

PANDAS/PANS Advisory Council Meeting

Libbie Mill Library – Large Meeting Room  
Tuesday, September 26, 2017  
1:00 p.m. – 4:00 p.m.

**Meeting Minutes**

---

Legislative Members Present: Del. Richard Bell, Del. Eileen Filler-Corn, Del. Roxann Robinson, 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. Vanessa Walker Harris

---

***Welcome and Introductions***

Dr. Vanessa Walker Harris, Director of the Virginia Department of Health's (VDH) Office of Family Health Services (OFHS), called the meeting to order. She introduced herself and stated that she will serve as designated staff to the PANDAS/PANS Advisory Council. She welcomed all council members and asked that all council members introduce themselves by name and organization. Dr. Walker Harris then acknowledged the presence of VDH staff: Joe Hilbert, Director of Governmental and Regulatory Affairs, and Robin Buskey, OFHS Grant Consultant.

***Agenda Overview and Review of HB 2404 Requirements***

Dr. Vanessa Walker Harris provided a review of the meeting purpose to include:

- formal introduction of council members;
- establish council governance;
- provide an overview of PANDAS/PANS from both clinical and advocacy perspectives; and
- begin development of a three-year work plan.

Dr. Walker Harris then provided an overview of the meeting agenda in its entirety before reviewing specified sections of HB 2404. Dr. Walker Harris read sections C, D, E and the report requirements. Council members were advised to read along from the materials provided in the meeting packets, as well as on the overhead screen.

***Election of Chair and Vice Chair***

Delegate Richard Bell made a motion to elect Delegate Eileen Filer-Corn as Chair of the PANDAS/PANS Advisory Council. The motion was seconded. Delegate Eileen Filler-Corn was elected as Chair by unanimous vote.

Delegate Eileen Filler-Corn moved to elect Senator David Suetterlein as Vice Chair of the PANDAS/PANS Advisory Council. The motion was seconded. Senator David Suetterlein was elected as Vice Chair by unanimous vote.

## *Review of Draft Council Bylaws*

Dr. Walker Harris asked council members if there were any questions or concerns regarding the draft PANDAS/PANS Advisory Council By-laws that were distributed to members for review prior to the meeting. A question was raised regarding the requirement for council members to attend *all* council meetings; a council member wanted to know if participation could be done via teleconference. Joe Hilbert responded that the ability to attend meetings electronically is governed by FOIA. Under current statute, there are provisions for two tracks:

1. A member can meet electronically by phone from a location that is accessible to the public. A quorum must be present in one place. The member who is meeting remotely by phone is not counted in the quorum. The meeting notice will have to indicate who is calling in and the location from where they are calling.
2. A member can participate from a location that is not open to the public. The public body must develop a written policy that governs such meetings. Each member can participate remotely in this manner for no more than two meetings each year.

In response to various inquiries, Joe Hilbert also provided the following points:

- The PANDAS/PANS advisory council meeting will not always be held at the Libbie Mill Library location; Ms. Stefanie Levensalor offered her company's facilities as an option.
- A council member who participates via an electronic format will not be counted in the quorum.
- With regard to communication among council members between meetings, per FOIA, if three or more members are engaged in a phone call or another format of communication, that is considered a meeting. Members were advised not to "Reply All" when communicating via email. All communication should be sent through Dr. Vanessa Walker Harris.
- In response to the inquiry about forming subcommittees, Mr. Hilbert advised that this is possible as long as public notice is provided in advance. Ms. Champion indicated that she would like to reserve the right to hold subcommittee meetings.
- In response to Del. Filler-Corn's inquiry regarding the requirement to call a meeting ahead of sending out information to council members, Mr. Hilbert advised council members to send information through Dr. Vanessa Walker Harris.
- In response to Dr. Sood's inquiry that all information will be centralized in one place, Mr. Hilbert advised that is seen as part of VDH's role to the council.
- In response to Dr. Sood's inquiry, Mr. Hilbert confirmed that a quorum is met when eight members of the 15-member advisory council is present.
- Mr. Hilbert advised that he will request a copy of the written policy regarding conducting remote meetings that was recently developed by the Commission on Healthy Youth. Once obtained, the policy can be reviewed and potentially adopted for use by the PANDAS/PANS advisory council.

Senator Suetterlein made a motion to strike the commitment requirement to attend all Council meetings contained in Section IV. The Council unanimously approved the motion. Senator Suetterlein also suggested deleting the second line in Section V regarding term appointments for legislative members.

Delegate Bell made a motion to accept the PANDAS/PANS Advisory Council Bylaws as amended. The motion was unanimously approved.

