



150 YEARS
OF ADVANCING
PUBLIC
HEALTH

Massachusetts Department of Public Health

DPH PANDAS/PANS Advisory Council

March 9, 2022
4:00 – 6:00 PM

Please stand by. The meeting will begin shortly.

Agenda

- **Welcome:** Roll call & vote to approve 1/12/22 minutes
- **Share:** Guidance for submitting public comments and concerns for Essential Service Closure Process
- **Vote:** Advisory letter/memo
- **Review:** Work plan and next steps
 - Vote: Report proposal
 - Vote: Approach to meetings: work groups &/or individual contributions
- **Next meeting:** Wednesday, May 11, 2022, 4-6 pm
- **Vote:** Adjourn

Opening roll call & vote

- Attendance roll call
- Vote to approve Meeting Minutes (January 12, 2022)

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

Advisory Council culture

- Highly flexible, encouraging & positive environment
- No wrong ideas
- Open, clear, proactive, & collaborative communication
- Clearly defined goals & roles, effective decision making
- Participative leadership, balanced participation, valued diversity
- Complete tasks within constraints of scope, quality, time & cost

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).

Essential Services Closure Process (105 CMR 130.122)

- When a hospital decides to discontinue services within their facility or satellite campuses, there are **several requirements that it must fulfill before it can complete the closure**. This process is referred to as the essential service closure process.
- This process provides a mechanism for DPH to review a proposed closure and to ensure that **measures have been put in place to minimize the impact on the community and address concerns** that have been brought to DPH's attention.
- **DPH cannot legally require a hospital to keep a service open.**

Essential Services Closure Process

Timeline	Actions
120 Days Before Closure*	<ul style="list-style-type: none"> The hospital must notify DPH of its intent to submit notification about the intended closure. The hospital must also notify those impacted by the service closure, including the hospital's patient and family council, hospital staff, labor organizations representing the hospital's workforce, and local and state elected officials.
90 Days Before Closure	<ul style="list-style-type: none"> The hospital must submit a formal notice of the closure to DPH.
60 Days Before Closure	<ul style="list-style-type: none"> DPH is required to hold a public hearing on the proposed closure. Information on the public hearing, including date and time, will be posted to the DPH Essential Services webpage (https://www.mass.gov/info-details/hospital-essential-service-closures)
15 Days After Public Hearing	<ul style="list-style-type: none"> DPH must provide the hospital with a determination as to whether the service provided by the hospital is necessary for preserving access and health status within the hospital's service area.
15 Days After DPH Determination	<ul style="list-style-type: none"> The hospital is required to submit a plan for assuring access to DPH.
10 Days After Receiving Plan	<ul style="list-style-type: none"> DPH reviews the plan and if more information is needed, DPH will send the hospital written comments within 10 day of receiving the plan. The hospital must then submit a response to any comments by DPH within 10 days.

Guidance for submitting public comments

- The Council's role in addressing concerns affecting PANDAS/PANS community
- For the Essential Service Closure Process:
 - Written comments to DPH.BHCSQ@MassMail.State.MA.US
 - Oral comments at public hearing
 - Specific, detailed comments and questions re: PANDAS/PANS needs and concerns are recommended to assist DPH with the hospital closure review to minimize the impact on the community and address concerns that will preserve access and health status in the hospital's service area.

Vote: Advisory Letters/Memos

- Annual report is the main vehicle to advise DPH Commissioner and the General Court
- All advisories must align with the Council's legislative purpose
- Review a proposed letter from Council members for consensus and a vote

Work plan and work groups review

- Review **work plan** updated draft
 - Aim, why, audience, approach, goals, scope, roles, timeline, etc.
- Review **options** and decide best approach
 - Workgroup option
 - Document outlining workgroup procedures and roles
 - Individual option
- Determine **next steps**

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 disorder 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).

Why statement

- Accurate diagnoses and symptom management for PANDAS/PANS is not widely understood.
- The physical and behavioral changes in impacted individuals range from mild to severe, relapsing and remitting and long term, resulting in serious, possibly life-threatening conditions. It can impact all facets of life including mental health, special health needs and education.
- The disorder can be devastating for the entire family, especially when mismanaged or delayed, potentially leading to chronic illness.
- Because of this, individuals with PANDAS/PANS and their families in the state of Massachusetts need a better-informed, more effective system of care to provide sound diagnoses and appropriate treatment grounded in evidence-based research.

