANS work that is being conducted outside of the U.S. There was a general consensus that there is little to no controversy about the disorder in Europe; however, there is continued opposition regarding the existence of the disorder in the U.S.

Dr. Swedo announced that the draft beta ICD 11 has a code with updated diagnostic criteria that should be narrow enough for the PANDAS diagnosis.

#### *Review and approval of November meeting minutes*

Delegate Filler-Corn presented a motion to approve the November 2017 meeting minutes, which had been provided to all council member for review in advance of the meeting. Dr. David Jaffe requested that the minutes be amended to reflect inclusion of his name on the subcommittee that is working on the practice guidelines for diagnosis and treatment. The motion to approve the amended minutes was approved by unanimous vote.

***Review and approval of January meeting minutes***

Delegate Filler-Corn presented a motion to approve the January 2018 meeting minutes, which had been provided to all council member for review in advance of the meeting. The meeting minutes were approved by unanimous vote.

Senator David Suetterlein inquired if any feedback had been received regarding the final report since its submission to the General Assembly. Dr. Vanessa Walker Harris confirmed that the Virginia Department of Health had not received any comments or feedback from the Secretary of Health and Human Resources.

***Discussion of plans to invite external groups to future meetings***

Dr. Melissa Nelson inquired if the council subcommittee develops a tool to educate others, whose role is it to educate? Dr. Walker Harris informed the council that she had consulted with Deputy Commissioner Norman Oliver regarding the previous inquiry related to implementation. Dr. Oliver confirmed to Dr. Walker Harris that the role of the advisory council is to provide recommendations to the Health Commissioner. It will not be the role of the advisory council to implement; however, the council can include a rollout plan in the recommendations.

Council members discussed the purpose of inviting external groups. Dr. Bela Sood stated that external groups would be invited to provide feedback. Ms. Teresa Champion stated that the advisory council should invite the groups from which they will need action so that they can learn about who is on the council and what the council is doing. Members discussed potential groups to invite, as well as the pros and cons of presenting an actual product to the external groups to obtain feedback. Some highlights of the discussion include:

- The council should provide a general overview of PANDAS/PANS and advisory council activities without a product; allow external groups to provide feedback on what type of product should be developed and what to include.
- What would the Virginia Chapter of the AAP need in order to push information? Who should approach the AAP and Dr. Colleen Kraft? Should it be Dr. Nelson? Dr. Sood has a relationship with Dr. Kraft.
- Will the groups come to the advisory council or will the council go out to the groups?
- Dr. Jaffe suggested that an alternative to having an in-person meeting would be for the council to provide a webinar presentation followed by a chat with ZOOM technology. Dr. Nelson suggested that YouTube is another format that can be used. Senator George Barker suggested that a combination of both in-person and web-based approaches can be used.
- Who are the thought leaders? Can the council send a survey (i.e. Survey Monkey) to the medical providers of children to gauge who they deem are the thought leaders on this issue? Are the thought leaders already on the council?
- Ms. Jessica Gavin agreed to draft a list of invitees. Delegate Filler-Corn stated that the purpose of the invite is to reiterate the purpose of the PANDAS/PANS advisory council and to solicit advice and suggestions from the experts. If the identified experts cannot attend, they can send someone else on their behalf.
- Delegate Filler-Corn and Senator Suetterlein agreed to obtain a response from the Governor's office regarding his position on PANDAS and PANS.

### ***Structure of subcommittees***

Delegate Filler-Corn asked council members if they wanted to keep the current structure of the subcommittees. There was some discussion about who would work on the invitation list for the upcoming meeting; however, no definitive feedback was provided regarding the structure of the subcommittees in terms of meeting frequency, agendas, etc.

### ***PANDAS flow chart***

Dr. Nelson provided a draft of the flow chart for PANDAS diagnosis prior to the meeting. Members provided feedback on the draft to include the following:

- the final product will need a graphic; it will need to look slicker and cleaner
- include a definition at the very top of the flow chart
- include references (Dr. Swedo will add those and will expand the diagnosis)
- include an asterisk for the labs that are required
- the psychiatric component needs to be added

### ***PANDAS Physician Network (PPN) resources***

Ms. Teresa Champion shared two resources that were developed by the PPN. Electronic versions of the trifold and index card were provided prior to the meeting; Ms. Champion also provided hard copy versions during the meeting. Ms. Champion indicated that she thought both tools are good examples of what should be included on the guidance tool that will be recommended by the council. Dr. Swedo stated that the trifold needs to be revised.

