

Massachusetts Department of Public Health

DPH PANDAS/PANS Advisory Council

November 9, 2022 4:00 – 6:00 PM

Please stand by. The meeting will begin shortly.

Agenda

- Welcome: Roll call & vote to approve 9/14/22 minutes
- Announcements: General & housekeeping
- <u>Discussion</u>: Year reflection & moving forward
- Present: No work group updates this month
- Vote: Work group meeting times
- Wrap Up: Next steps for work groups
- Next Meeting: Wednesday, January 11, 2023, 4-6 pm
- Vote: Adjourn

Opening Roll Call & Vote

- Attendance roll call
- Vote to approve Meeting Minutes (September 14, 2022)

Meeting Rules

- Open Meeting Law applies:
 - Chat function disabled
 - Texting, emails, etc. are public records
 - Council member attendance taken to establish quorum
- Agenda pre-planned
- Cameras on during the meetings
- Mute your mic unless you are speaking
- Meeting not recorded
- "Raise your Hand" option to speak

Statutory Authority

Section 26 of Chapter 260 of the Acts of 2020, or the Health Care Omnibus bill establishes a special advisory council, chaired by the Commissioner of the Department of Public Health, or her designee, 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).

Aim statement

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).

The Advisory Council will issue a report to the general court annually with recommendations concerning:

- Practice guidelines for the diagnosis and treatment of the disorder and syndrome;
- Development of screening protocols;
- Mechanisms to increase clinical awareness and education regarding the disorder and syndrome among physicians, including pediatricians, school-based health centers and providers of mental health services;
- Outreach to educators and parents to increase awareness of the disorder and syndrome;
 and
- Development of a network of volunteer experts on the diagnosis and treatment of the disorder and syndrome. (From Section 26 of Chapter 260 of the Acts of 2020).

General Announcements

- Jennifer, Sheilah and Mark met with the Deputy Commissioner of Insurance
- Elaine visited the Dearborn Academy at the invitation of Sheilah and Rebecca Altepeter (Head of School), and Peggy Chapman attended as medical advisor as well

Please contact <u>Elaine.Gabovitch@mass.gov</u> to add any other Advisory Council updates, announcements to future agendas.

2022 Bi-Monthly Meeting Schedule

Meeting #	Month and Day		Time	Week of Month
1	January 12	Wednesday	4-6 PM	2nd Complete
2	March 9	Wednesday	4-6 PM	2 nd Complete
3	May 11	Wednesday	4-6 PM	2 nd Complete
4	July 13	Wednesday	4-6 PM	2 nd Complete
5	September 14	Wednesday	4-6 PM	2nd Complete
6	November 9	Wednesday	4-6 PM	2nd Pending

2023 Bi-Monthly Meeting Schedule

Meeting #	Month and Day		Time	Week of Month
1	January 11	Wednesday	4-6 PM	2 nd
2	March 8	Wednesday	4-6 PM	2 nd
3	May 10	Wednesday	4-6 PM	2 nd
4	July 12	Wednesday	4-6 PM	2 nd
5	September 13	Wednesday	4-6 PM	2 nd
6	November 8	Wednesday	4-6 PM	2 nd

Reflection Discussion re: 2022

- Let's take a moment to reflect on the past year!
 - What worked?
 - What didn't?
 - What would you like to keep/discard/change, etc.?

Please take *no more than 2 minutes* to share your reflection.

Future Discussion re: 2023

- How do we want to approach Council meetings in 2023?
 - What questions do you want answered over the next year?
 - Who do you want to invite to Council meetings?
 - Subject matter experts, families, government officials, etc.
 - What would that look like?
 - When?
 - What questions do you have for each? (see next "workspace" slide)

Workspace for 2023 Invited Experts

Month	SME	Questions

Work Group Reporting Guidelines

- High level reports from work group reporter
- Timing: 15 minutes
- Share:
 - Each group's process
 - General topics team discussed
 - Each team's plans moving forward
 - Engage Council with questions
- No need to vote on content until Council is ready to do so.

Work Group Meeting Times

- Work Group Scheduling:
 - Set all work group meetings for 2023
 - DPH will need to provide meeting links
 - Option 1: DPH employee email is posted to monitor for public access during the meeting time
 - If before or after standard business hours, the Council will need to agree upon a regular meeting time
 - Example: Meet 2nd Wed 4-6 or 7-9PM bi-monthly between full AC meetings and use breakout rooms
 - Option 2: Work group members offer a personal or business phone number for public access
 - Work groups can choose a regular meeting time that work best for them, however we ask that they
 are preplanned for the year and between the hours of 7AM-9PM (to allow for reasonable public
 access)
- We recommend meeting bi-monthly between full AC meetings on a regular basis.

Next Steps

- First meeting of 2023
 - Wednesday, January 11, 2023, 4-6 PM
 - Future meetings via WebEx Events
 - If you need help, please email Amy Benison in advance who will find assistance

Next steps:

- Continue to work on baselines from work groups through January
- Amy will reach out to all work groups for missing documents
- Invite a family member to tell their story and/or invite a subject matter expert to inform the Council
- Email Elaine.Gabovitch@mass.gov to get on the January agenda
- Anything else?

Motion to Adjourn

Thank You!