

PANDAS/PANS Advisory Council – Subcommittee Meeting  
Focus Area – Outreach to parents and educators  
Libbie Mill Library – Conference Room  
Monday, May 20, 2019  
1:00 p.m. – 3:00 p.m.

**Meeting Minutes**

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Members Present: Ms. Teresa Champion, Ms. Jessica Gavin, Ms. Stefanie Levensalor, Ms. Stacey Link

VDH Staff Present: Ms. Robin Buskey

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***Welcome and Agenda Overview***

Ms. Teresa Champion, subcommittee chair, called the meeting to order and provided an overview of the agenda; the purpose of the meeting was to revise the FAQs document, which will supplement the parents and educators guidance document

***Discussion regarding development of PANDAS action plan for schools***

Per Ms. Champion's request, Robin Buskey provided sample action plan documents for subcommittee members to review. The documents were retrieved from the Chesterfield County Public Schools website, and they included action plans for general health care, diabetes, life threatening allergies, and asthma. Members reviewed the documents and asked Ms. Stacey Link to explain how the action plans are used in the school to include who develops the action plan and the role of the school nurse, parents/guardians, pediatrician and teachers in communicating and implementing the plan.

Subcommittee members discussed the need for simple instructions for teachers and school nurses to be included like an "Individualized Healthcare Plan" document or including instructions into an IEP or 504 Plan. The instructions would serve as "Cliff Notes" for teachers and school nurses for what to look for in an individual student if they see changes (such as symptoms of OCD and anxiety) and provide guidance on what supports could be put in place. Subcommittee members see this as more of an "Emergency Action Plan" for this diagnosis rather than a "health plan". The subcommittee recognized that school nurses can go to IEP meetings; that should be encouraged as an option to increase parental awareness. Subcommittee members decided that further research is needed and that the discussion would resume at a later date. The balance of the meeting was devoted to revising the FAQs document.

***Revisions to the FAQs document***

Ms. Buskey shared an updated electronic version of the FAQs document, which included Dr. Sue Swedo's revisions, with subcommittee members in advance of the meeting. Hard copies were provided at the meeting and the document was projected onto the screen for review. The group discussed Dr. Swedo's revisions and expressed concerns that some of the language may be too technical for parents and lay persons unfamiliar with PANS and PANDAS. Ms. Champion made additional edits to the FAQs document throughout the meeting discussion based on group consensus. Ms. Champion planned to send an electronic version of the revised document to Ms. Buskey for distribution to the full committee.

***Adjournment***

The meeting adjourned at 3:00 p.m.