

PANDAS/PANS Advisory Council Meeting

Libbie Mill Library  
Thursday, June 20, 2019  
1:00 p.m. – 4:00 p.m.

**Meeting Minutes**

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Members Present: Senator George Barker, Delegate Richard Bell, Ms. Teresa Champion, Del. Eileen Filler-Corn, Ms. Jessica Gavin, Dr. David Jaffe, Ms. Stefanie Levensalor, Ms. Stacey Link, Dr. Melissa Nelson, Senator David Suetterlein

Ex Officio Member Present: Dr. Vanessa Walker Harris (Commissioner's designee)

VDH Staff Present: Ms. Robin Buskey

Guests: Ms. Sagé Blaska (Parent), Ms. Arin Barker (Children's Hospital of Richmond at VCU)

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***Welcome and agenda overview***

Delegate Eileen Filler-Corn called the meeting to order at 1:18 p.m. and provided an overview of the meeting agenda.

***Review and approval of meeting minutes***

Delegate Filler-Corn made a motion to approve the minutes for the April advisory council meeting and the May subcommittee meeting. The meeting minutes were approved by unanimous vote.

***Updates and announcements***

The following updates and announcements were shared:

- Ms. Teresa Champion provided an update that the autism insurance legislation was signed into law. She thanked everyone for his or her contributions in getting that accomplished.
- Dr. Melissa Nelson shared some feedback from an ENT meeting that she attended at Georgetown University. Some of the ENT specialists who provide care to children with PANDAS/PANS felt that 1/3 were improved; 1/3 had no change; and 1/3 were worse after treatment.
- Ms. Jessica Gavin stated that there is a publication coming out this summer regarding PANS/PANDAS biomarkers.
- Dr. Vanessa Walker Harris provided an update regarding outreach to the Medical Society of Virginia; MSV still has not set a date for the Dean's Forum but will reconnect with VDH once the date is set. She provided an update regarding outreach to the Department of Social Services; there is a meeting scheduled with Carl Ayers in July to discuss the work of the advisory council. Dr. Walker Harris also provided an update regarding the Virginia Mental Health Access Program (VMAP) and shared that there had been a site visit for the HRSA component of the grant. The major pieces of VMAP include:
  - REACH Fellowship program for pediatricians
  - Telehealth/telepsychiatry consultative services
  - Contracts with five academic centers across the state
  - DBHDS expansion to include social workers and psychologists

- Ms. Robin Buskey shared that VDH had not received a response from Secretary Thomasson regarding advisory council member reappointments. Delegate Filler-Corn added that she also had not received a status update.
- Senator David Suetterlein suggested that it might be beneficial to get a mention of PANDAS/PANS in some of the many publications (i.e. NCSL) that he receives, even if the mention is via other states.

### ***Review of PANS/PANDAS Evaluation and Treatment Algorithm***

Advisory council members reviewed the revised algorithm document that had been formatted by VDH’s communications staff. Council members inquired if the VDH logo should be included on the document. Dr. Vanessa Walker Harris agreed to follow up on the request. No other changes were recommended.

### ***Review of PANS/PANDAS Parent and School Guidance Handouts***

Advisory council members reviewed the parent and school guidance documents that had been formatted by VDH’s communications staff. Council members recommended edits to include removing all references to “CPAE” in both documents, as well as revisions to the list of symptoms and inclusion of [www.praikids.org](http://www.praikids.org) as a support group reference. Ms. Buskey made edits to the electronic version of the documents, which were displayed on the overhead during the meeting. Edits will be provided to communications staff to revise the documents. Ms. Buskey will send the revised documents to the advisory council for review and feedback.

Dr. David Jaffe inquired about the process for making updates to the documents once the advisory council has completed its work in 2020. Dr. Walker Harris advised that the council could recommend a standard schedule for revising the documents. The council should consider what resources should be in place for future review and revision. Senator George Barker suggested that the council recommend a process for obtaining review and recommendation. Ms. Champion added that references and website links would also need to be verified and updated as needed.

### ***Review of Draft Parent and School FAQs Document***

Ms. Champion highlighted the revisions that Dr. Susan Swedo and the subcommittee made to the draft FAQs document following the June advisory council meeting. Council members reviewed the revisions. A few minor edits were suggested to include additional reference sources and deletion of the last question regarding abrupt onset. Ms. Buskey made edits directly onto the document, which was displayed on the overhead during the meeting. Council members requested that VDH communications staff format the FAQs document once all revisions are final.

Dr. Jaffe inquired where the FAQs document would be kept. Dr. Walker Harris responded that the document could potentially be maintained within VDH’s Division of Child and Family Health as PANS/PANDAS could fit with either the Early Childhood or Children with Special Health Care Needs program.

Dr. Jaffe inquired if the government would provide funding for ongoing expert consultation to update the PANS/PANDAS documents that the council has developed. Dr. Walker Harris stated that council members could recommend that general funds be appropriated to support payment of any consultants. Sen. Suetterlein and Barker then stated that a more likely successful strategy would be for the agency to forward a budget proposal.

Ms. Gavin inquired if it would be acceptable for the FAQs document to be posted on her organization's website, [www.praikids.org](http://www.praikids.org). Council members agreed that the site would be appropriate. Dr. Walker Harris shared that VDH routinely shares information and FAQs on the agency's website.

#### ***Discussion regarding recommendations for educating the judicial system***

Ms. Champion informed the group that she asked to include this topic on the agenda because she had become aware of more incidents involving adults who have been diagnosed with PANDAS/PANS coming into contact with law enforcement. She stated that there is a need for education throughout the judicial system. Delegate Filler-Corn described the bill that she introduced in 2018 that would have addressed law enforcement's ability to deal with individuals on the spectrum. The bill did not advance because the Department of Criminal Justice Services (DCJS) had indicated that this work was already in progress. Delegate Filler-Corn stated that she would follow up with DCJS and provide a status update to the advisory council.

Senator Barker described the recent changes that have been implemented for the transport of individuals with temporary detention orders. The state has now contracted with a private contractor to provide transportation services. Drivers that have been trained on how to handle and manage situations involving persons with mental illness will transport them. Law enforcement will be contacted for assistance if needed.

#### ***Public comment period***

Ms. Sagé Blaska shared her personal experience with law enforcement and the manner in which they treated her son. She stated that she did not think that law enforcement should be transporting or handling children who have a mental illness. Ms. Blaska stated that her recommendation would be for emergency medical transportation (EMT) personnel to transport individuals in those situations. Ms. Blaska also stated that there are silos regarding medical treatment to treat PANDAS/PANS and she thinks it would be beneficial to have the perspective of an immunologist and gastrointestinal specialist on the advisory council. Ms. Blaska also described her family's traumatic experience in dealing with the Department of Social Services (DSS) and the foster care system. She stated that it is important that DCJS and DSS be informed about the disorders that cause certain behaviors.

#### ***Next steps***

Delegate Filler-Corn asked council members if the scheduled September 23<sup>rd</sup> meeting date worked for everyone. No changes were made to the meeting date. She then asked council members to suggest a November meeting date. Delegate Filler-Corn asked Ms. Buskey to send out a Doodle poll to determine member availability for November 13<sup>th</sup> and 18<sup>th</sup>.

#### ***Adjournment***

The meeting was adjourned at 3:29 p.m.