



150 YEARS
OF ADVANCING
PUBLIC
HEALTH

Massachusetts Department of Public Health

DPH PANDAS/PANS Advisory Council

January 12, 2022
4:00 – 6:00 PM

Please stand by. The meeting will begin shortly.

Agenda

- Welcome: Roll call & vote to approve 11/29/21 minutes
- Review: Meeting rules, statutory authority, 2022 meeting dates
- Introduction: Amy Benison, DPH report writer
- Vote: Logic model
- Review/draft: Work plan/aim statement
- Vote: Work groups
- Presentation: Known resources for report content (*time permitting*)
- Next meeting: Wednesday, March 9, 2022, 4-6 pm
- Vote: Adjourn

Opening Roll Call & Vote

- Attendance roll call
- Vote to approve Meeting Minutes (November 29, 2021)

Meeting rules

- Open Meeting Law applies
- Agenda pre-planned
- Council Member attendance taken to establish quorum
- Cameras on during the meetings
- Mute your mic unless you are speaking
- Chat function disabled
- 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).

2022 Bi-Monthly Meeting Schedule

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

Introduction and Update

- Introducing Amy Benison, CDC Foundation, Annual Report Writer
- CCIS Webinar on Caregiver Findings
- By-Laws and other advice from the Autism Commission

Aim statement/work plan development

- During today's meeting, the Council will:
 - Review **logic model** draft
 - Review and work on **aim statement & work plan** draft
 - Determine goals, scope, timeline, etc.
 - Determine Council **member roles** for work groups based on skills & experience
 - Determine **next steps** for documents to complete & implement

Vote: Logic Model

DPH PANDAS/PANS Advisory Council Logic Model

Rev. 11/29/21

Situation: The advisory council was created in Section 26 (242) of Chapter 260 of the Acts of 2020, or the Health Care Omnibus bill. The Council is slated to report to the DPH Commissioner. To represent the Commissioner as her designee, the Division for Children & Youth with Special Health Needs are most appropriate for this role.

Advisory Council Purpose: 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).

Short Term Goal: By January 12, 2022, the Council will have developed a work plan and aim statement to begin its research and writing of its first annual report to the Commissioner.

Inputs	Activities	Outputs	Outcomes		
			S/T	M/T	L/T
Source Documents: <ul style="list-style-type: none">• Acts of 2020 Ch 260 Section 242• Lit Review research done by MA Coalition• Model Reports	<ul style="list-style-type: none">• Elaine G to chair & two advisory council members to facilitate• Write aim statement and work plan with members to determine guiding principles, meeting structure, agenda setting, key concept/terms	1 Environmental Scan in Year One 1 Report to Commissioner in Year One # <u>of</u> meetings held # <u>of</u> meeting	<ul style="list-style-type: none">• Environmental scan of PANDAS/PANS in Massachusetts and US• First year	<ul style="list-style-type: none">• More families engaged in the science and advocacy for these disorders.• More research	<ul style="list-style-type: none">• CYSHN with PANDAS/PANS and their families in MA will experience a higher quality of life

Aim Statement & Work Plan

PROJECT AIM STATEMENT & WORK PLAN

PANDAS/PANS Advisory Council

OVERALL PROJECT AIM

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).

We aim to: *(What are you trying to accomplish? Which focus area(s) are you working in? What is your specific project within that focus area? Use words like improve, reduce, and increase to identify the overall goal. Make it specific, measurable, achievable, and relevant.)*

The DPH PANDAS/PANS Advisory Council aims to advise the DPH Commissioner each year through annual reports about research, diagnosis, treatment and education relating to pediatric autoimmune neuropsychiatric disorder associated with streptococcal infections and pediatric acute neuropsychiatric syndrome (PANDAS/PANS).

because: *(Why is it important? Answer the “so what” question and describe the rationale and reasons to work on this improvement project.)*

Doing so will drive progress in each of these domains that will ultimately result in improved

Poll Results

FIRST Choice Work Group Responses

Diagnosis	Education	Research	Treatment
Sylvia Fogel Melissa McCormack Julia Zhang Mark Pasternack Karen Colwell John Gaitanis	Lisa Grisolia Kate Maher Michelle Pinto	Blake Poggi Kyle Williams	Peggy Chapman Melissa Glynn-Hyman

SECOND Choice Work Group Responses

Diagnosis	Education	Research	Treatment
Peggy Chapman Lisa Grisolia Blake Poggi	Karen Colwell Melissa Glynn-Hyman	Michelle Pinto Julia Zhang Mark Pasternack	Sylvia Fogel Kate Maher Melissa McCormack Kyle Williams

Poll Results

THIRD and FOURTH Choice (note some council members identified more than 2 preferences, which may help in even distribution of talent and resources in each work group)

Diagnosis	Education	Research	Treatment
Kyle Williams Sheilah Gauch Jennifer McCormack Vitelli	Melissa McCormack Sheilah Gauch Jennifer McCormack Vitelli	Sheilah Gauch Jennifer McCormack Vitelli	Mark Pasternack Sheilah Gauch Jennifer McCormack Vitelli

Possible Work Group Participant Scenario (based on 1st & 2nd choices) - FINAL SELECTED TEAMS

Diagnosis	Education	Research	Treatment
Julia Zhang John Gaitanis Sylvia Fogel Melissa McCormack	Lisa Grisolia Kate Maher Michelle Pinto Karen Colwell	Blake Poggi Kyle Williams Mark Pasternack	Peggy Chapman Melissa Glynn-Hyman Melissa McCormack

Discussion: Previous research on annual report resources

- Diagnosis
 - Treatment
 - Education
 - Research
- Sheilah Gauch, Co-Facilitator
 - Jennifer Vitelli, Co-Facilitator
 - Amy Benison, CDC
Foundation Fellow to DPH,
annual report writer

Next Steps

- Second bi-monthly meeting for 2022
 - Wednesday, March 9, 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

Motion to Adjourn

Thank You!