

PANDAS/PANS Advisory Council Meeting

Patrick Henry Building – Reading Room East
1111 E. Broad Street
Richmond, VA 23219
Friday, November 15, 2019
1:00 p.m. – 4:00 p.m.

Meeting Minutes

Members Present: Delegate Richard Bell, Ms. Teresa Champion, Del. Eileen Filler-Corn, Ms. Jessica Gavin, 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, Mr. Joe Hilbert

Guests: Ms. Sagé Blaska (Parent), Ms. Arin Barker (Children's Hospital of Richmond at VCU); Dr. Carl Hoegler (Liberty University)

Call to Order

Delegate Eileen Filler-Corn called the meeting to order at 1:10 p.m., welcomed guests and provided an overview of the meeting agenda. Del. Filler-Corn recognized Dr. Carl Hoegler, an invited guest from Liberty University College of Osteopathic Medicine who participated via remote conference call.

Background of PANDAS/PANS Advisory Council

Dr. Vanessa Walker Harris provided background on the establishment and purpose of the PANDAS/PANS advisory council and shared a high-level summary of activities since the council's establishment to include:

- Established council governance and elected Del. Filler-Corn and Sen. Suetterlein as the chair and co-chair, respectively.
- Formed subcommittees for the three of the four focus recommendation areas and elected chairs of the subcommittees – Ms. Teresa Champion, Ms. Jessica Gavin and Dr. David Jaffe.
- Held a stakeholder meeting in June 2018 to receive feedback on four focus areas. Guests included representatives from Children's Hospital of Richmond at VCU, Virginia Department of Behavioral Health and Developmental Services, Department of Medical Assistance Services, Department of Education, University of Virginia Children's Hospital, Virginia Premier, Loudoun Community Services Board, and parent community members.
- Developed four PANDAS/PANS resources:
 - Developed PANS/PANDAS Evaluation and Treatment Algorithm as both a practice guideline for the diagnosis and treatment of PANDAS/PANS and as a mechanism to increase awareness for clinicians
 - Developed PANDAS/PANS Parent Handout to increase awareness among parents and caregivers
 - Developed PANDAS/PANS School Systems Handout to increase awareness among educators
 - Developed PANDAS/PANS Frequently Asked Questions (FAQ)s Resource

- Wrote and submitted 2017 and 2018 PANDAS annual reports with recommendations to the state health commissioner; will submit 2019 report in December 2019.
- Continues to develop strategies for marketing the resources to increase awareness and education of clinicians and outreach strategies to increase awareness of parents and educators.

Discussion of proposed Center of Excellence in Virginia

Dr. Walker Harris led the discussion regarding the council's proposed recommendation to establish a center of excellence in Virginia. Representatives from the states six medical schools were invited to provide input on this recommendation. Summary information was provided in the meeting materials, which included:

- A summary of the Stanford and Arizona models with feedback that VDH staff obtained from Dr. Jennifer Frankovich, Director of the PANS Program at Stanford Children's Health, and Mr. Paul Ryan, President of the PACE Foundation.
- Dr. Wei Zhao's business proposal that was provided to the council in September. Dr. Zhao was asked to summarize the section of the proposal that describes the hybrid model.
- Discussion questions

Council members and invited guests discussed the feasibility of implementing the proposed models in Virginia. Council members expressed agreement that the Arizona clinic model more closely matched the hybrid model proposed by Dr. Zhao. Both Dr. Zhao and Dr. Jaffe stated that VCU currently does not have the capacity to establish a center, which is more research based; a clinic would be most feasible to implement.

Review and approval of September meeting minutes

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

Advisory Council Updates

Dr. Walker Harris provided the following updates:

- Discussed the revisions completed by the VDH Communication team regarding the FAQs document and inclusion of cross reference on three resource materials
- Following the September meeting, Ms. Teresa Champion suggested that she would like for advisory council members to present to the Joint Commission on Mental Health. Dr. Walker Harris asked the council if there was any feedback regarding this suggestion. Senator Suetterlein stated that this should be planned in terms of who will present and what will be shared. The council can make this request through a letter.
- The DSS Permanency Advisory Council Meeting is scheduled for December 4, 2019. DSS responded to the Ms. Champion's previous inquiry about public participation at the Permanency Advisory Council meeting. The meetings are normally not open to the general public. Ms. Champion and Ms. Jessica Gavin are confirmed to present. They have been allotted a one-hour window at the top of the meeting.

Review of draft annual report and recommendations

A copy of the draft 2019 annual report that was prepared by VDH was included in the packet. In addition, Ms. Champion provided a substantial amount of text regarding background information and

charter topics as suggested text to include in the report. Ms. Champion also provided a separate document that outlined revisions to the draft report's Recommendations section. Ms. Champion's revisions included two new recommendations and revisions to eight of the twelve recommendations included in the draft report.

