PANDAS/PANS Advisory Council – Subcommittee Meeting Focus Area – Outreach to parents and educators Varina Library – Conference Room Monday, March 25, 2019 1:00 p.m. – 3:00 p.m.

Meeting Minutes

Members Present: Ms. Teresa Champion, Ms. Stefanie Levensalor

By Phone: Ms. Jessica Gavin

VDH Staff Present: Ms. Robin Buskey

Guests: Ms. Sagé Blaska (by phone), Mr. Jason Schiller, Ms. M.J.

Welcome and Agenda Overview

Ms. Teresa Champion, subcommittee chair, called the meeting to order and informed the group that Ms. Jessica Gavin had previously requested to participate via conference call, as she was unable to attend in person. Ms. Champion stated that a parent guest would also participate via conference call. Ms. Champion provided an overview of the agenda; the purpose of the meeting was to develop a FAQs document to supplement the parent and educators guidance document. Ms. Champion stated her preference to forego the scheduled public comment period in lieu of having the participants provide comment throughout the working subcommittee meeting. All members were in favor of the proposed approach.

Ms. Champion provided an update to the subcommittee that the PANS/PANDAS algorithm document would focus on the diagnosis and treatment of PANS, not PANDAS and asked Ms. Gavin to provide an update from the subcommittee that met on Friday, March 22, 2019 to finalize the algorithm. Ms. Gavin stated that due to the past controversy surrounding PANDAS, the algorithm focuses on the overarching umbrella of PANS. Ms. Robin Buskey provided copies of the parent and school guidance and the updated algorithm.

Development of the FAQs document

Ms. Champion provided hard copies of two draft FAQs documents. The first document consisted of a table format that included questions, responses and references for the given responses. The table also included two check columns to indicate if the question was from the perspective of a parent, an educator or both. The second document was a sample format of a FAQ document for parents. Ms. Champion noted that the documents were intended to provide a starting point based on feedback she had received after soliciting parents to determine the type of information they would find most useful.

Ms. Champion made a motion to use the table document as the working document to include all potential questions in one document. Ms. Levensalor seconded the motion. The members voted in favor to develop one comprehensive table during the meeting. The electronic version of the draft FAQs table was placed on the overhead screen and Ms. Champion made all edits to the document based on feedback and consensus of the group. Language, wording and text placement changes were made to the document for consistency and clarity, and reference links were added so that individuals can obtain additional information on a given topic. In addition, Ms. Levensalor sent a number of reference links via email to Ms. Champion during the meeting for inclusion in the table. Ms. Champion stated that she would incorporate the links into the table and send a clean version to Ms. Buskey for distribution to the full advisory council.

In addition to feedback regarding development of the FAQs document, parent guests noted the following points of consideration:

- There is a need for the advisory council to educate beyond parents and educators. Individuals working within child protective services and foster care at the Virginia Department of Social Services need to be educated on PANS and PANDAS.
- The Department of Behavioral Health and Developmental Services also need to be informed about PANS and PANDAS; the agency provides money for certain in-home services.

Adjournment

The meeting adjourned at 3:06 p.m.