Population/target audience

- People with PANDAS/PANS
- Their families
- DPH Commissioner
- MA Legislature
- Healthcare providers
- Mental health providers
- Pharmaceutical companies
- Judicial system
- Insurers
- Schools, including school nurses
- After school programs and extracurricular activities, including sports
- State agencies
- Advocates
- Researchers

Vote: Approach re: annual reports - proposal

- The Council will issue its **first annual report** to the DPH Commissioner and the General Court by XX (date TBD) that will **document its process of getting started and some preliminary recommendations** from September 2021 through March 2022.
- The Council will issue its **second annual report** to the DPH Commissioner and the General Court by XX (date TBD) that will provide the **current state of PANDAS/PANS diagnosis, treatment, education, and research** in Massachusetts and nationally as appropriate to **set the baseline**.

Approach re: work groups and/or individual work

Option #1: Work Groups

- Must comply with OML.
- Work on each of the four topics within related groups
- Select a facilitator responsible for managing the group process according to OML
- Present member contributions to a quorum of the work group
- Then present work group findings to the full Council
- Other Council members beyond group weigh in and deliberate for inclusion of group findings in report
- Email any written attachments with report content to work group to review *before a work group meeting*
- Email Administrator to request a work group presentation on the agenda 10+ days *before full Council meeting* including any written materials, if appropriate.

Option #2: Individual work

- Does not need to comply with OML
- Work on sections of the four topics individually (voluntary or assigned by Chair)
- Can reach out to fewer than a quorum of subject matter experts 1:1 for input
- Email Administrator to request an item on the agenda 10+ days *before a full Council meeting* including any written materials
- Present individual member findings to the full Council when Chair schedules topic
- All Council members can weigh in and deliberate on final selections for report

Member responsibilities by option, then a vote

Option #1: Work Groups

1. Public meeting notice & agenda posted 48 hours before meeting online
2. 10+ days notice to DPH to prep post
3. Email public meeting notice & agenda to AG/ANF at least 48 hours before meeting
4. Offer accessible meeting platform/space to public
5. Roll call taken for attendance
6. Roll call for any votes if virtual
7. Meeting minutes must be taken
8. Meeting minutes draft voted on in next meeting
9. Approved meeting minutes posted online w/ DPH
10. Email Administrator to request group time on the agenda
11. Present proposed work group findings to full Council
12. Present for maximum of 15 minutes with 5 min of Q&A per group at bi-monthly meeting

Option #2: Individual work

1. Email Administrator to request individual item on the agenda
2. Chair determines with Council how to coordinate priorities and order of topics and time to be allotted to individual presenters at bi-monthly meetings
3. Members are responsible for Council's compliance overall with all requirements for a public meeting but do not need to work on:
 - Public meeting notices
 - Offering meeting platform or space open to public
 - Roll call for attendance and any votes
 - Meeting minutes
 - Meeting minutes draft for vote in next meeting
 - Approved minutes posted

Current work groups and facilitators

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

Work Groups Organized and accepted in 1/12/22 meeting.

Council goals

1. Meet on a bi-monthly basis in 2022 from January through November on the 2nd Wednesday of the month from 4:00-6:00 pm
2. **COMPLETE:** Share previous research, policy and practice literature gathered prior to January 1, 2021 by Council members as starting information for the environmental scan
3. **COMPLETE:** Enlist four workgroups to scan the environment on the current state of diagnosis, treatment, research and education by January 12, 2022
4. **PENDING:** Determine work group roles and/or divide up activities among 15 Council members by March 9, 2022
5. **PENDING:** Present a draft of the first annual report to the Council by May 11th for their approval to document its initial process
6. **PENDING:** Edit and publish first annual report by June 30, 2022.
7. **PENDING:** Research and draft four sections of the second annual report from 3/9 to 11/9/22.
8. **PENDING;** Edit and publish second annual report by early winter 2023 (date TBD).