Ms. Stefanie Levensalor informed the council that she had developed a draft resource targeting parents. She distributed the resource among council members.

### ***UpToDate resource***

Ms. Champion discussed the email communication that was sent by her husband to representatives responsible for the *UpToDate* resource. The email communication had been sent to council members in advance of the meeting. In summary, the *UpToDate* resource does not include relevant and/or recent PANDAS/PANS studies that have been conducted. Ms. Champion inquired of Dr. Swedo if her staff had made any progress with *UpToDate*. Dr. Swedo responded that they have not made any progress given staff capacity and other priorities; however, they intend to follow up on this issue.

Ms. Champion suggested the possibility of the advisory council drafting a letter to *UpToDate*. She asked if the council has the authority to do so. Dr. Walker Harris responded that this could be included in the recommendations to the Health Commissioner. Ms. Champion affirmed that she would like to make this recommendation. She would also like Dr. Swedo to follow up with the advisory council regarding any feedback that she and/or her team receives from *UpToDate* representatives.

### ***Additional PANDAS/PANS updates***

Ms. Champion discussed the issue of medical facilities that are unwilling to admit and/or treat individuals. She shared that her family has experienced this with her son, who has autism. She would like to know what the requirement is for nonprofit hospitals in terms of what they do in their communities and for certain populations. What do they do with regard to the medical needs of certain populations? She would like to include in the recommendations to the Health Commissioner a requirement that all 501c3 hospitals in Virginia make provisions for PANDAS and PANS.

Dr. Walker Harris responded that is a reasonable request to ask/recommend that hospitals include PANDAS and PANS, as well as the capacity to treat the disorders, in the data collection as part of the broader community health needs assessment. Currently, local health districts are planning community health assessments so that they are coordinated with the community health system needs assessment. In the recommendation, specific data sources could be suggested. Ms. Champion affirmed that she would like to include the recommendation as an action item for later.

Senator Barker inquired if there is an estimate of the number of PANDAS/PANS diagnosis in Virginia. Dr. Swedo provided data on the prevalence of PANDAS/PANS. Diagnosis of the disorder is linked to symptoms; there is no specific PANDAS diagnosis code.

### ***Public comment period***

No members of the general public were present for comment.

### ***Next Steps***

The next meeting is Monday, June 18, 2018 from 1:00 – 4:00 p.m. Per Senator Suetterlein's request, the meeting will be held near capitol square to accommodate legislative members who have other meetings adjacent to the advisory council meeting. The June meeting will include individuals from external groups.

Dr. Swedo will send comments regarding the algorithm to Robin.

Council members agreed to change the date for the November meeting. The advisory council meeting is now scheduled for Monday, November 26, 2018 from 1:00 – 4:00 p.m.

### ***Adjournment***

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

## Appendix E – June 2018 Meeting Discussion Question Handout

### Discussion Points

1. The council is developing an algorithm/flow chart for clinicians to use in the diagnosis and treatment of PANDAS/PANS and would like input on the approach. Are you currently using guidelines for the diagnosis and treatment of PANDAS/PANS?
  - a. What guidelines do you currently use?
  - b. How do you access the guidelines?
  - c. What do you like or dislike about the resources that you are currently using?
  - d. What modalities of dissemination would facilitate use of the aforementioned algorithm or similar resource in your practice/clinic setting?
  - e. What mechanisms would be most effective for broad distribution of a resource tool to clinicians for use in their practice?
  
2. What tools and resources can provide the greatest reach for increasing clinical awareness and education among physicians, including pediatricians, providers of mental health services, infectious disease specialists, etc.?
  - a. Are there existing tools and resources (i.e. SAM for MOC, conferences/webinar platforms, ECHO, etc.) that can be expanded upon to include PANDAS/PANS?
  - b. What new products should be developed?
  - c. What existing channels can be utilized to promote clinical awareness and education?
  - d. What other stakeholder organizations should be included in outreach?
  
3. Which evidence-based practices are most effective in providing outreach to the targeted groups to increase awareness of PANDAS/PANS?
  - a. Educators
  - b. Parents
  
4. In thinking about a statewide network of volunteer experts on PANDAS/PANS who assist in the delivery of education and outreach, who should be included?

How should such a network be structured and how should it function?

