

PANDAS/PANS Advisory Council Meeting

Libbie Mill Library
Monday, November 26, 2018
1:00 p.m. – 4:00 p.m.

Meeting Minutes

Members Present: Senator George Barker, Ms. Teresa Champion, Del. Eileen Filler-Corn, Ms. Jessica Gavin, Dr. David Jaffe, Ms. Stacey Link, Del. Roxann Robinson, Dr. Bela Sood, Senator David Suetterlein

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)

Welcome and agenda overview

Delegate Eileen Filler-Corn called the meeting to order at 1:15 p.m. Dr. Vanessa Walker Harris provided an overview of the meeting agenda.

Selection of Chairs for Subcommittees

Chairs were chosen to lead future meetings of the three subcommittees. The following chair assignments were determined:

- Diagnosis and treatment – Dr. David Jaffe
- Clinicians – Jessica Gavin
- Parents and educators – Teresa Champion

Updates and announcements

Advisory committee member shared updates regarding PANS and PANDAS activities and/or events to include the following highlights:

- Ms. Gavin shared that there is increasing clinical awareness of PANDAS/PANS based on caseloads at various health systems and practices. VCU has 80+ patients. Bon Secours St. Mary's does not have as many patients. Dr. Jaffe asked if there are any stats on the number of patients that Bon Secours is treating. Gavin responded that they are treating approximately 25 pediatric patients.
- Ms. Gavin also stated that UVA is making slow progress. They have agreed to complete workups for infections; however, they are not willing to do immune therapy.
- Ms. Gavin shared that the PACE Foundation is funding a multi-center IVIG center to see if it is an effective treatment for PANS.
- Dr. Jaffe inquired if VCU has given any feedback on developing a center. He was told that Dr. Zhao indicated that VCU will not develop a center based on the Arizona model. Dr. Jaffe would like to talk to someone else about moving forward with developing a center in Virginia. Ms.

Gavin responded that there was push for a center but there was no feedback from VCU. The plan is to move forward with working with Bon Secours and UVA.

- Ms. Gavin shared that her organization, PRAI, has developed an online patient registry. The organization will need to determine how they will reach PANS and PANDAS patients. The registry will be parent reported.
- Dr. Jaffe shared that the research from the consortium shows that there is a particular type of blood cell in individuals that meet the criteria for PANS. There is ongoing research related to this.
- Ms. Champion suggested that judges and prosecutors will need to be educated on various mental health issues as more kids age and certain behaviors cause them to come into contact with the judicial system. Education outreach efforts need to target the judicial system.

Review and approval of meeting minutes

Delegate Filler-Corn made a motion to approve the June, August and October 2018 meeting minutes, which were provided to all advisory council members for review in advance of the meeting. The meeting minutes were approved by unanimous vote.

Review of Draft PANS/PANDAS Algorithm

Advisory council members reviewed the draft algorithm. Dr. Sood suggested that Dr. Swedo prioritize the labs that are “musts” and she noted that the clinical diagnosis must be clearly stated on the final draft. Dr. Jaffe stated that the final algorithm must not contradict existing guidelines. The subcommittee will need to meet again so that the physicians can finalize the algorithm. In the absence of Drs. Swedo, Nelson and Zhao, no additional edits were made to the draft algorithm

Review of Draft Parent and School Guidance Document

Advisory council members reviewed the draft guidance document for parents and schools. Ms. Champion inquired where the document will be housed; who will update it; and who will distribute it?

Dr. Jaffe indicated that Dr. Swedo had discussed a similar topic among the consortium. She envisioned trying to find a way that the various organizations throughout the country will interact with each other, form an umbrella connection, and attain consensus. There is concern that there is a significant amount of difference in how various groups approach this. The documents would be updated by the groups that form the association.

Dr. Sood indicated that the document must have a Virginia flavor. The document should reside in centers and parent groups. Government agencies could also play a role in pushing the information out into the community. The physical hard copy of the document should look like the version that will be posted on the internet.

Ms. Gavin inquired about the next step for the advisory council if the recommendations are not acted upon; how does the council get these recommendations to happen? Senator Barker replied that the council needs to make the recommendations as clear as possible then go to the legislators to determine the best course of action, which will depend on what is happening at the time. The council should start making recommendations now through when the legislation sunsets.

Delegate Robinson inquired about how the guidance document will reach parents. Council members responded that it will likely be disseminated through physicians, school staff and parent groups.

Ms. Link stated that Chesterfield County Public Schools and the Department of Education is ready for the information. The FAQs document is the missing link, as people currently do not know where to go for medical help.

