

PANS/PANDAS Advisory Council Meeting

Libbie Mill Library
Monday, April 8, 2019
1:00 p.m. – 4:00 p.m.

Meeting Minutes

Members Present: Senator George Barker, Delegate Richard Bell, Ms. Teresa Champion, Del. Eileen Filler-Corn, Ms. Stacey Link, Dr. Melissa Nelson, Dr. Bela Sood, Senator David Suetterlein, Dr. Susan Swedo

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 1:13 p.m. and provided an overview of the meeting agenda. She then asked Ms. Teresa Champion to share an update regarding the Virginia Autism Project. Ms. Champion informed the council that after ten years of advocating to get the age cap lifted, the Virginia Autism Project was successful in getting the age cap lifted off state-regulated plans for all therapy services. She also shared that April is Autism Awareness Month.

Review and approval of meeting minutes

Delegate Filler-Corn made a motion to approve the minutes for the November advisory council meeting and the two March subcommittee meetings. The meeting minutes were approved by unanimous vote.

Updates and announcements

Dr. Vanessa Walker Harris informed the group that VDH has submitted a decision memo to Governor Northam to request reappointment of the nine non-legislative members to the PANDAS advisory council, as the current terms expire June 30, 2019. The decision memo was submitted mid-March; VDH is awaiting a response. Delegate Filler-Corn stated that she would follow up on this request. Advisory committee members shared updates to include the following highlights:

- Dr. Susan Swedo retired from NIH. She now serves as the Chief Science Office for the PANDAS Physicians Network (PPN). She stated that the resource materials developed through the PANDAS advisory council could be disseminated through the PPN.
- Dr. Bela Sood provided an update on the Virginia Mental Health Access Program (VMAP). This project is funded by a small HRSA grant and includes:
 - 24/7 telephone consultation between child psychiatrists and pediatricians
 - Provision of tele-psychiatry when child psychiatric assessment is necessary
 - Education component for pediatricians through an ECHO Lab platform once or twice per month. REACH Fellowship immersion in mental health topics will be available to pediatricians over a three day period. PANS could be a part of the didactic series. Pediatricians are expected to participate in the series monthly.

- Care coordination office to provide resources and information to families where appropriate

The project will provide these services in five regions of the state. Dr. Sood stated that the materials developed by the PANDAS advisory council could be shared through this initiative.

Contact information for each of the five areas is as follows:

1. Virginia Commonwealth University – Bela Sood, MD
 2. University of Virginia – Roger Burkett, MD; Beth Ellen Davis, MD
 3. Carilion Clinic – Felicity Adam, MD
 4. INOVA/Children’s National Medical Center – Adelaide Robb, MD; Laura Willing, MD
 5. Children’s Hospital of the King’s Daughters – Peter Dozier, MD; Stephanie Osler, LCSW
- Delegate Filler-Corn shared that three states now have mandates for insurance coverage; an insurance mandate for one additional state is currently in progress. There are also twelve advisory councils established to address PANDAS/PANS.

Review of Revised PANS/PANDAS Algorithm

Advisory council members reviewed the revised algorithm. Dr. Swedo stated that members of the subcommittee cleaned up the prior version to make it more succinct so that practitioners will know what to do. The goal is to keep the guidance related to what applies to 75% of PANS cases. Dr. Swedo reviewed edits that were made to page one of the algorithm; Dr. Melissa Nelson reviewed the edits that were made to page two. Council members approved the following additional edits to the algorithm:

- Remove “if exam warrants” from the laboratory work up section
- Include a bulleted list in place of the narrative text under diagnosis item 2
- Remove the comma after “Chang” under diagnosis item 3
- Replace “management” with “skills” in the treatment section
- Remove the entire sentence below “At follow-up evaluation:”
- Include “in all setting” after “If clinical improvement”

VDH will have the communications staff format the algorithm document for a better presentation once the content is final.

