

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

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

Meeting Minutes

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

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

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

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

Call to Order

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

Welcome and Introduction of New Members

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

Agenda Overview

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

Election of Chair and Vice Chair

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

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

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

Review and approval of November 2019 meeting minutes

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

Overview of PANDAS Advisory Council

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

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

Advisory Council Updates

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

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

Public comment period

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

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

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

- Disseminate the PANDAS resources through VDH to stakeholder organizations as outlined in the 2019 report recommendations; expand to other entities as appropriate.
- Educate other state agencies and law enforcement about PANDAS/PANS; disseminate resource materials to law enforcement agencies.
- Continue previous discussions to push for insurance coverage for treatment of PANDAS/PANS.
 - Address the issue of insurance as it relates to essential health benefits in Virginia in order to gain widespread coverage
- Reach out to PANDAS/PANS organizations external to Virginia (Arizona, California) to have experts provide education in Virginia.
- Propose PANDAS/PANS as a requirement for continuing medical education units.
- Promote upcoming PANDAS/PANS conferences throughout the PANDAS advisory council member network; research and develop a list of upcoming conferences and events.

- The Foundation for Children with Neuroimmune Disorders Conference is May 13-14, 2021.

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

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

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

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

Next Steps

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

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

Adjournment

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