## Appendix F – June 2018 Meeting Minutes

### PANS/PANDAS Advisory Council Meeting

State Capitol Building – House Room 3  
Monday, June 18, 2018  
1:00 p.m. – 4:00 p.m.

#### Meeting Minutes

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Members Present: Senator George Barker, Ms. Teresa Champion, Del. Eileen Filler-Corn, Ms. Jessica Gavin, Dr. David Jaffe, Ms. Stefanie Levensalor, Ms. Stacey Link, Dr. Melissa Nelson, Del. Roxann Robinson, Dr. Bela Sood, Dr. Susan Swedo, Senator David Suetterlein, Dr. Wei Zhao

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. Jan Kirby (Children's Hospital of Richmond at VCU), Ms. Holly Mortlock (Department of Behavioral Health and Developmental Services), Dr. James Nataro (UVA Children's Hospital), Dr. Helen Ragazzi (Virginia Premier), Dr. Kathleen Sardegne (Department of Medical Assistance Services), Ms. Johanna Van Doren-Jackson (Loudoun CSB), Ms. Tracy White (Virginia Department of Education)

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#### *Welcome and agenda overview*

Delegate Eileen Filler-Corn called the meeting to order at 1:13 p.m. Dr. Vanessa Walker Harris provided welcoming remarks and an overview of the meeting agenda. Dr. Walker Harris then introduced Dr. Susan Swedo, council member and principal investigator for the National Institute on Mental Health.

#### *Overview of PANS/PANDAS*

Dr. Swedo provided a slide presentation of an overview of PANS and PANDAS for the benefit of all invited guests.

#### *Introductions and background of PANS/PANDAS advisory council*

At the conclusion of the presentation, Del. Eileen Filler-Corn thanked the invited guests for attending the meeting before introducing herself and asked that council members give a brief introduction to include name, title and affiliate organization. Del. Filler-Corn then asked the invited guests to introduce themselves to the council.

Dr. Walker Harris provided a brief explanation of HB2404, which established the advisory council during the 2017 General Assembly Session. A copy of the legislation was provided in the meeting handouts. Dr. Walker Harris reviewed the purpose of the advisory council, which is to provide recommendations to the state health commissioner on the four focus areas regarding PANS and PANDAS:

- Practice guidelines for diagnosis and treatment
- Mechanisms to increase clinical awareness and education
- Outreach to educators and parents

- Development of a network of volunteer experts

The council must provide an annual report to the Governor and the General Assembly December 1<sup>st</sup>.  
HB2404 sunsets on July 1, 2020.

Dr. Walker Harris then reviewed a summary list of council activities accomplished within the first nine months. A handout of the council's timeline and activities was provided. Dr. Walker Harris also acknowledged the time and effort that had been devoted to PANS and PANDAS activities prior to formal establishment of the council.

Dr. Walker Harris thanked the invited guests for attending and restated the intent of from the meeting invitation -- to obtain feedback from external guests to help inform development of the recommendations that the council will provide to the state health commissioner. She then directed everyone's attention to the discussion questions handout. Dr. Walker Harris initiated the discussion with guided questions to the invited guests. Some key highlights from the discussion include:

Practice guidelines for diagnosis and treatment:

- Dr. Melissa Nelson shared her concerns about what she is currently seeing in her own practice. There is an increased awareness of PANS and PANDAS among parents. There are more children seeking treatment for mental health and more presenting with PANDAS. Parents want immediate help for their children. She has nowhere to send parents for education. She does not think her patients are getting any better.
- Dr. David Jaffe offered that there are existing resources for parents to include the PANDAS Physician Network and research articles on the internet. He stated that while there is currently no gold standard for therapy, in the interim, there are things that providers can do.
- Ms. Sagé Blaska, parent of a child with PANDAS, stated that she initially learned of the disorder through a school nurse in Chesterfield County Public Schools. Her child was tested for strep and was treated with antibiotics. She was told that VCU did not believe in PANDAS and she was not given a referral to a specialist. She also learned that many health professionals (psychiatrists, ER doctors) do not support PANDAS.
- Dr. James Nataro, Chair at UVA Children's Hospital, stated that treatment or therapy is a shared decision between the physician and patient. The physician should be competent, knowledgeable, committed and able to communicate the risk/benefit to the patient. Treatment of antibiotics is not outside the standard for treating PANDAS; pediatricians would then refer the patient to a neurologist. It is up to the provider to make a recommendation.
- Dr. Nataro also shared comments regarding Dr. Swedo's presentation. He stated that Dr. Singer is well respected and has a reputation that he is disinterested. He stated that there is a need for research beyond anecdotal evidence. The research needs to be supported. The studies need to be seen as reputable and performed by those who are disinterested.
- Dr. Swedo shared that Dr. Singer has co-authored anti-PANDAS articles and has said that the disorder does not exist. He and other doctors are treating tic disorders. She agreed that the investigators need to be squeaky clean and not have conflicts of interest.
- Dr. Jaffe agreed with Dr. Nataro and Dr. Swedo that research is the way to move forward. He suggested that Dr. Nataro speak with Ms. Jessica Gavin to get others included in the studies.
- Dr. Wei Zhao stated that his practice currently refers to the three publication guidelines when diagnosing and treating PANS/PANDAS. More objective evidence is needed.

