

PANDAS/PANS Advisory Council  
Virginia Department of Health  
Friday, October 15, 2021  
1:00 – 3:00 p.m.

GoToWebinar Virtual Meeting

General Public Link: <https://attendee.gotowebinar.com/register/5647244970581781517>

*Draft Meeting Minutes*

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Members Present: Senator George Barker, Ms. Megan Bonfili, Ms. Teresa Champion, Delegate Joshua Cole, Dr. David Jaffe, Ms. Stefanie Levensalor, Dr. Melissa Nelson, Delegate Roxann Robinson, Delegate Danica Roem, Delegate Shelly Simonds, Senator David Suetterlein, Dr. Susan Swedo, Ms. Christina Teague, Dr. Wei Zhao

Ex officio Member Present: Heather Board (Commissioner's designee)

Members Absent: Dr. Bela Sood

VDH Staff Present: Ms. Robin Buskey

Guests Signed onto Webinar: Mary Blalock, Douglas Gray, Erin Whit

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### **Welcome and Agenda Overview**

Senator David Suetterlein called the meeting to order at 1:05 p.m., and Robin Buskey performed the roll call. Senator Suetterlein welcomed new members to the advisory council. Ms. Christina Teague introduced herself to the council. Senator Suetterlein acknowledged that, through a provision of the 2021 Appropriations Act, the council is allowed to meet virtually; however, no formal votes or recommendation would be made.

### **Overview of Insurance Mandate Process**

Bradley Marsh and Julie Blauvelt, representatives from Virginia's Bureau of Insurance, provided a presentation overview of the insurance mandate process. The focus of the presentation covered three main points—1) essential health benefits; 2) state-mandated health benefits; and 3) review of Virginia's mandated benefits review process. Council members engaged in a question and answer discussion following the presentation. Members expressed views concerning the need to establish an insurance mandate for the diagnosis and treatment of PANDAS/PANS as a way to make sure that care is made available to individuals and families in Virginia.

### **Follow Up Discussion – JLARC Report on Mental Health Parity**

Senator George Barker led a discussion regarding JLARC's report on Oversight of Mental Health Parity in Virginia. The report had been provided to advisory council members in advance of the meeting. Members shared concerns regarding mental health access, insurance denials and enforcement of mental health parity. Senator Barker fielded questions about the status of mental health parity in the Commonwealth, and he advised that proposed legislation would be forthcoming in the 2022 General Assembly Session. Seventeen states have passed laws and set up enforcement mechanisms to address mental health parity. Virginia's proposed legislation should include mechanisms to ensure compliance.

### **Discussion – Replicating Texas webinar in Virginia**

Ms. Teresa Champion inquired about the feasibility of developing and hosting a webinar to educate clinicians on PANDAS/PANS in Virginia. The webinar would follow the format of the Texas webinar, which was disseminated to council members in advance of the meeting. The general idea is that VDH would host the webinar. Council members

discussed the advantages and disadvantages of developing a Virginia-specific webinar versus using one of the many resources that have already been developed.

- Dr. Susan Swedo identified a number of PANDAS/PANS experts who have already developed such resources, including some developed by fellow members Dr. David Jaffe and Dr. Wei Zhao.
- The council reached consensus that council members will forward suggested webinar resources to Ms. Robin Buskey for dissemination to the full advisory council. The council will then vote on the resources that should be included in a “resource library” to be included on the VDH PANDAS webpage along with the other approved resources.
- The recommendation to develop a Virginia-specific webinar may still be addressed at some point in the future.
- Ms. Heather Board provided clarification that the council can make a recommendation to the state health commissioner regarding the development and hosting of a VDH-led webinar and reminded the council that there were no resources allocated to VDH for the advisory council. To that end, the actual development of the webinar, and the associated resources needed, would fall to the advisory council.

Council members inquired on the status of the PANDAS/PANS resource dissemination and whether or not they had been disseminated to clinicians throughout the state.

- Ms. Buskey reminded the council of the efforts that had been underway with disseminating the resources to the stakeholder organizations outlined in the 2019 report recommendations.
- Ms. Buskey also confirmed that a request had been made to include the PANDAS/PANS resources in communication from the state health commissioner, and the information was disseminated via email on June 15, 2021. However, that particular communication was not sent to clinicians across the Commonwealth.
- The appropriate communications vehicle to reach clinicians is through a clinician’s letter.
- Delegate Danica Roem suggested that Senator Suetterlein could draft a letter to be sent to the state health commissioner regarding the clinician’s letter request.
- Based on consensus of the advisory council, Senator Suetterlein determined that he will send a letter to the state health commissioner to follow up on the previous 2019 recommendation to disseminate the PANDAS/PANS resources through a clinician’s letter.

Ms. Stefanie Levensalor inquired if PANDAS/PANS resources, including the proposed webinar(s), could be promoted through VDH’s social media platforms.

- Ms. Board confirmed that there are opportunities to use VDH social media channels, and she advised that the council should include this as a recommendation to the state health commissioner.
- Senator Suetterlein stated that he would include the request to use VDH’s social media channels in a letter.

### **Public Comment Period**

Two members of the public pre-registered to speak during the public comment period. Ms. Mary Blalock and Ms. Erin Whitt both shared their personal experiences with PANDAS/PANS, as well as comments in support of an insurance mandate.

### **Other Council Business**

Senator Suetterlein reminded the council that the annual report is due December 1, 2021. Ms. Buskey will draft the report to include a summary of the council’s activities. The following deadlines were reviewed:

- Ms. Buskey will send the draft report to council members by October 22, 2021
- Feedback due to Ms. Buskey from council members November 1, 2021
- VDH will submit the report to the General Assembly by December 1, 2021

Senator Suetterlein reminded members that the PANDAS advisory council is set to sunset effective July 1, 2022 without further action from the General Assembly. There was general consensus among council members to extend the council beyond July 1, 2022. Legislative members discussed the various options to extend the council through either legislation or budget language. Senator Suetterlein suggested that the legislative members revisit the discussion in 3-4 weeks to determine the best path going forward.

The next advisory council meeting was tentatively set for March 2022. Council members will be polled at a later time to determine the exact meeting date.

### **Adjournment**

The meeting was adjourned at 2:49 p.m.