

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

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

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 member 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.