

PANDAS/PANS Advisory Council  
Meeting of the Subcommittees

Libbie Mill Library – Conference Room  
Monday, August 20, 2018  
1:00 – 4:00 p.m.

**Meeting Minutes**

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Subcommittee Members Present: Ms. Teresa Champion, Ms. Stacey Link, Dr. Melissa Nelson, Dr. Bela Sood, Dr. Susan Swedo, Dr. Wei Zhao

By phone: Ms. Stefanie Levensalor

VDH Staff Present: Ms. Robin Buskey

Guests: Ms. Sagé Blaska, Mr. Jason Schiller

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***Welcome and Agenda Overview***

Robin Buskey called the meeting to order and informed the group that Ms. Stefanie Levensalor had requested participation by phone, as she was unable to travel due to immediate work commitments. Ms. Buskey provided an overview of the meeting agenda. The purpose of the meeting was to finalize revisions to the PANS/PANDAS algorithm and parent and school guidance documents.

Two members of the public were present. Sage Blaska and Jason Schiller introduced themselves as parents. Ms. Blaska and Mr. Schiller had obtained copies of the draft working documents and attended the meeting intending to provide feedback on the final revisions. Ms. Buskey asked committee members to determine whether Ms. Blaska and Mr. Schiller could actively participate throughout the meeting. Committee members allowed their participation.

***Revisions to the PANS/PANDAS Diagnosis and Treatment Algorithm***

Ms. Robin Buskey had provided committee members with an electronic copy of the most recent version of the algorithm, as edited by council members, prior to the meeting. Hard copies of the document were also provided at the meeting. Mr. Schiller announced that he had a more updated version of the algorithm from which to make the final revisions. Committee members determined that the draft version provided by Ms. Buskey would remain the official working document from which all changes would be made. The draft document was placed on the overhead screen and all edits to the draft algorithm were made directly in the documents during the meeting.

Key points raised by committee members included the following:

- What are the “mays” vs. what are the “musts”? Will need to determine which labs are definitely needed in the flowchart.
- Dr. Swedo will expand her organization’s website to include the labs that are absolutely necessary and those that are not.
- Dr. Swedo will send the web link to the FAQs to Ms. Buskey for inclusion in the algorithm document.
- Is the flowchart on the PPN website helpful?

- Where on the algorithm can there be a mention of autism?
- What are the points where parents experience the most distress?

### ***Revisions to the PANDAS Parent and School Guidance***

Ms. Robin Buskey had provided committee members with an electronic copy of the most recent version of the parent and school guidance document, originally drafted by Ms. Stefanie Levensalor and edited by council members, prior to the meeting. Hard copies of the document were also provided at the meeting.

Ms. Teresa Champion distributed a handout that had been developed by the PANDAS Network. She inquired if it might be useful to adopt the resource that had already been developed for families and schools rather than reinventing the wheel.

Key points raised by committee members included the following:

- Cause is very PANDAS specific, but not PANS; it might be helpful to lead off with definitions of the two to show how they are different.
- The guidance document is more helpful with what parents need to know and is more user-friendly; recommend continue with needed revisions as agreed by the full council.
- The document should incorporate what the “newbie” needs to know.
- What is the desired outcome of the guidance document? That is what should be included, keeping in mind that it is one page.
- It is helpful for the guidance document to include “what to do”.

Due to time constraints, the committee was unable to make the edits the parent and school guidance document.

### ***Adjournment***

Ms. Buskey provided closing remarks and thanked the committee members for their time. She stated that she would arrange a follow-up committee meeting to complete the final revisions to the guidance document. The meeting adjourned at 4:00 p.m.