

PANDAS/PANS Advisory Council  
Meeting of the Subcommittees

Libbie Mill Library – Large Meeting Room  
Tuesday, January 16, 2018  
1:00 p.m. – 4:00 p.m.

**Meeting Minutes**

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Subcommittee Members Present: Ms. Teresa Champion, Dr. David Jaffe, Ms. Stefanie Levensalor, Ms. Stacey Link, Dr. Melissa Nelson, Dr. Susan Swedo

Ms. Jessica Gavin participated via telephone conference.

VDH Staff Present: Ms. Robin Buskey

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***Welcome and Agenda Overview***

Robin Buskey called the meeting to order and informed the group that Ms. Jessica Gavin had called that morning to inform her that she would not be able to attend the meeting in-person due to illness and requested to participate via telephone conference. Ms. Gavin was conferenced into the meeting. Ms. Buskey provided an overview of the meeting agenda. Committee members agreed to meet in the order of the prepared agenda versus meeting concurrently by subcommittee topic area so that all members could participate in the full discussion of each topic.

***Focus Areas: Practice guidelines for diagnosis and treatment***

Committee members discussed possible approaches to systematizing and simplifying the guidelines into pocket guides that can then be distributed among providers. Dr. Susan Swedo suggested that VDH could help with development of the pocket guidelines. Dr. Melissa Nelson volunteered to make a checklist and create a flowchart of the discussion for the pocket guide. Key points raised by committee members included the following:

- Which tests will be ordered as standard?
- In addition to *what* tests to order, determine what is low, what is high and what is expected on the test results.
- What are the most relevant history questions (lab results do not make or exclude the diagnosis)?
- Target the top three symptoms for treatment.
- What defines abrupt onset?
- How does one know when he/she should continue to consider PANS?
- What antibiotics are prescribed? What dosage and for how long?
- When is follow up after the start of treatment?
- What happens if there is a relapse?
- What other tests, such as EKG, are performed?
- Use of antidepressants and cognitive behavioral therapy as treatment options
- What is the biology of the family?
- Can development of the pocket guide be considered creating a standard of care? Committee members think there needs to be legal approval so that they are not liable.

Dr. Swedo and Dr. David Jaffe described the Arizona model, of which Dr. Nelson drew a diagram on the white board. Dr. Jaffe stated that he has a whole PowerPoint presentation on the Arizona model that can be shared with the full council. Dr. Swedo stated that she visited Arizona four times; they are well coordinated and have the ability to call in whomever (pediatrician, psychiatrist, etc.) they need for service provision. The goal is to have all services in place once the child is at the center. Dr. Swedo stated that the cystic fibrosis model was the source used for other models.

***Focus Areas: Mechanisms to increase clinical awareness***

Ms. Teresa Champion stated that there must be a systematic education of physicians in the five regions of the state. Other members agreed that it would be necessary to have the large education universities on board this process. Once the pocket guide is developed, it will need to be shared with the universities to get their feedback; that feedback should be incorporated into final development of the guide.

Ms. Champion shared information gathered from her research on the *UpToDate* resource used by physicians. She stated the importance of ensuring that the resource is updated with all of the most recent studies related to PANS and PANDAS because physicians reference that resource when providing an explanation about them not being valid disorders. Based on her research, she found that there are one or two people running *UpToDate*. Dr. Swedo stated that NIMH would look into providing updates to the resource.

***Focus Areas: Outreach to educators and parents***

Ms. Stefanie Levensalor shared her family's personal experience in dealing with PANDAS. She volunteered to draft an outline of an action plan that describes what helped them navigate through the school. Committee members thought that would be helpful. Dr. Swedo stated that schools need a comparable pocket guide. Committee members discussed the disparities that exist across and within school divisions; many schools lack adequate resources and some have nursing staff that are available less on a part-time basis only, if that.

Ms. Nelson inquired about implementation of the pocket guide. She stated that she had previously asked Mr. Joe Hilbert if in fact the council can implement this and would like more clarification. Ms. Buskey stated that the role of the advisory council is to advise the health commissioner on the council's recommendations regarding the four focus areas. Ms. Buskey also stated that she would follow up with Mr. Hilbert regarding implementation.

***Public Comment Period***

No members of the public were present for the subcommittee meetings.

Committee members discussed efforts around developing a Center of Excellence in Virginia. Ms. Gavin stated she would initiate an invitation for someone to come speak to the advisory council to provide an update on this initiative. Members conferred about what is needed to move this effort forward. There is some cost information available through the PANDAS Network. There is also money available through the General Assembly for the Virginia Neuroscience Initiative, which encourages hospitals to work together.

Ms. Champion asked if any of the committee members were aware of Governor Northam's position on PANDAS and PANS. Members discussed the possibility of sending an introductory letter from the advisory council through VDH.

Dr. Nelson stated that she would send the draft checklist/flow chart of the pocket guide to Ms. Buskey to disseminate to the full council.

***Adjournment***

Ms. Buskey provided closing remarks and thanked the committee members for their time. Committee members agreed that it had been a productive meeting. The meeting adjourned at 4:00 p.m.