# PANDAS/PANS Advisory Council Meeting September 14, 2022 Final Meeting Minutes

Via WebEx (Zoom) Event

**Present:** Elizabeth (Beth) Bostic, PANDAS/PANS Advisory Council Temporary Acting Chair & DPH Ex-Officio Member; Margaret Chapman, RN, MSN, PMHCNS-BC; Karen Colwell; Sylvia Fogel, MD; Sheilah Gauch, LICSW, Med; Melissa Glynn-Hyman, LICSW; Lisa Grisolia; Kathleen (Kate) Maher; Melissa McCormack, MD, PhD; Blake Poggi, MA, CCC-SLP; 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 July 13, 2022, meeting minutes
2. Announcements: General and Housekeeping
3. Vote: 2023 Bi-Monthly Meetings
4. Work Group Presentations: Treatment, Research, Diagnosis, Education
5. Wrap-up: Next steps for work groups
6. Next Meeting: Wednesday, November 9, 2022, 4-6 PM
7. Vote: Adjourn

# Welcome, Agenda and Meeting Rules (slides 2)

Elizabeth (Beth) Bostic, PANDAS/PANS Advisory Council Temporary Acting Chair, called the meeting to order and welcomed the Advisory Council. Elizabeth (Beth) stood in for Elaine Gabovitch who was unable to make the meeting. She reviewed the agenda and meeting rules.

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

Elizabeth (Beth) managed the virtual open roll call and Betsy Day tracked this information for the meeting record. Elizabeth (Beth) led the vote to approve the July 13, 2022, meeting minutes. There was a quorum with 10 Advisory Council members in attendance.

# Statutory Authority (slide 5)

Elizabeth (Beth) shared 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 associated 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 disorder associated with streptococcal infections and pediatric acute neuropsychiatric syndrome (PANDAS/PANS).

# General Announcements (slide 7)Elizabeth (Beth) reviewed this slide and explained that it was moved to the beginning part of the meeting from the end, as to not to miss out on important updates, announcements and other due to time constraints.Some updates: October 1, 2022, Peggy Chapman will be a speaker at the PANDAS/PANS meeting, Sheilah Gauch will be speaking at an International Conference, and October 9 is PANDAS/PANS Day in Hull, MA.Suggestion: Discussion for the larger group – Who do we invite as subject matter experts (SME) to the Advisory Council meetings, i.e., division of insurance, Russell Johnson.November meeting will be used to reflect, take stock and plan.

# Work Group Contact/Public Access Changes (slide 8)Significant changes: DPH requires a secure DPH email contact and video link, and also that a DPH representative is available during work group meetings to assist the public as needed. Two other points here included options for work group meetings (in-person, bimonthly, flex), and asking if the work groups could set the 2023 calendar in the meeting? While continuity was expressed as a good idea (meeting every month in-between the Advisory Council Meeting) a challenge for the doctors is availability during usual business hours included between patients and being on-call. We ended without resolution, but with two actions: work groups will bring timelines to the next Advisory Council meeting on 11/9/22 and will take a vote. Casey Hall pointed out about quorum regarding flexing and combining workgroups from 4 for example to 2. No group can have 8 people as that would be a quorum.

# EB reviewed 2022 Regular Bi- monthly Meeting schedule (slides 9)

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

1. **Vote on 2022 Bi-Monthly Meeting Schedule for the Advisory Council (slide #10)**This schedule was accepted.

|  |  |
| --- | --- |
| January 11 Wednesday | 4-6 PM  |
| March 8 Wednesday | 4-6 PM  |
| May 10 Wednesday | 4-6 PM  |
| July 12 Wednesday | 4-6 PM  |
| September 13 Wednesday | 4-6 PM  |
| November 8 Wednesday | 4-6 PM |

1. **Work Group Report Guidelines (slide 11)**

High level reports from each work group reporter

Timing: 10 min + 5 Q&A

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

**10.Work group Reporting Order (slide 12)**Please note that each presentation was interactive with Q&A taking 10 or more minutes for discussion. **Treatment**, **Research and Diagnosis** not reporting today.

**Education**

Michelle Pinto, Reporter; Lisa Grisolia, Facilitator Lisa Grisolia presented on behalf of the group and included slides in her presentation. Slides 13-23 were education work group slides included into the overall presentation.

 **Slide 13:** Education Workgroup Environmental Scan **Slide 14:** Education Workgroup Target Audiences

**Slide 15:** Education for School Personnel **Slide 16:** Sources for Education for School Personnel **Slide 17-18:** Education for Parents & Families **Slide 19:** Type of Media for Family Education **Slide 20-22:** Education for Medical Professionals **Slide 23:** Education for Public Service/DepartmentsGroup conversation ensued with requests for others to share resources, tools, diagnostics and more with each other. There is cross-over which would be helpful to all.

# Next Steps (slide 24)

# Sixth and final bi-monthly meeting for 2022

# Wednesday, November 9, 2022, 4-6 PM

# Future meetings via WebEx Events

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

# Next steps for Work Groups

# Continue to work on baseline through January

# Use November to reflect, listen and plan (see General Announcements)

# Invite families to tell their stories

# Email Elaine.Gabovitch@mass.gov to get on Nov. agenda for updates

# Anything else?

# 12. Vote to Adjourn the Meeting (slide 25)

Elizabeth (Beth) Bostic thanked everyone in attendance, led 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. One vote, motion #2 was not identifiable so could not be recorded.