

PANS/PANDAS Advisory Council Meeting

State Capitol Building – House Room 3
Monday, June 18, 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. Stefanie Levensalor, Ms. Stacey Link, Dr. Melissa Nelson, Del. Roxann Robinson, Dr. Bela Sood, Dr. Susan Swedo, 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. Jan Kirby (Children’s Hospital of Richmond at VCU), Ms. Holly Mortlock (Department of Behavioral Health and Developmental Services), Dr. James Nataro (UVA Children’s Hospital), Dr. Helen Ragazzi (Virginia Premier), Dr. Kathleen Sardegne (Department of Medical Assistance Services), Ms. Johanna Van Doren-Jackson (Loudoun CSB), Ms. Tracy White (Virginia Department of Education)

Welcome and agenda overview

Delegate Eileen Filler-Corn called the meeting to order at 1:13 p.m. Dr. Vanessa Walker Harris provided welcoming remarks and an overview of the meeting agenda. Dr. Walker Harris then introduced Dr. Susan Swedo, council member and principal investigator for the National Institute on Mental Health.

Overview of PANS/PANDAS

Dr. Swedo provided a slide presentation of an overview of PANS and PANDAS for the benefit of all invited guests.

Introductions and background of PANS/PANDAS advisory council

At the conclusion of the presentation, Del. Eileen Filler-Corn thanked the invited guests for attending the meeting before introducing herself and asked that council members give a brief introduction to include name, title and affiliate organization. Del. Filler-Corn then asked the invited guests to introduce themselves to the council.

Dr. Walker Harris provided a brief explanation of HB2404, which established the advisory council during the 2017 General Assembly Session. A copy of the legislation was provided in the meeting handouts. Dr. Walker Harris reviewed the purpose of the advisory council, which is to provide recommendations to the state health commissioner on the four focus areas regarding PANS and PANDAS:

- Practice guidelines for diagnosis and treatment
- Mechanisms to increase clinical awareness and education
- Outreach to educators and parents
- Development of a network of volunteer experts

The council must provide an annual report to the Governor and the General Assembly December 1st.
HB2404 sunsets on July 1, 2020.

Dr. Walker Harris then reviewed a summary list of council activities accomplished within the first nine months. A handout of the council's timeline and activities was provided. Dr. Walker Harris also acknowledged the time and effort that had been devoted to PANS and PANDAS activities prior to formal establishment of the council.

Dr. Walker Harris thanked the invited guests for attending and restated the intent of from the meeting invitation -- to obtain feedback from external guests to help inform development of the recommendations that the council will provide to the state health commissioner. She then directed everyone's attention to the discussion questions handout. Dr. Walker Harris initiated the discussion with guided questions to the invited guests. Some key highlights from the discussion include:

Practice guidelines for diagnosis and treatment:

- Dr. Melissa Nelson shared her concerns about what she is currently seeing in her own practice. There is an increased awareness of PANS and PANDAS among parents. There are more children seeking treatment for mental health and more presenting with PANDAS. Parents want immediate help for their children. She has nowhere to send parents for education. She does not think her patients are getting any better.
- Dr. David Jaffe offered that there are existing resources for parents to include the PANDAS Physician Network and research articles on the internet. He stated that while there is currently no gold standard for therapy, in the interim, there are things that providers can do.
- Ms. Sagé Blaska, parent of a child with PANDAS, stated that she initially learned of the disorder through a school nurse in Chesterfield County Public Schools. Her child was tested for strep and was treated with antibiotics. She was told that VCU did not believe in PANDAS and she was not given a referral to a specialist. She also learned that many health professionals (psychiatrists, ER doctors) do not support PANDAS.
- Dr. James Nataro, Chair at UVA Children's Hospital, stated that treatment or therapy is a shared decision between the physician and patient. The physician should be competent, knowledgeable, committed and able to communicate the risk/benefit to the patient. Treatment of antibiotics is not outside the standard for treating PANDAS; pediatricians would then refer the patient to a neurologist. It is up to the provider to make a recommendation.
- Dr. Nataro also shared comments regarding Dr. Swedo's presentation. He stated that Dr. Singer is well respected and has a reputation that he is disinterested. He stated that there is a need for research beyond anecdotal evidence. The research needs to be supported. The studies need to be seen as reputable and performed by those who are disinterested.
- Dr. Swedo shared that Dr. Singer has co-authored anti-PANDAS articles and has said that the disorder does not exist. He and other doctors are treating tic disorders. She agreed that the investigators need to be squeaky clean and not have conflicts of interest.
- Dr. Jaffe agreed with Dr. Nataro and Dr. Swedo that research is the way to move forward. He suggested that Dr. Nataro speak with Ms. Jessica Gavin to get others included in the studies.
- Dr. Wei Zhao stated that his practice currently refers to the three publication guidelines when diagnosing and treating PANS/PANDAS. More objective evidence is needed.

Mechanisms to increase clinical awareness:

- Dr. Zhao indicated that the publication articles re: the PANS/PANDAS guidelines should be used to increase awareness.
- Ms. Stefanie Levensalor stated that pediatricians should be knowledgeable about the diagnostic guidelines then move from there.

- Dr. Bela Sood stated there should be a clearinghouse for resources.