Short term aims by phase

Phase 1 (January 12 - March 9, 2022)

- Determine skills of Council members to contribute to report; finalize work plan draft; determine workgroups and/or divide activities; use previous research on 4 topics to begin environmental scan; select preliminary facilitators.

Phase 2 (March 9 – May 11, 2022)

- Determine options for report researching and writing: work group, individual, both?
 - Decision: Work groups
 - Share first draft of 1st annual report with the Council (DPH to lead) on 5/11; edit as needed for final

Phase 3 (Start/End dates TBD)

- TBD by Council: Meet in work groups for each category; divide up work and conduct research on assigned topics; use feedback loop with work group or full Council to refine the drafts, etc.

Phase 4 (Start/End dates TBD)

- Compile all activities and findings into second annual report draft; write, review, edit and finalize the report; submit to DPH Commissioner and General Court.

Council scope

In Scope

- All activities named in Section 242 of Acts of 2020, Chapter 260
- To advise the DPH Commissioner and General Court on research, diagnosis, treatment, and education related to PANDAS/PANS or other topics as specified in the law in their annual report including recommendations.
- Having equal representation for PANDAS and PANS
- Using work plan to name, update and monitor actions
- Making evidence-informed or -based recommendations after conducting environmental scan.

Out of scope

- Any activities not named in in Section 242 of Acts of 2020, Chapter 260
- Advising the DPH Commissioner and General Court with a report about other topics not specified in the law.
- Having a greater focus on one disorder
- Moving on to actions without a work plan
- Making recommendations without an evidence-informed or evidence-based foundation

Support roles

Name, Title	Council Role
Director DPH DCYSHN Elaine Gabovitch	Executive: Chairs Council, sets agendas, facilitates meetings, provides support/guidance/possible resources
Project Manager Betsy Day	Administrative: Provides support with meeting planning and scheduling, assists with agenda setting, time keeping, minutes taking, meeting follow up, posting on mass.gov, and follow up
Co-facilitators Jennifer Vitelli Sheilah Gauch	Support: Lead certain Council discussions and deliberations, assist in meeting planning, and follow up, contact Council members <ul style="list-style-type: none"> • Participate in planning agenda, sharing expertise, tools, and resources in planning meetings (pre-advisory council meetings) with chair, admin, and report writer. • Express concerns, frustrations, challenges, successes and more in planning meetings prior to advisory council meetings. • Propose agenda items and attachments to admin within OML timeframes. Earlier when they need to be reviewed and discussed with Chair and submitted to meet Communications and AG's office deadlines • Model the way for the advisory council. For example: support and uphold the provisions of the work plan. • Assist with work group facilitation, work within OML and assist with report writing. • Gather updates on data to share in Council meetings. Meet with Chair to determine what falls under purview of Council.
CDC Foundation Fellow Amy Benison	Support: To support Council members with researching and drafting report.

Possible timeline

3/9:
Members
review
prior
research

7/13:
Gap analysis
15 + 5 Q&A
Where are gaps
to be filled?

11/9:
Prioritize
15 min +
5 Q&A

5/11:
Set
baseline
in 4
domains
15 min + 5
Q&A

9/14:
SWOT
15 min + 5 Q&A
What are the
strengths,
weaknesses, oppy's,
threats?

Early 2023 date
TBD:
Vote to finalize
report for
submission to
Commissioner

Summary/Next Steps

- Next steps for Council
 - Work groups
 - Choose sections
- Next bi-monthly meeting for 2022
 - Wednesday, May 11, 2022, 4-6 PM
 - Agenda:
 - DPH will present the first annual report draft to the Council for vote
 - Work groups present baseline data gathered on four topics to Council
 - Set baseline on four domains

Resources

For more guidance, please attend OML [Open Meeting Law trainings | Mass.gov](#)

- link for the AG's webinar dates
- opportunity to ask questions specific to work groups

Please reference the Attorney General's latest notice: [Subcommittees and Sub-quorum Communications](#)

Suggestion to chairs of each subgroup to subscribe to [updates from the Attorney General's Division of Open Government](#)

Questions: please contact Betsy Day at betsyday@betsy-day.com

Motion/Vote to Adjourn

Thank You!