

PANDAS/PANS Advisory Council Meeting

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

Meeting Minutes

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

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.