Council members reviewed the draft report and the suggested revisions. Council members provided general feedback that the draft report should continue to follow the format that has been used in the prior annual reports. Senator Suetterlein suggested that it is most important that the main points are made in the report to highlight the materials that have been developed and the recommendation for the center of excellence as the next step. Dr. Walker Harris suggested that some of Ms. Champion's suggested background information can be incorporated into the report. Robin Buskey will revise the draft report.

The following recommendations contain edits based on the group's feedback during the meeting:

1. The Council recommends the establishment of a center of excellence at a Virginia academic medical center that will:
 - conduct basic, clinical, and translational research for PANDAS/PANS and autoimmune encephalopathy (AE);
 - provide assessment and treatment for patients, children and adults, with a diagnosis of PANDAS/PANS and AE; and
 - establish a network of community providers to provide support and education for local delivery of care including the use of all available modalities such as telemedicine.
2. The Council recommends that VDH disseminate a PANDAS/PANS diagnosis and treatment algorithm to physicians and clinicians throughout the state. The advisory council has developed a draft evaluation and treatment algorithm to address two focus areas -- practice guidelines for diagnosis and treatment and mechanisms to increase clinical awareness. Once the product is finalized and approved, the resource can be made available to physicians and clinicians for use in daily practice.
3. The Council recommends that VDH work with Virginia American Academy of Pediatrics (AAP), the Medical Society of Virginia (MSV), Virginia College of Emergency Physicians (VACEP) and other relevant stakeholders to promote and increase awareness of and access to the 2015 and 2017 PANS Consortium guidelines to all clinical providers involved in the assessment and treatment of PANDAS/PANS.
4. The Council recommends that VDH work with relevant partners such as the AAP, MSV and VACEP to coordinate dissemination of the PANDAS/PANS evaluation and treatment algorithm to the pediatric providers and through Virginia's six schools of medicine.
5. The Council recommends that the state health commissioner disseminate information about PANDAS/PANS to physicians and clinicians throughout the state via a clinician letter with an attachment of the evaluation and treatment algorithm.
6. The Council recommends that VDH disseminate PANDAS/PANS parent and school guidance documents throughout the state. The advisory council has developed a draft guidance handout for parents and a handout for school staff to address the outreach to parents and educators focus area. Once finalized and approved, the resources can be made available to parents and schools to promote education and awareness.

7. The Council recommends that VDH work with the Virginia Department of Education to coordinate dissemination of the PANDAS/PANS school handout to educational staff and school nurses in all K-12 schools.
8. The Council recommends that VDH educate other state agencies including, but not limited to, the Department of Behavioral Health and Developmental Services, Department of Social Services, Department of Corrections, Department of Juvenile Justice, Commonwealth's Attorneys' Services Council, Department of State Police, Department of Criminal Justice Services including the courts, Office of Children's Services, Health Insurance Reform Commission and Virginia Association of Health Plans on using the PANDAS/PANS informational handouts to promote awareness of PANDAS/PANS.
9. The Council recommends that VDH work with relevant professional associations such as Commonwealth Parenting, Children's Advocacy Center of Virginia, The Arc, statewide Autism Societies, Virginia Autism Project, Virginia Statewide Parent Education Coalition, Virginia Parent Teacher Association and Special Education Parent Teacher Association to coordinate dissemination of the PANDAS/PANS parent informational handout.
10. The Council recommends that VDH disseminate a PANDAS/PANS informational resource throughout the state. The advisory council has developed a draft FAQs document to address the outreach to parents and educators focus area. Once finalized and approved, the resource can be posted on the Pediatric Research and Advocacy Initiative (PRAI) website, www.praikids.org.
11. The Council recommends that VDH update relevant VDH webpages to include current PANDAS/PANS information and approved resources.
12. The Council recommends that VDH work with relevant stakeholder organizations to encourage use of the PANDAS Physicians Network through AAP, MSV, child psychiatrists, neurologists, and immunologists to expand the network of PANDAS/PANS providers for children and adults, including those with disabilities.
13. The Council recommends that the General Assembly continue the PANDAS/PANS advisory council for another two years.

After substantive discussion regarding the recommendation for the General Assembly to mandate insurance coverage for the treatment of PANDAS/PANS in Virginia similar to that passed in five other states (Arkansas, Delaware, Illinois, Minnesota, New Hampshire), the majority of the council members expressed opposition to including the recommendation in the report.

Del. Filler-Corn made a motion to approve the thirteen recommendations as revised. The motion was approved by unanimous vote. In addition, Ms. Champion asked that the meeting minutes and annual report reflect her opposing vote regarding removal of the insurance mandate recommendation.

Public comment period

Ms. Sagé Blaska shared a passionate plea for the advisory council members to consider including the insurance mandate in the report recommendations.

Adjournment

The meeting was adjourned at 4:05 p.m.