

PANDAS/PANS Inaugural Advisory Council Meeting

November 29, 2021, 9:00 – 11:00 AM

Via WebEx Event

Present: Elaine Gabovitch, PANDAS/PANS Advisory Council Chair & DPH Ex-Officio Member; Margaret Chapman, RN, MSN, PMHCNS-BC; Karen Colwell, PTA; Sylvia Fogel, MD; John Gaitanis, MD, Sheilah Gauch, LICSW, Med; Melissa Glynn-Hyman, LICSW; Lisa Grisolia; Melissa McCormack, MD, PhD; Mark Pasternack, MD; Michelle Pinto, MSN, RN; Blake Poggi, MA, CCC-SLP; Jennifer McCormack Vitelli, MBA; Kyle Williams, MD, PhD; Yujuan Julia Zhang, MD; Nicole Roos; Betsy Day, CHTA; Casey Hall, CHTA

Meeting Agenda

1. Welcome, Agenda and Meeting Rules
2. Roll Call: Attendance and Vote: October 25, 2021, meeting minutes approval
3. OML & work groups: Sophia Apostola, DPH
4. Introductions: Melissa McCormack, MD & John Gaitanis, MD
5. Logic Model, Aim Statement & work plan review, edits and voted
6. Resources for report content (as time allows)
7. Plans and preparation for meeting on January 12, 2022
8. Vote: Adjourn

1. Welcome, Agenda and Meeting Rules (slides 2,4)

Elaine Gabovitch, PANDAS/PANS Advisory Council Chair called the meeting to order and welcomed the Advisory Council. She reviewed the agenda and meeting rules.

2. Open Roll Call & Vote (slide 3)

Elaine Gabovitch managed the virtual open roll call and Betsy Day tracked this information for the meeting record. Elaine led the vote to approve the 9/29/21 meeting minutes. There was a quorum with 13 Advisory Council members in attendance.

3. Statutory Authority (slide 5)

Elaine Gabovitch, Chair (designee of the Commissioner of DPH) shared the following with the Advisory Council:

Statutory Authority, Section 26 of Chapter 260 of the Acts of 2020, Advisory Council to advise the Commissioner on *research, diagnosis, treatment, and education* relating to pediatric autoimmune neuropsychiatric disorder associate with streptococcal infections and pediatric acute neuropsychiatric syndrome (PANDAS/PANS).

4. EG reviewed 2022 Regular Bi- monthly Meeting schedule (slides 6)

January 12	Wednesday	4-6 PM	2nd
March 9	Wednesday	4-6 PM	2nd
May 11	Wednesday	4-6 PM	2nd
July 13	Wednesday	4-6 PM	2nd
September 14	Wednesday	4-6 PM	2nd
November 9	Wednesday	4-6 PM	2nd

5. Sophia Apostola, DPH Legal Counsel to Bureau of Family Health and Nutrition (slide 7)

Presentation, discussion, and Q&A regarding PANDAS/PANS council workgroups, which resulted in deep conversation, brainstorming, confusion and frustration, and many questions. Below includes topic or theme areas:

- Open Meeting Law review of restrictions and intricacies
- Work groups meetings have to be public meetings, need clarity around quorum # 8 or less per group?
- Cautioned about breaking OML via outside discussions, sharing documents, commenting on documents
- Role of volunteers/researchers regarding interaction with workgroups and individuals
- Recommendation is for 4 work groups: Diagnosis, Education, Research and Treatment – questions: how can they effectively and efficiently work together to fulfill mission and goals?
- Sophia Apostola said yes to 4 work groups and clarity is needed regarding how this would work for the Advisory Council.
- A vote was taken with a Yea response to break into 4 work groups as mentioned above.

6. Two More Council Member Introductions (slide 8)

1. What is your connection to PANDAS/PANS, and what brought you here?
2. What skills and experience will you contribute to the Council?
3. What do you hope to achieve?
 - Dr. Melissa McCormack (Pediatrician): Some key hopes to achieve are research and education.
 - Dr. John Gaitanis (Neurologist): Some key hopes to achieve are access to care and equity, get more physicians to work with PANDAS/PANS

7. Aim statement/work plan development (slide 9)

Elaine Gabovitch reviewed the drafts of the logic model, aim statement and workplan drafts. In real time the council could comment and make suggestions for changes. The drafts were updated at once. There was a council vote facilitated with a Yea response to approve the model, statement and workplan. More work is to be done on all documents. For now the work that has been identified is approved.

To do moving forward:

- determine Council members roles based on skills and experience
- determine next steps for documents to complete and implement

Sheilah Gauch and Jennifer Vitelli both co-facilitators for the Advisory Council will provide resources for the annual report. Resources include PANDAS/PANS studies and reports from other States, and other environmental scan activities and information relating to Diagnosis, Education, Research and Treatment.

8. Next Steps: Setting the Agenda together, the meeting and method

First bi-monthly meeting for 2022 will held on January 12, 4-6 PM using MS Teams

General Agenda topics include: reviewing update aim statement, logic model and work plan; reviewing research (diagnosis, education, research, and treatment) that will be sent out ahead of time; discuss setting up a doodle poll to establish the 4 working groups.

9. Vote to Adjourn the Meeting (slide 11)

Elaine Gabovitch thanked everyone in attendance, lead the vote to adjourn the meeting. Motions 1 and 2 obtained and voting roll call (Yea or Nay) was completed.

All votes during this meeting obtained two motions and have been recorded.