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PUBLIC
HEALTH

Massachusetts Department of Public Health

PANDAS/PANS Advisory Council Launch Meeting

September 29, 2021
10 am – 11:30 am

Please stand by. The meeting will begin shortly.

Agenda

- Welcome & Introductions
- Open Meeting Law and Conflict of Interest Policy
- Overview of the Council's Charge and Deliverables
- Council Expectations
- Next Steps
 - Meeting Schedule
- Adjournment

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. *Is anyone recording this meeting?*
- “Raise your Hand” option to speak

Brief Introductions

- Your name
- Your organization (limit to 2)
- Your specialty or affiliation to PANDAS/PANS

Welcome PANDAS/PANS Advisory Council Members

Council Member	Affiliation	Council Seat
Elaine Gabovitch, MPA	DPH Division for Children & Youth with Special Health Needs	Commissioner's Designee Chair
Sheilah Gauch, LICSW, MEd	Dearborn Academy Massachusetts Coalition for PANDAS/PANS Legislation	Special Educator Administrator Council Co-Facilitator
Jennifer M. Vitelli, MBA	JBC PANS & PANDAS Foundation Massachusetts Coalition for PANDAS/PANS Legislation	Parent of a child with PANDAS/PANS Council Co-Facilitator
Margaret Chapman, APRN, MSN, PNMHCNS	Bridge Consultants	Child psychiatric practitioner
Karen Colwell	Massachusetts Coalition for PANDAS/PANS Legislation	Appointed council member
Sylvia Fogel MD	Mass General Hospital Lurie Center for Autism Harvard Medical School	Appointed council member
John Gaitanis, MD	Tufts Medical Center Floating Hospital for Children	Health care provider/medical specialist
Melissa Glynn-Hyman, LICSW	Private Practice New England PANS/PANDAS Association	Licensed social worker

Welcome PANDAS/PANS Advisory Council Members

Council Member	Affiliation	Council Seat
Lisa Grisolia	New England PANS/PANDAS Association	Representative of a Massachusetts non-profit PANDAS/PANS Advocacy Organization.
Kathleen Maher, MS-PHCNS, RN	Perkins School for the Blind	Representative of a professional organization in this State for school nurses.
Melissa McCormack, MD, PhD	Wholistic Pediatricians Bridge Consultants	Pediatrician
Mark Pasternack, MD	Massachusetts General Hospital for Children	Physician specializing in infectious diseases
Michelle Pinto, RN	Worcester State University Massachusetts Coalition for PANDAS/PANS Legislation	Parent of a child with PANDAS/PANS
Blake Poggi, MA, CCC-SLP	Mending Minds Foundation for the Diagnosis and Treatment of Post-infectious Neuroimmune Disorders	Appointed council member
Kyle Williams, MD, PhD	Massachusetts General Hospital MGH Lurie Center for Autism	Medical researcher
Yujuan (Julia) Zhang, MD	Tufts Children's Hospital	Health care provider/medical specialist

Open Meeting Law and Conflict of Interest Policy

Open Meeting Law (OML)

- The purpose of OML is transparency in government.
- All meetings of a public body must be open to the public.
- A public body includes any multi-member board, commission, committee, or subcommittee if established to serve a public purpose.

Deliberation

- A meeting is “a deliberation by a public body with respect to any matter within the body’s jurisdiction.”
- **Deliberation** is defined as “an oral or written communication through any medium, including electronic mail, between or among a quorum of a public body on any public business within its jurisdiction.”
- Deliberation does not include scheduling or procedural information.
- If a quorum of a public body wants to discuss public business within that body’s jurisdiction, they must do so during a properly posted meeting.
 - ***NOTE: If a public body member sends an email to a quorum of the public body expressing an opinion on any matter that could come before that body, the communication violates the OML, even if no recipient responds.***

Posting Notice of Meetings

- A public body must post notice of its meetings on its website at least 48 hours before the meeting, excluding Saturdays, Sundays, and legal holidays.
- The notice must include the following:
 - Date;
 - Time and place; and
 - List of topics the chair reasonably anticipates will be discussed at the meeting.
- The list of topics should provide sufficient information to inform the public of the issues to be discussed at the meeting.

What is a Quorum?

- A Quorum is defined as:
 - A **simple majority** of the members of a public body, unless otherwise provided in a general or special law, executive order, or other authorizing provision. G.L. c. 30A, § 18.
 - As applied to the PANDAS/PANS Advisory Council quorum equals 15 members ($\frac{1}{2}$ of 15 members + 1) (8 members = quorum).

Avoiding OML Violation-Best Practice Recommendations

- Public body members must not engage in “serial deliberations”—a series of separate, independent conversations outside of a meeting among a quorum of the members regarding a topic within its jurisdiction.
- In order to avoid even the appearance of a potential OML violation, the AGO advises public body members to refrain from communications over email except for distributing meeting agenda, scheduling meetings and distributing documents created by nonmembers.