Mechanisms to increase clinical awareness:

- Dr. Zhao indicated that the publication articles re: the PANS/PANDAS guidelines should be used to increase awareness.

- Ms. Stefanie Levensalor stated that pediatricians should be knowledgeable about the diagnostic guidelines then move from there.
- Dr. Bela Sood stated there should be a clearinghouse for resources.

Outreach to parents and educators:

- Ms. Johanna Van Doren-Jackson, representative from Loudoun Community Services Board (CSB), shared that the practitioners see that there is something going on with children. They refer children back to the medical community but the CSB does not refuse to treat them. There may be existing issues that are related. There should be cautious and careful information shared with the parents. There needs to be an ongoing conversation; we do not want to be behind the curve on new data and research. At the same time, parents should not be given false hope.
- Ms. Blaska (parent guest) stated that she has been connected to Ms. Jessica Gavin's group and other social media groups related to PANS/PANDAS. She has not been able to get help or information from the medical community. Research is needed because many doctors are not trained to treat the disorder. She has tried to explore how to pay for the doctors who are experts in this area. She would like to be able to contact groups that have information on clinical trials.
- Dr. Swedo stated that in treating PANS/PANDAS patients, the therapist is involved with educating the parents.
- Ms. Tracy White, representative from the Virginia Department of Education (DOE), stated that there needed to be collaboration among interdisciplinary professionals in the schools (nurse, psychologist, social worker). These staff need to be trained so that they can provide information to the families. They serve as intermediaries. School nurses are valuable resources. Information is also shared through the PTA. DOE is open to training to serve on an interdisciplinary team. There need to be strategies in place for how to handle children; there should be people in place to provide a "warm handoff". It will take everyone to provide feedback on how school nurses and staff can best undergird this issue.
- Dr. Nelson stated that pediatricians also need training in this area of developmental behavior. She feels that she and many of her colleagues would not know what to say to a school nurse, as they are not mental health experts.
- Ms. Jan Kirby, patient advocate at the Children's Hospital at VCU, stated that there is a lot of talk about PANS and PANDAS but not a lot of forward movement or collaboration on it. They receive many families that are self-referred. The Arizona Treatment Center of Excellence has a process in place. Virginia needs a process; we should look at developing the process from what is already in place. She also recommended that the topic of PANDAS could be included as a topic at the conferences for school nurses.
- Ms. Blaska inquired where cognitive behavior therapy fits into the discussion. She stated there needs to be a bridge for getting the information to people who are currently in crisis.
- Dr. Sood acknowledged that there is an access issue. She also stated that there should be practical resources for pediatricians. Pediatricians should be able to connect with a psychiatrist.

Senator David Suetterlein inquired if there has been any response from the administration regarding the PANDAS annual report that was submitted last December or anything to do with the PANDAS advisory council in general. Dr. Walker Harris responded that children's health is a specific area of priority with the administration and that Dr. Norman Oliver, state health commissioner, has shared the work of the council with the administration. Mr. Joe Hilbert, VDH deputy commissioner, added that the administration is updated regularly and VDH will continue to feed information to the Secretary's office as it is received. Delegate Filler-Corn stated that she had spoken briefly with Governor Northam about the PANDAS advisory council.



### ***Break***

Dr. Walker Harris informed invited guests that the council would break for ten minutes before resuming regular council business. She thanked guests for their participation and providing valuable feedback. She recognized that some guests may need to leave during the break and welcomed those who wished to stay to do so.