### ***PANDAS/PANS Presentations***

Delegate Filler-Corn provided introductory remarks prior to Dr. Susan Swedo's presentation, *Recognition, Diagnosis and Treatment of PANDAS*, to the council. Dr. Swedo is a principal investigator for the National Institute on Mental Health and was one of the first researchers to discover the PANDAS disorder in the 1990s. Following Dr. Swedo's presentation, the council engaged in a question and answer session.

Delegate Filler-Corn acknowledged that no members of the general public were in attendance at the meeting. She suggested a revision to the agenda to include only one break since the designated public comment period would not be utilized. Council members recessed for a fifteen-minute break before resuming presentations.

Delegate Filler-Corn introduced Ms. Jan Kirby as the second presenter at the meeting. Ms. Kirby works as a patient advocate at the Children's Hospital of Richmond at VCU. She provided an informal presentation to the council, offering an advocacy perspective on the challenges and hurdles faced by children with the PANDAS and PANS disorder. Following Ms. Kirby's presentation, the council engaged in discussion regarding current PANDAS/PANS treatment options, treatment costs, current and past studies and PANDAS/PANS activity in other states.

### ***Review of Draft Work Plan***

Delegate Filler-Corn directed everyone to the draft preliminary outline contained in the meeting packets and provided on the screen. The document was provided to council members for review in advance of the meeting. Dr. Walker Harris provided a brief review of the document and asked council members to provide feedback on the draft preliminary outline, which includes council activities through December 2018.

Ms. Teresa Champion proposed that the council develop/state the end goals then work backwards to fill in what needs to be done to reach those goals.

Del. Filler-Corn indicated that the preliminary outline was a good starting place and proposed that the council could flesh it out in the current meeting or work individually and send comments later. In response to Dr. Sood's inquiry about the purpose of the council's makeup, Del. Filler-Corn reviewed the four areas included in the outline on which the council is to provide recommendations.

Council members discussed various ideas and possible actions that should take place. Mr. Hilbert reminded the council of HB 2404's three-year sunset. He reminded members that the Council has three years to accomplish the goal of providing recommendations in the four areas. For the report that is due December 1, 2017, Mr. Hilbert indicated that there are no set requirements for what has to be included in the report. He suggested that the council could build upon the preliminary outline by thinking about which groups to include/invite to present at future meetings.

Dr. Vanessa Walker Harris followed up with suggestions that the December 1<sup>st</sup> report will serve as a status report and include the following:

- Requirements of the bill
- First meeting minutes as approved by the Council
- Final work plan for the first year based on revisions to preliminary outline

Delegate Robinson suggested that the report also include progress that has been made in the last three months and what has been done prior to the first meeting to lay the groundwork.

### *Next Steps*

Ms. Jessica Gavin indicated that she would like to have workgroups within the Council. She offered to present the Arizona council format to the PANDAS/PANS advisory council as a starting point for moving forward. Dr. Wei Zhao acknowledged that Ms. Gavin's organization has already done a great deal of work in this effort and that the work of the council should begin there. Delegate Filler-Corn shared comments in agreement with Dr. Zhao, acknowledging and thanking Ms. Gavin for the work that has already been done. She suggested that all council members look at Ms. Gavin's information.

Dr. Zhao inquired if it would be appropriate for the advisory council to develop a wish list for the Governor (i.e., mandating that insurance companies include coverage for treatment of PANDAS/PANS). Mr. Hilbert replied that the PANDAS/PANS advisory council is advisory to the State Health Commissioner; the report is to the Governor and General Assembly. Mr. Hilbert also said that there is time for the advisory council to figure out the right questions and right groups to include, and how the council will use that information in the report.

### Future Meeting Dates:

Dr. Walker Harris reviewed the proposed future meeting dates as indicated in the preliminary outline – Nov 2017; April 2018; June 2018; Sep 2018; and Nov 2018. Council members held a general discussion about possible meeting dates in October and November. It was decided that Robin Buskey would send out a Doodle poll to members with possible November meeting dates.

Dr. Walker Harris provided a summary agenda for the November meeting to include the following:

- Ms. Gavin's presentation of the Arizona council format
- Review and comment of the draft report due December 1, 2017
- Review of written policy regarding remote meetings

Dr. Walker Harris advised that the meeting minutes and draft report will be sent out to council members for review in advance of the November meeting. VDH staff will write the draft minutes and report. Dr. Swedo said she would provide a copy of the PowerPoint slide presentation (version without video footage) to VDH staff for dissemination to the advisory council.

### *Adjournment*

Delegate Filler-Corn provided closing remarks and thanked council members for their time and participation. The meeting was adjourned at 3:56 p.m.