Remote Participation

Chapter 20 of the Acts of 2021, *An Act Extending Certain COVID-19 Measures Adopted During the State of Emergency* (June 16, 2021), authorized remote participation of public bodies:

- Public bodies are permitted to have live “adequate, alternative means” of public access, including video conference;
- Remote participation is allowed by all members of the public body; and
- All votes taken during a meeting in which a member participates remotely **must be by roll call vote.**

Public Meetings – Miscellaneous

- A member of the public may not address the public body without permission of the chair.
- A member of the public may not disrupt the meeting.
- The public body must create and maintain minutes of all meetings.
- Records reviewed by the public body during the meeting are public records.
- The Attorney General's Office enforces OML.
- A member of the public may file a complaint alleging an OML violation, first with the public body, and subsequently with the Attorney General's Office if necessary.

Conflict of Interest Law

- The Conflict of Interest (COI) law, M.G.L. c. 268A, is meant to prevent conflicts (and appearances of conflict) between a state employee's private interests and his or her public duties.
- As statutory public body members, you are considered to be “special state employees” subject to the COI law.
- The COI law is complex; State Ethics Commission attorneys are available, through the “Attorney of the Day” program, to provide confidential advice/guidance on how the COI law applies to you in a particular situation.
 - **Contact Attorney of the Day @ (617) 371-9500**

Conflict of Interest Law: More Details

- Asking for and taking bribes is prohibited.
- Asking for or accepting a gift because of your official position is prohibited.
- Using your official position to get something you are not entitled to, or to get someone else something they are not entitled to, is prohibited.
- Participating as a state employee in a matter in which you, your immediate family, your business organization, or your future employer has a financial interest is prohibited.
- Acting in a manner that would make a reasonable person think you can be improperly influenced is prohibited.

Conflict of Interest Law: Training Requirements

- All state employees subject to the COI law are required to:
 - Certify they received and reviewed the annual Summary of Conflict-of-Interest Law, and
 - Complete the biannual online training program

Training Requirements

Required Conflict of Interest Law PACE Online Trainings

Conflict of Interest Law Online Training Program

Conflict of Interest Law Summary

Summary of COI law:

<https://www.mass.gov/service-details/summary-of-the-conflict-of-interest-law-for-state-employees>

COI training:

<https://www.mass.gov/how-to/complete-the-online-training-program-for-state-and-county-employees>

Conflict of Interest Trainings

State Ethics Commission

For information regarding the Education & Training requirements, refer to the State Ethics Commission website:

<http://www.mass.gov/ethics/revised-implementation-procedures.html>

Phone: (617) 371-9500

- **You must complete the training within 30 days.**

Additional References

Conflict of Interest Law:

- <https://www.mass.gov/laws-regulations-rulings-opinions-and-advisories>
- <https://www.mass.gov/learn-more-about-conflicts-of-interest>

Office of Attorney General, Open Meeting Law Website and Guide:

- <https://www.mass.gov/files/documents/2017/09/25/2017%20Guide%20online.pdf>
- <http://www.mass.gov/ago/government-resources/open-meeting-law/>

Overview

The Council's Charge & Deliverables

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).

Statutory Requirements

The council is required to create an annual report to the DPH Commissioner with recommendations for:

- **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.

Statutory Requirements: Allowable Actions

- The advisory council **may request from all state agencies** such information and assistance as the council may require.
- The advisory council **may accept and solicit funds**, including any gifts, donations, grants or bequests or any federal funds, for any of the purposes of this section.
 - *Such funds shall be deposited in a separate account with the state treasurer, be received by the treasurer on behalf of the commonwealth and be expended by the advisory council in accordance with the law.*

Council Member Expectations

Advisory Council Member Requirements

Each member of the council will serve for a term of 3 years without receiving compensation.

- There is no maximum term.
- Any member of the advisory council appointed by the commissioner may be a member of the general court.
- The advisory council shall meet upon the call of the chair or upon the request of a majority of council members.

Voting and Meeting Notes

- **Depending on the agenda, votes may be needed:**
 - The Chair will make a motion for a vote.
 - One member should approve, and another should second it.
 - The DPH Administrator will record all votes.
- Voting results, main actions taken, and decisions made will be recorded in the meeting notes.
- Meeting notes will be posted on the Council landing page on [mass.gov](https://www.mass.gov).

A Working Council

The council will work during meetings to create an annual report with recommendations.

