# PANDAS/PANS Advisory Council Meeting July 13, 2022, Meeting Minutes

Via WebEx (Zoom) Event

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

# Meeting Agenda

1. Welcome: Roll Call & vote to approve May 11, 2022, meeting minutes
2. Vote: Annual Report draft
3. Work Group Presentations: Treatment, Research, Diagnosis, Education
4. Share Council Updates
5. Next Meeting: Wednesday, September 14, 2022, 4-6 PM
6. Vote: Adjourn

# Welcome, Agenda and Meeting Rules (slides 2)

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

# Open Roll Call & Vote and meeting rules (slide 3 and 4)

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 May 11, 1022, meeting minutes. There was a quorum with 13 Advisory Council members in attendance.

# 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).

1. **Aim Statement review (slide 6)
The DPH PANDAS/PANS Advisory Council aims to advise the DPH Commissioner on research,** diagnosis, treatment, and education relating to pediatric autoimmune neuropsychiatric discovered associated with streptococcal infections and pediatric acute neuropsychiatric syndrome (PANDAS/PANS).

# EG reviewed 2022 Regular Bi- monthly Meeting schedule (slides 7)

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

1. **Vote on Annual Report Draft (slide 8)**- Final thoughts & discussion of conclusion
- Vote
- Next Steps

An interactive discussion occurred around a particular sentence in the report. Amy Benison the report writer posted a question to the council… Do you all agree with this sentence?
***Countless children with PANDAS/PANS are relegated to a life of mental illness and symptom management when in fact they have a physical illness that cannot only be treated but cured.***

After an open group dialogue the sentence was reworked. Here is the sentence as it currently stands.

***Countless children with PANDAS/PANS are sub-optimally treated exclusively for mental illness with
 a focus on symptom management. In fact, many have a neuroimmune illness that when identified
 and treated is critical to their recovery.***

1. **Work Group Report Guidelines (slide 9)**High level reports from each work group reporter

Timing: *10 min + 5 Q&A*

 Share: each group’s process, general topics team discussed and each team’s plans moving forward

1. **Work group Reporting Order (slide 10)**Please note that each presentation was interactive with Q&A taking 10 or more minutes for discussion. **Treatment** Sheilah Gauch, Reporter; Melissa Glynn-Hyman, Facilitator
 Key point: challenge keeping the discussion on track versus symptoms of P/P
 1. Not finding a lot of research or data on treatment of other symptoms
 (OCD, PMS)related to P/P.

 2. Will continue to work on baseline. Question to the council: Are we only sticking to
 data for P/P?

 3. Will only focus on research and not assumptions for only P/P.

 4. Plan to meet in August.
2. **Research** Kyle Williams, Reporter/Facilitator
 1. Followed-up on original approach to survey. Looked at research, correlations
 between, and what other research needs to be done.

 2. Blake Poggi put together a comprehensive research list with 270 total research
 hits to review.

 3. Will also get list from American Pediatrics Association.

 4. Research is not P/P specific (includes inflammation & other).

**Diagnosis** John Gaitanis, Reporter; Sylvia Fogel, Facilitator
 1. Focus on community clinicians
 - this is a clinical diagnosis
 - emphasize presentation
 - evidence based to be included in diagnosis

 2. Work group thinking about a simple, hands-on table with criteria, symptoms, initial
 and secondary workups and more to help and educate clinicians.

 3. Propose a broad outline of table … look at historical diagnosis, next steps, broad
 clinical symptoms, testing (neuroimmune work-up).

 4. Diagnosis through trials to give clinicians a tool.

 5. Next meeting scheduled for 7/25 and goal is to have a draft.

**Note:** Discussed during this presentation the format of the Report and Sources, i.e., should it be AMA or other? Elaine Gabovitch stated this decision should come from the group (council). It will appear on the next meeting agenda for the group to make a determination.

**Education** Michelle Pinto, Reporter; Lisa Grisolia, Facilitator
 1. Meeting 2 focused on families, siblings, clinicians, educators, insurance companies,
 justice system and more

 2. Finding: big information gap with medical and insurance companies. Burden is on
 providers to wrestle with the insurance companies.

 3. Draft is complete enough to submit (includes 10 pages of links). This
 work group will not meet again.

 4. Asked the council for help with connecting to insurance companies:
 - Jennifer Vitelli suggested inviting an official (Kevin Beagan, Deputy Director of
 Insurance) who has insurance knowledge on how to access information.
 - Elaine Gabovitch suggested a resource: Center for Autism & Mental Health,
 U-Mass Shriver Center.

# Other - Elaine Gabovitch suggested work groups send out their agenda ahead of the Advisory Council meeting so each group can respond based on looking over the agenda before the meeting. - Jennifer Vitelli asked if the work groups would want to dedicate a meeting to review before getting into the Gap Analysis. Question for next meeting: Would work groups want to agree to share documents? Sharing documents would cut down on redundancies.  - Work groups need to embed links into their draft reports and findings.

# Possible Timeline Discussion (Slide 11) 1. Gap Analysis goal – November 9  2. Review of slide

# Council Updates (Slide 12) 1. P/P Awareness Day at the State House, October 8, 2022. Jennifer Vitelli spoke about this and asked if the people wanted to celebrate this day. 2. Lisa Grisolia mentioned that other USA P/P groups want to do a walk (virtual or in-person) Peggy Chapman suggested sending a thank you note to the legislators…DPH, EHS or council. Elaine Gabovitch to get answers about these ideas. 3. Both John Gaitanis and Kyle Williams have role changes coming up

# Next Steps (slide 13) Fifth bi-monthly meeting for 2022

#  Wednesday, September 14, 2022, 4-6 PM

#  Future meetings via WebEx Events

#  If you need help, please email Betsy Day in advance who will find assistance

#  Agenda for next time:

#  Final baseline report outs from work groups (before moving to gap analysis)

#  Schedule CY23 meetings

#  Possible future meeting agenda items for Council consideration

#  Anything else?

# 11. Vote to Adjourn the Meeting (slide 114)

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.