

PANDAS/PANS Advisory Council Meeting

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

Meeting Minutes

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

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

VDH Staff Present: Ms. Robin Buskey

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

Welcome and agenda overview

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

Review and approval of meeting minutes

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

Updates and announcements

The following updates and announcements were shared:

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

council to present on PANDAS/PANS. Robin previously reached out to chairs of the three subcommittees to inquire if they would like to present at the meeting. Ms. Champion and Ms. Jessica Gavin confirmed they would like to present at the December meeting. Ms. Buskey was asked to inquire if the meeting will be open to the public.

Review of FAQs layout

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

Discussion of council recommendations for 2019 General Assembly report

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

Establish Center of Excellence

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

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

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

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

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

Marketing Plan for Resource Materials

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

Other Recommendations

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

Public comment period

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

Next steps

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

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

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

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

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

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

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

Adjournment

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