

PANDAS/PANS Advisory Council Meeting
Friday, May 14, 2021
1:00 – 3:00 p.m.

GoToWebinar Virtual Meeting
<https://attendee.gotowebinar.com/register/1667701168748238348>

Draft Meeting Minutes

Members Present: Senator George Barker, Ms. Teresa Champion, Delegate Joshua Cole, Ms. Stefanie Levensalor, Ms. Stacey Link, Dr. Melissa Nelson, Delegate Roxann Robinson, Delegate Danica Roem, Dr. Bela Sood, Senator David Suetterlein, Dr. Susan Swedo, Dr. Wei Zhao

Members Absent: Ms. Jessica Gavin, Dr. David Jaffe, Delegate Shelly Simonds

VDH Staff Present: Ms. Robin Buskey

Guests Signed onto Webinar: Kristin Paul

Call to Order

Senator David Suetterlein called the meeting to order at 1:05 p.m.

Welcome and Roll Call

Senator Suetterlein welcomed members and asked Robin Buskey to perform roll call to determine a quorum. Ms. Buskey called the roll and confirmed a quorum.

Agenda Overview

Council members were asked to review the agenda while Senator Suetterlein provided an overview of the agenda. Council members adopted the meeting agenda.

Review and approval of November 2020 meeting minutes

Del. Danica Roem moved to adopt the November 2020 meeting minutes. The motion was seconded by Del. Joshua Cole. The advisory council unanimously approved the meeting minutes.

Advisory Council Updates

Senator Suetterlein announced that Ms. Jessica Gavin would be resigning from the PANDAS advisory council and asked if there was any additional information regarding her resignation. Ms. Buskey confirmed that the resignation would be effective May 31, 2021, as Ms. Gavin is moving and will no longer be a resident of Virginia. Ms. Buskey informed council members that Ms. Gavin had provided a recommendation for an individual from her organization to be appointed as her replacement and was advised to have that individual submit an application to the Secretary of the Commonwealth. There were no further updates regarding a replacement appointment.

Ms. Buskey provided an update regarding the status of the State Health Commissioner's designee to serve as ex officio member to the advisory council. Ms. Heather Board will replace Dr. Laurie Forlano as the designee. Ms. Board was not in attendance because she was on medical leave.

Ms. Teresa Champion was asked to provide an update regarding her previous request for the advisory council to write a letter of recommendation to Congressman Ben Cline requesting support for including targeted language that focused on National Institutes of Health research in the upcoming federal appropriation legislation. Ms. Champion informed the council that while initial deadline for the council to make a recommendation to the subcommittee had passed, she still felt that council members could request support of the language. Del. Roem informed the council that Congresswoman Wexton serves on the larger appropriations committee and should be contacted as well. Council members discussed and agreed on the importance of supporting this effort. Senator George Barker raised a question about the PANDAS advisory council's authority to make this request of the Virginia Congressional delegation, as it could be misinterpreted as a request from the executive branch.

After much discussion to determine the best approach to move forward with the request, Del. Roam made a motion recommending that Senator Suetterlein send a letter to the State Health Commissioner informing him of the proposed language and encouraging the Virginia Congressional delegation to support inclusion of language that supports research by the National Institute of Health on Childhood Post-Infectious Neuroimmune Disorders (CPINDs) in the upcoming federal appropriations legislation. Senator Barker seconded the motion. Council unanimously approved the motion. Senator Suetterlein also asked council members to individually reach out to Congressman Cline and Congresswoman Wexton to encourage support of the language. Senator Suetterlein asked Ms. Buskey to circulate contact information for the Congress members to the full council via email.

Public Comment Period

Senator Suetterlein opened the floor to receive public comment. Ms. Buskey advised that no members of the public signed up to provide public comment; however, Ms. Buskey acknowledged that an individual by the name of Kristin Paul was signed into the virtual meeting as an attendee.

Center of Excellence Discussion

Council members who attended the Inflammatory Brain Disorders Conference provided updates regarding the information that was shared during the conference, including the presentation on *Plasmapheresis in Treatment of PANS* provided by Dr. Wei Zhao. Members also mentioned the PANS registry/database developed and maintained by Ms. Jessica Gavin's organization, Pediatric Research and Advocacy Initiative (PRAI). Ms. Champion noted that any discussion about a Center of Excellence needs to include the topic of an insurance mandate in order to advance diagnosis and treatment of PANDAS/PANS for families. Council members shared thoughts and assumptions on what they perceive to be the barriers to establishing a Center of Excellence.

Dr. Susan Swedo recommended that Virginia look at what other states have done. There are currently 17 centers. She also shared that the American Academy of Pediatrics is overdue in issuing a policy statement on PANDAS/PANS. The tentative date for providing a statement has been updated to fall 2021. Council members agreed that a multi-pronged approach that addresses the medical, behavioral and psychiatric elements is needed for treatment of PANDAS/PANS. A number of council members voiced support of establishing the Center of Excellence at VCU. Dr. Zhao shared that there is interest and support for establishing a center at VCU; however, leadership is currently in transition.

Senator Barker briefly described the process for how an insurance mandate is established in Virginia through the Health Insurance Reform Commission and the types of insurance plans that are covered by a mandate.

Ms. Champion suggested that the council consider mental health parity as an alternative approach to a mandate as a way of getting insurance coverage for PANDAS/PANS. She proposed that legislation should be developed to include language regarding the treatment needed for this biologically-based mental illness. Senator Barker shared that mental health parity is the law and significant detailed analysis has been done in the last two years; however, Virginia is a few years away from necessary improvement in this area.

PANDAS/PANS Resources Dissemination Update

Ms. Buskey provided a status update regarding the outreach VDH conducted to request that specified stakeholder organizations disseminate the PANDAS/PANS resources within their networks. She shared the responses received for six of the 16 organizations contacted. Council members discussed how the response rate might be improved and requested that Ms. Buskey continue to reach out to the organizations on a regular basis. Senator Suetterlein encouraged council members to reach out to stakeholder organizations where they have a good relationship and ask them to disseminate the resource. Dr. Melissa Nelson made a motion to recommend that VDH include the resources and request for dissemination in one of the alerts that are routinely sent via email. Dr. Swedo seconded the motion. Council voted unanimously in favor of the motion.

Next Steps

Senator Suetterlein outlined the next steps:

- Senator Suetterlein is going to draft a letter to the State Health Commissioner, encouraging Virginia's Congressional delegation to support inclusion of language that support's NIH's research on CPINDs in upcoming federal appropriations legislation.
- Ms. Buskey will email contact information for Congressman Cline and Congresswoman Wexton.
- Dr. Sood will pursue disseminating PANDAS/PANS resources through the Virginia Mental Health Access Program's (VMAP) Project Extension for Community Healthcare Outreach (Project ECHO).
- Ms. Buskey will continue outreach to the stakeholder organizations to request that they disseminate the PANDAS/PANS resources.
- Dr. Swedo will provide information on the 17 sites that have been established as a Center of Excellence.
- Senator Barker will request the report document through JLARC and distribute the report regarding mental health parity to the advisory council.
- Senator Barker will request that an appropriate person provide a presentation on the insurance mandate process to the advisory council.
- Ms. Champion offered to arrange an opportunity for families to speak to council members so that new members gain a better understanding of the PANDAS/PANS diagnosis.

The next advisory council meeting was tentatively scheduled for Friday, July 9 at 1:00 p.m.

Adjournment

The meeting was adjourned at 3:10 p.m.