Outreach to parents and educators:

- Ms. Johanna Van Doren-Jackson, representative from Loudoun Community Services Board (CSB), shared that the practitioners see that there is something going on with children. They refer children back to the medical community but the CSB does not refuse to treat them. There may be existing issues that are related. There should be cautious and careful information shared with the parents. There needs to be an ongoing conversation; we do not want to be behind the curve on new data and research. At the same time, parents should not be given false hope.
- Ms. Blaska (parent guest) stated that she has been connected to Ms. Jessica Gavin's group and other social media groups related to PANS/PANDAS. She has not been able to get help or information from the medical community. Research is needed because many doctors are not trained to treat the disorder. She has tried to explore how to pay for the doctors who are experts in this area. She would like to be able to contact groups that have information on clinical trials.
- Dr. Swedo stated that in treating PANS/PANDAS patients, the therapist is involved with educating the parents.
- Ms. Tracy White, representative from the Virginia Department of Education (DOE), stated that there needed to be collaboration among interdisciplinary professionals in the schools (nurse, psychologist, social worker). These staff need to be trained so that they can provide information to the families. They serve as intermediaries. School nurses are valuable resources. Information is also shared through the PTA. DOE is open to training to serve on an interdisciplinary team. There need to be strategies in place for how to handle children; there should be people in place to provide a "warm handoff". It will take everyone to provide feedback on how school nurses and staff can best undergird this issue.
- Dr. Nelson stated that pediatricians also need training in this area of developmental behavior. She feels that she and many of her colleagues would not know what to say to a school nurse, as they are not mental health experts.
- Ms. Jan Kirby, patient advocate at the Children's Hospital at VCU, stated that there is a lot of talk about PANS and PANDAS but not a lot of forward movement or collaboration on it. They receive many families that are self-referred. The Arizona Treatment Center of Excellence has a process in place. Virginia needs a process; we should look at developing the process from what is already in place. She also recommended that the topic of PANDAS could be included as a topic at the conferences for school nurses.
- Ms. Blaska inquired where cognitive behavior therapy fits into the discussion. She stated there needs to be a bridge for getting the information to people who are currently in crisis.
- Dr. Sood acknowledged that there is an access issue. She also stated that there should be practical resources for pediatricians. Pediatricians should be able to connect with a psychiatrist.

Senator David Suetterlein inquired if there has been any response from the administration regarding the PANDAS annual report that was submitted last December or anything to do with the PANDAS advisory council in general. Dr. Walker Harris responded that children's health is a specific area of priority with the administration and that Dr. Norman Oliver, state health commissioner, has shared the work of the council with the administration. Mr. Joe Hilbert, VDH deputy commissioner, added that the administration is updated regularly and VDH will continue to feed information to the Secretary's office as it is received. Delegate Filler-Corn stated that she had spoken briefly with Governor Northam about the PANDAS advisory council.

Break

Dr. Walker Harris informed invited guests that the council would break for ten minutes before resuming regular council business. She thanked guests for their participation and providing valuable feedback. She recognized that some guests may need to leave during the break and welcomed those who wished to stay to do so.

Review and approval of April meeting minutes

Delegate Filler-Corn made a motion to approve the April meeting minutes, which had been provided to all advisory council members for review in advance of the meeting. The meeting minutes were approved by unanimous vote.

Updates and announcements

Status of draft diagnosis/treatment algorithm:

In response to the comments that Dr. Sood provided to the algorithm, Dr. Nelson asked if the psychiatry consult should happen early. Dr. Sood affirmed that the behavioral piece will help early on in the process. Dr. Swedo stated that she agreed completely with having the psychiatry consult explicitly and implicitly stated in the algorithm. She also added that the algorithm is starting to fail as a pocket guide and cannot be all things. Dr. Walker Harris asked if the plan is to continue to revise the algorithm until it is final. Council members agreed that further revision is needed. Dr. Walker Harris stated the Ms. Robin Buskey would poll the physician group (subcommittee) to provide dates for a meeting to complete the revisions to the algorithm.

UpToDate resource:

Dr. Swedo stated that she had made the protest regarding the *UpToDate* resource. No further work has been done on this effort. The response from UpToDate is that they have reputable studies and articles included. Dr. Swedo stated that she would get one of her colleagues to continue with this effort; right now, they do not have the resources to make this a priority.

Draft parent resource feedback:

Ms. Levensalor stated that she received input from school nurses and staff to develop some parts of the guide. She would like other resources that can be included in the guide. Dr. Swedo offered that she can provide additional resources for inclusion. Dr. Nelson stated that the parent guide is a great resource.

Announcements:

Dr. Swedo shared that 20/20 is supposed to air a special on PANS/PANDAS. Ms. Champion shared that the *Brain on Fire* movie is now on Netflix.

Public comment period

Ms. Blaska stated that she wanted to thank the council for the work they are doing. When asked by Dr. Nelson what advice she would give to pediatricians, Ms. Blaska stated that the doctors need to listen to the parents; they are the best source to know when there are outliers. The public comment period ran from 3:52 – 3:54 p.m.

Adjournment

Delegate Filler-Corn asked for confirmation of the next meeting date. Ms. Buskey confirmed that members agreed at the April meeting to change the November meeting date to Monday, November 26,

2018 from 1:00 – 4:00 p.m. 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.