Dr. Walker Harris shared that VDH had reached out to the Medical Society of Virginia (MSV) to request that representatives from the PANDAS advisory council be included on an agenda to inform the heads of medical schools about the council’s progress to date. MSV staff responded that the appropriate meeting for this request is the Medical Dean’s Forum. Plans are in progress for the forum; the coordinator will contact Dr. Walker Harris once the date has been determined. Senator George Barker stated that he had also reached out to the Medical Society of Virginia to make the same request. Delegate Filler-Corn stated that she would follow up with MSV about the Medical Dean’s Forum.

Break

The council recessed for a break from 2:15 – 2:30 p.m.

Review of Draft Parent and School FAQs Document

Ms. Champion informed the group that she queried parent groups to obtain feedback on the types of questions they had when they first learned about PANS/PANDAS. She then compiled those questions into a table format, along with appropriate responses and reference sources. The document was provided

to subcommittee members to make revisions. She asked advisory council members to review the document and provide input regarding edits or better reference sources needed.

Senator Suetterlein inquired about the sources referenced in the document. Dr. Swedo explained that academic centers with a history of laboratory and clinical trial research into PANDAS are more likely to have contributed information regarding best practices for diagnosis and treatment as opposed to those centers that do not have clinician-scientists researching PANDAS/PANS.

Advisory council members suggested the following edits to the draft FAQs document (noted by page number, as the questions are not numbered):

- p.1 – Dr. Swedo will provide a correct response to the question, as it is incorrect as written.
- p.2 – Remove the age requirement.
- p.3, second question – Replace “has” with “may have”; include the OCD source link.
- p.4 – Dr. Swedo will edit the response.
- p.5 – Revise the question to “What treatments are commonly used for PANS/PANDAS?” or focus the question on why vs. what. Dr. Walker Harris suggested an introductory response such as, “PANS/PANDAS treatment is so complex it often requires collaboration with a multi-disciplinary team”. Dr. Swedo will provide the response; the approach is three-fold.
- p.8 – Dr. Swedo will provide a response.

In addition to the suggested edits to the draft FAQs document, council members discussed the possibility of developing a PANS/PANDAS action plan for use in schools similar to other medical disorder action plans (i.e. asthma action plan) that are currently used. Members also discussed the possibility of developing a standard checklist for pediatricians to use with PANS/PANDAS patients that will help families provide the child’s history.

Council members also revisited the topic about the establishment of a center of excellence in Virginia. Dr. Swedo shared that Dr. Zhao had previously indicated that there had been no progress on this initiative when she spoke with him about it at the March subcommittee meeting.

Review of the Maryland PANDAS Legislative Report

Ms. Champion stated that she had provided the Maryland PANDAS report to the advisory council to determine if any information included in the report could be used in Virginia’s efforts. Many members agreed that communication strategy contained in the report (pp.9-10) might be useful.

Public comment period

Ms. Sagé Blaska thanked the advisory council for the work that they are doing to address PANS/PANDAS. She shared her family’s experience with various providers and human services agencies. She urged the council to inform and educate the Department of Social Services (DSS, child protective services program) and the Department of Behavioral Health and Developmental Services about PANS/PANDAS and the complexities of treating individuals with these disorders. The PANDAS advisory council will make contact with DSS to present progress and activities of the council to date.

Ms. Arin Barker introduced herself as a representative of the Children’s Hospital at VCU and Dr. Wei Zhao. Ms. Barker stated that she understood the frustrations of not having an established center in Virginia and would follow up with Dr. Zhao about the status.

Next steps

Delegate Filler-Corn reviewed the scheduled meeting dates of June 20th and September 23rd to determine if those dates were still good for the majority of the council. No changes were made. Delegate Filler-Corn then polled members to see what dates might work for a November meeting; November 11th and 18th were provided as potential meeting dates. Delegate Filler-Corn will check the General Assembly calendar and provide additional dates to consider. Ms. Robin Buskey will poll subcommittee members to determine a meeting date in May to continue developing the FAQs document.

Adjournment

Delegate Filler-Corn provided closing remarks and thanked council members and guests for their time and participation. The meeting was adjourned at 3:53 p.m.