

PANDAS/PANS Advisory Council
Meeting of the Subcommittees

Libbie Mill Library – Conference Room
Monday, October 15, 2018
10:00 a.m. – 12:00 p.m.

Meeting Minutes

Subcommittee Members Present: Ms. Teresa Champion, Ms. Jessica Gavin, Ms. Stefanie Levensalor, Dr. Bela Sood

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

VDH Staff Present: Ms. Robin Buskey

Guests: Ms. Sagé Blaska, Mr. Jason Schiller

Welcome and Agenda Overview

Robin Buskey called the meeting to order and reviewed the meeting agenda. The purpose of the meeting was to finalize revisions to the PANDAS parent and school guidance documents. A motion to approve the meeting agenda was approved. Ms. Buskey stated that the public comment period, which informs the work of the group, was placed upfront on the agenda so that any feedback or information received from the public that might influence the working document could be considered.

Public Comment Period

Ms. Sage Blaska shared comments related to the following: 1) concern that the reference to autism was removed from the algorithm document; 2) determination of where ASO titers should reside on the algorithm because it is good to have a baseline measure; and 3) if there will be any focus by the advisory council on mandating that insurance covers PANS and PANDAS.

Mr. Jason Schiller shared comments regarding the inclusion of other criteria for diagnosing PANDAS and PANS; he had made prior recommendations for references that he found while scouring the internet. Mr. Schiller stated that the documents are incomplete. A distinction of PANDAS and PANS should be included in the document. Mr. Schiller further suggested that the development of a resource list include summary information in addition to the web links.

Dr. Walker Harris advised that insurance mandates were outside the scope of what the council was specifically charged to do. However, council recommendations to the Health Commissioner can broadly relate to the four focus areas. The committee considered public comments and feedback when revising the guidance document during the working session of the meeting.

Revisions to the PANDAS Parent and School Guidance

Committee members discussed developing an FAQs document as an accompaniment to the parent and school guidance document because including all of the relevant resources would be too lengthy for the one-page document. Committee members agreed that the FAQs document should include a summary of the web links.

Key points raised by committee members included the following:

- When taking the prescriptive view, all information does not make its way to into the one-page document.
- The document should speak to practice patterns.
- The guidance document should not include references to ASO titers.
- An outside group should review the documents; should also obtain feedback from parents and educators on the FAQs document.
- The FAQs should be linked to the parent and school guidance document; include a web link on the FAQs.
- The committee will develop a Google Doc for the FAQs; would like to get input from other people regarding the questions to include.

Committee members determined final revisions to the parent and school guidance document. Ms. Buskey made all edits directly to the document, which was displayed on the overhead screen.

Adjournment

The meeting adjourned at 11:50 a.m.