### ***Review and approval of April meeting minutes***

Delegate Filler-Corn made a motion to approve the April meeting minutes, which had been provided to all advisory council members for review in advance of the meeting. The meeting minutes were approved by unanimous vote.

### ***Updates and announcements***

#### Status of draft diagnosis/treatment algorithm:

In response to the comments that Dr. Sood provided to the algorithm, Dr. Nelson asked if the psychiatry consult should happen early. Dr. Sood affirmed that the behavioral piece will help early on in the process. Dr. Swedo stated that she agreed completely with having the psychiatry consult explicitly and implicitly stated in the algorithm. She also added that the algorithm is starting to fail as a pocket guide and cannot be all things. Dr. Walker Harris asked if the plan is to continue to revise the algorithm until it is final. Council members agreed that further revision is needed. Dr. Walker Harris stated the Ms. Robin Buskey would poll the physician group (subcommittee) to provide dates for a meeting to complete the revisions to the algorithm.

#### UpToDate resource:

Dr. Swedo stated that she had made the protest regarding the *UpToDate* resource. No further work has been done on this effort. The response from UpToDate is that they have reputable studies and articles included. Dr. Swedo stated that she would get one of her colleagues to continue with this effort; right now, they do not have the resources to make this a priority.

#### Draft parent resource feedback:

Ms. Levensalor stated that she received input from school nurses and staff to develop some parts of the guide. She would like other resources that can be included in the guide. Dr. Swedo offered that she can provide additional resources for inclusion. Dr. Nelson stated that the parent guide is a great resource.

#### Announcements:

Dr. Swedo shared that 20/20 is supposed to air a special on PANS/PANDAS. Ms. Champion shared that the *Brain on Fire* movie is now on Netflix.

### ***Public comment period***

Ms. Blaska stated that she wanted to thank the council for the work they are doing. When asked by Dr. Nelson what advice she would give to pediatricians, Ms. Blaska stated that the doctors need to listen to the parents; they are the best source to know when there are outliers. The public comment period ran from 3:52 – 3:54 p.m.

*Adjournment*

Delegate Filler-Corn asked for confirmation of the next meeting date. Ms. Buskey confirmed that members agreed at the April meeting to change the November meeting date to Monday, November 26, 2018 from 1:00 – 4:00 p.m. 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 G – August 2018 Meeting Minutes

PANDAS/PANS Advisory Council  
Meeting of the Subcommittees

Libbie Mill Library – Conference Room  
Monday, August 20, 2018  
1:00 – 4:00 p.m.

### Meeting Minutes

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Subcommittee Members Present: Ms. Teresa Champion, Ms. Stacey Link, Dr. Melissa Nelson, Dr. Bela Sood, Dr. Susan Swedo, Dr. Wei Zhao

By phone: Ms. Stefanie Levensalor

VDH Staff Present: Ms. Robin Buskey

Guests: Ms. Sagé Blaska, Mr. Jason Schiller

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#### *Welcome and Agenda Overview*

Robin Buskey called the meeting to order and informed the group that Ms. Stefanie Levensalor had requested participation by phone, as she was unable to travel due to immediate work commitments. Ms. Buskey provided an overview of the meeting agenda. The purpose of the meeting was to finalize revisions to the PANS/PANDAS algorithm and parent and school guidance documents.

Two members of the public were present. Ms. Sagé Blaska and Mr. Jason Schiller introduced themselves as parents. Ms. Blaska and Mr. Schiller had obtained copies of the draft working documents and attended the meeting intending to provide feedback on the final revisions. Ms. Buskey asked committee members to determine whether Ms. Blaska and Mr. Schiller could actively participate throughout the meeting. Committee members allowed their participation.

#### *Revisions to the PANS/PANDAS Diagnosis and Treatment Algorithm*

Ms. Robin Buskey had provided committee members with an electronic copy of the most recent version of the algorithm, as edited by council members, prior to the meeting. Hard copies of the document were also provided at the meeting. Mr. Schiller announced that he had a more updated version of the algorithm from which to make the final revisions. Committee members determined that the draft version provided by Ms. Buskey would remain the official working document from which all changes would be made. The draft document was placed on the overhead screen and all edits to the draft algorithm were made directly in the documents during the meeting.

Key points raised by committee members included the following:

- What are the “mays” vs. what are the “musts”? Will need to determine which labs are definitely needed in the flowchart.
- Dr. Swedo will expand her organization’s website to include the labs that are absolutely necessary and those that are not.