- The contents of the report should reflect the experience and expertise of Council members
- Between meetings, all Council members will produce **agreed-upon deliverables** to advance the goals and objectives for each annual report by year
- In Year One, the report should include a full **environmental scan** to document what's known and what's needed for:
 - practice guidelines for diagnosis and treatment;
 - development of screening protocols;
 - clinical awareness and education needed among physicians, including pediatricians, school-based health centers and providers of mental health services;
 - educators' and parents' awareness of the disorder and syndrome

The Work Ahead: Getting to Know the Council

- For our next meeting, please prepare to **share your background** with fellow Advisory Council members
- Please address:
 1. *What is your connection* to PANDAS/PANS? What brought you here?
 2. What *skills & experience will you contribute* to the Council?
 3. What do you *hope to achieve*?
- We will spend up to two hours establishing our identity as an Advisory Council before moving on to the work.
- **Due to limited time, please plan for no more than 5 minutes.**

The Work Ahead: Logic Model

DPH PANDAS/PANS Advisory Council Logic Model

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).

Goal: To create the process for setting up the Council to begin its work in researching and writing its annual report.

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 • KII notes with stakeholders • Lit Review research done by MA Coalition • Model Reports Advisory Council Candidates <ul style="list-style-type: none"> • 15 members 	<ul style="list-style-type: none"> • Research roles and activities of other DPH Councils and Commissions as models for the new PANS/PANDAS Council • Orient administrative consultant to provide support to Council • Orient 1 or 2 interns to support project assisting Chair • Notify 15 council candidates of their nomination and invite to be on Council • Coordinate booking the first meeting 	15 Advisory Council members 1 administrative consultant to support council 1-2 interns trained and assisting Chair 1 Environmental Scan in Year One 1 Report to Commissioner in Year One # of meetings held	<ul style="list-style-type: none"> • Environmental scan of PANDAS/PANS in Massachusetts and US • First year Advisory Council Report submitted to Commissioner and Secretary • Publication of 	<ul style="list-style-type: none"> • More families engaged in the science and advocacy for these disorders. • More research articles produced to gain a closer understanding of causes and treatments. 	<ul style="list-style-type: none"> • CYSHN with PANDAS/PANS and their families in MA will experience a higher quality of life • Providers will be aware, trained and ready to provide informed,

The Work Ahead: Aim Statement



Aim Statement Template

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.)*


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

for: *(Who is your specific target population? Is it every patient who meets your CMC definition or is it a subset of those patients?)*

by when: *(specific time frame, i.e., month/year in which we intend to complete the improvement)* _____

We will achieve this by: *(How will you carry out the work and reach your overall aim? Think of the resources at your disposal.)*

The Work Ahead: Charter

PROJECT CHARTER					
Project Title	Project and Portfolio Management Tool			Project Manager	Sameer Patel
Project Start Date	May 21, 2017	Project End Date	August 31, 2017	Project Sponsor	Randy Hadden
Business Need					
All Information Technology projects that require agreement on the Memorandum of Understanding between the Customer and the Service Provider are approved through email. This project was initiated to reduce the manual approvals and create a system to obtain and track the approvals to reduce any discrepancies and loss of data.					
Project Scope			Deliverables		
Create an in-house PPM to include all Global IT projects.			<ol style="list-style-type: none"> 1. Generate consolidated project status report 2. Extract Global Headcount details for all projects 		
Risks and Issues			Assumptions/Dependencies		
<ol style="list-style-type: none"> 1. Data discrepancy due to large amount of projects 2. Involvement of multiple teams 			<ol style="list-style-type: none"> 1. All Global IT projects to be added to the tool 2. Managers to provide regular updates for the projects 		
Financials					
Budget to complete this project is \$3000					
					
Milestones Schedule					
Milestone		Target Completion Date		Actual Date	
Upload all Global IT Projects to the tool		May 20, 2017			
Complete UAT testing for the tool		July 30, 2017			
Project Team			Approval/Review Committee		
Project Manager	Randy Hadden		Sponsor	Randy Hadden	
Project Manager	Sameer Patel		Business Division Head	Aniket Bhonsle	
Team Members	Vice President, Senior Manager, Analyst		Business Unit Head	Sunil Rajan	
			Finance Manager	Ketan Shah	

Next Steps

- **Two 2-hour monthly meetings in October and November**
 - Members will receive two Doodle polls with available meeting times for each month
 - October: Council members will exchange experience & expertise
 - *Members should prepare a 5-minute statement*
 - November: Set up Charter and Aim Statement with goals, objectives, timeline
 - *If there is no quorum to meet in October, we'll shift to Nov/Dec meetings.*
- **Bi-monthly meetings start in January 2022 to begin the work**
 - Members will receive a Doodle poll with regular meeting day/week
- **The Council will meet until it determines its work is complete.**

October & November Proposed Meeting Dates

October

10/22	11-1	F
10/25	9-1	M (<i>least preferred</i>)
10/28	9-11	Th

November

11/22	9-1	M
11/29	9-1	M
11/30	3-5	T

Vote to Adjourn

Thank You!