Dr. Sood stated that pediatricians and primary care physicians should be the portal of entry. Dr. Jaffe added that many patients come to him without a referral.

Ms. Gavin stated that 90% of pediatricians do not know about PANS and PANDAS. She would like to figure out a way to direct parents first to the doctors instead of coming through PRAI.

Senator Barker inquired if there is a way to establish a list for pediatricians to inform patients who to contact. Is there a way for specialists to opt in and opt out? Doctors should be able to self-select whether or not they are included on the list. Dr. Jaffe responded that there is an existing list on the PANDAS Physicians Network (PPN) and that it should be included on the algorithm document.

Ms. Champion raised the question of how to get the FAQs document developed. She then made a motion to accept the parent and school guidance document in final draft form and release it to the public to obtain feedback. Ms. Link suggested that the document be revised to remove the second sentence from item 4 on the school guidance. The council approved the motion to release the document for public feedback after the revision is made. Ms. Champion will release the document to parents of PRAI, the Facebook page, and PANDAS parent network.

Dr. Jaffe stated that he has developed a chart for parents to complete a chronological history of the events that occurred with the patient. He would like the council to review his chart and possibly include the chart in the handouts.

Subcommittee members discussed potentially meeting in January to develop the FAQs document for parents and schools, as well as revisions to the algorithm. The chairs will contact Robin to coordinate the respective subcommittee meetings. Dr. Jaffe stated that he would need to include Dr. Swedo and Dr. Nelson in a review of other existing documents. The three main categories for comparison are things in agreement; things in disagreement; and neither. Dr. Sood stated that the algorithm must be clear; in its current form, the clinical diagnosis is missing.

Discussion regarding the need for a Center of Excellence in Virginia

Ms. Champion stated that she wanted to discuss further the need for a center in Virginia. Dr. Jaffe suggested sending out a request to the heads of the pediatrics department at each of the medical schools to offer a meeting to discuss the possibility of a center. It was noted that a leaders of Virginia's medical schools meet regularly through the Medical Society of Virginia. Senator Barker stated that he could check into seeing how council members can get a spot on their agenda to inform the medical schools of where Virginia is on this issue and to request that they keep the PANDAS/PANS documents alive going forward once they are finalized.

Review of the Draft 2018 Annual Report

Advisory council members provided feedback on the draft annual report, which was provided in advance of the meeting for review. Council members agreed to include the following edits to the recommendation section of the report:

- Disseminate a PANS/PANDAS diagnosis and treatment algorithm to physicians and clinicians throughout the state. The advisory council has developed a draft 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.
- Disseminate a PANS/PANDAS parent and school guidance document throughout the state. The advisory council has developed a draft guidance document for parents and school staff to address the outreach to parents and educators focus area. Once finalized and approved, the resource can be made available to parents and schools to promote education and awareness.
- Reach out to the American Academy of Pediatrics (AAP) and the Medical Society of Virginia (MSV) to coordinate dissemination of the PANS/PANDAS diagnosis and treatment algorithm to the pediatric providers and through Virginia's six schools of medicine.
- Update the VDH website to include current PANS/PANDAS information.
- Encourage use of the PANDAS Physicians Network through AAP, MSV, child psychiatrists, neurologists, and immunologists to expand the network of PANS/PANDAS providers.
- Develop a consortium of clinicians model that will work collaboratively with Virginia statewide medical professional groups, community and primary care physicians and other hospital centers to develop areas of excellence, adapting best practices from research centers such as Arizona. Ms. Champion will provide additional clarifying text to include.

Public comment period

No comments were received during the public comment period.

Next steps

Ms. Buskey will make the final edits to the annual report as approved by the advisory council. Ms. Champion will forward additional text to Ms. Buskey to be incorporated in the recommendation to develop a consortium of clinicians model.

Delegate Filler-Corn asked council members to look at the potential 2019 meeting dates that were provided on the agenda. Dr. Jaffe asked if some Thursday and Friday dates could be included. There was also a suggestion to hold a council meeting in September vs. October to accommodate legislative meeting calendars. Ms. Buskey will include some additional dates and send out a Doodle poll to all members.

Subcommittee chairs will contact Ms. Buskey to arrange meeting dates to finalize the algorithm and parent and school guidance documents and to develop the FAQs. Ms. Champion will let Ms. Buskey know if Monday, January 28th is a good date for the parent and educator outreach subcommittee to meet.

Adjournment

Delegate Filler-Corn provided closing remarks and thanked council members and guests for their time and participation. The meeting was adjourned at 4:00 p.m.