- Dr. Swedo will send the web link to the FAQs to Ms. Buskey for inclusion in the algorithm document.
- Is the flowchart on the PPN website helpful?
- Where on the algorithm can there be a mention of autism?
- What are the points where parents experience the most distress?

### ***Revisions to the PANDAS Parent and School Guidance***

Ms. Robin Buskey had provided committee members with an electronic copy of the most recent version of the parent and school guidance document, originally drafted by Ms. Stefanie Levensalor and edited by council members, prior to the meeting. Hard copies of the document were also provided at the meeting.

Ms. Teresa Champion distributed a handout that had been developed by the PANDAS Network. She inquired if it might be useful to adopt the resource that had already been developed for families and schools rather than reinventing the wheel.

Key points raised by committee members included the following:

- Cause is very PANDAS specific, but not PANS; it might be helpful to lead off with definitions of the two to show how they are different.
- The guidance document is more helpful with what parents need to know and is more user-friendly; recommend continue with needed revisions as agreed by the full council.
- The document should incorporate what the “newbie” needs to know.
- What is the desired outcome of the guidance document? That is what should be included, keeping in mind that it is one page.
- It is helpful for the guidance document to include “what to do”.

Due to time constraints, the committee was unable to make the edits the parent and school guidance document.

### ***Adjournment***

Ms. Buskey provided closing remarks and thanked the committee members for their time. She stated that she would arrange a follow-up committee meeting to complete the final revisions to the guidance document. The meeting adjourned at 4:00 p.m.

## Appendix H – October 2018 Meeting Minutes

PANDAS/PANS Advisory Council  
Meeting of the Subcommittees

Libbie Mill Library – Conference Room  
Monday, October 15, 2018  
10:00 a.m. – 12:00 p.m.

### Meeting Minutes

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Subcommittee Members Present: Ms. Teresa Champion, Ms. Jessica Gavin, Ms. Stefanie Levensalor, Dr. Bela Sood

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

VDH Staff Present: Ms. Robin Buskey

Guests: Ms. Sagé Blaska, Mr. Jason Schiller

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#### *Welcome and Agenda Overview*

Robin Buskey called the meeting to order and reviewed the meeting agenda. The purpose of the meeting was to finalize revisions to the PANDAS parent and school guidance documents. A motion to approve the meeting agenda was approved. Ms. Buskey stated that the public comment period, which informs the work of the group, was placed upfront on the agenda so that any feedback or information received from the public that might influence the working document could be considered.

#### *Public Comment Period*

Ms. Sagé Blaska shared comments related to the following: 1) concern that the reference to autism was removed from the algorithm document; 2) determination of where ASO titers should reside on the algorithm because it is good to have a baseline measure; and 3) if there will be any focus by the advisory council on mandating that insurance covers PANS and PANDAS.

Mr. Jason Schiller shared comments regarding the inclusion of other criteria for diagnosing PANDAS and PANS; he had made prior recommendations for references that he found while scouring the internet. Mr. Schiller stated that the documents are incomplete. A distinction of PANDAS and PANS should be included in the document. Mr. Schiller further suggested that the development of a resource list include summary information in addition to the web links.

Dr. Walker Harris advised that insurance mandates were outside the scope of what the council was specifically charged to do. However, council recommendations to the Health Commissioner can broadly relate to the four focus areas. The committee considered public comments and feedback when revising the guidance document during the working session of the meeting.

#### *Revisions to the PANDAS Parent and School Guidance*

Committee members discussed developing an FAQs document as an accompaniment to the parent and school guidance document because including all of the relevant resources would be too lengthy for the

one-page document. Committee members agreed that the FAQs document should include a summary of the web links.

Key points raised by committee members included the following:

- When taking the prescriptive view, all information does not make its way to into the one-page document.
- The document should speak to practice patterns.
- The guidance document should not include references to ASO titers.
- An outside group should review the documents; should also obtain feedback from parents and educators on the FAQs document.
- The FAQs should be linked to the parent and school guidance document; include a web link on the FAQs.
- The committee will develop a Google Doc for the FAQs; would like to get input from other people regarding the questions to include.

Committee members determined final revisions to the parent and school guidance document. Ms. Buskey made all edits directly to the document, which was displayed on the overhead screen.

### *Adjournment*

The meeting adjourned at 11:50 a.m.