

PANDAS/PANS Advisory Council Meeting

November 8th, 2023, 4:00 – 6:00 PM

Via WebEx Event

Via WebEx (Zoom) Event

Present: Elaine Gabovitch, PANDAS/PANS Chair, Madelyn Goskoski, CHTA, PANDAS/PANS Meeting Consultant, Amy Benison, DPH, Program Support Specialist, Casey Hall, CHTA, PANDAS/PANS Meeting Consultant, Nicole Roos, DPH, Technical Assistance and Coordinator, Margaret Chapman, APRN, MSN, PNMHCNS, Karen Colwell, Sylvia Fogel MD, Sheilah Gauch, LICSW, MEd, Melissa Glynn-Hyman, LICSW, Lisa Grisolia, Kathleen Maher, MS-PHCNS, RN, Melissa McCormack, MD, PhD, Mark Pasternack, MD, Michelle Pinto, RN, Blake Poggi, MA, CCC-SLP, Jennifer M. Vitelli, MBA, Kyle Williams, MD, PhD, Yajuan (Julia) Zhang, MD.

Public Attendees: 1

Welcome and Agenda

Elaine Gabovitch, PANDAS/PANS Advisory Council Chair, called the meeting to order, welcomed the Advisory Council and reviewed the agenda:

- Welcome: Roll Call & Vote to Approve 9/13/2023 Minutes
- Announcements: General & Housekeeping
- Vote: Annual Report
- Discussion: Guest Speaker Questions: DOI & DPH
- Wrap Up: Next Steps
- Next Meeting: Wednesday, January 10, 2023, 4-6PM
- Vote: Adjourn

Open Roll Call & Vote on Meeting Minutes

Elaine Gabovitch managed the virtual open roll call and Maddy Goskoski tracked this information for the meeting record. Elaine led the vote to approve the May 10, 2023, meeting minutes. There was a quorum with 13 Advisory Council members in attendance for the vote, with one member joining later in the meeting for a total of 14 members.

Statutory Authority

Elaine Gabovitch reviewed the following Statutory Authority statement with the Advisory Council.

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

his 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

Elaine Gabovitch reviewed the following aim statement with the Advisory Council.

- 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).

Announcements: General & Housekeeping

Advisory Council Member Jennifer Vitelli presented the following information and updates to the entire Advisory Council committee.

- PANS/PANDAS Awareness Day Walk
- The Alex Manful Fund participated in the Head of the Charles'
- BC PANS & PANDAS Foundation hosted Dr. O'Hara presentation for caregivers & providers.
- JBC coordinated a CME training on PANS/PANDAS at South Shore Hospital as well as few pediatric practices.
- JBC hosted their annual fundraiser.
- Massachusetts Coalition for PANS/PANDAS Legislation testified twice this month at the State House on two separate bills.
- NEPANS was the recipient of the Granite Cares Grant program.
- Sheilah presented at the IOCDF conference (on PANS/PANDAS)

- A DMH office was trained on PANS/PANDAS
- Kate Maher shared a link to the upcoming Aspire PANS/PANDAS presentation for School nurses on Nov 14th in Plymouth.

Please contact Madelyn.M.Goskoski@mass.gov to add any other Advisory Council updates, announcements to future agendas.

Vote: Annual Report

- One vote on entire report
- This includes:
 - New summary section
 - Priorities and recommendations
 - Work groups sections in Appendix
- Please note: DPH will review for final formatting including references.

Conversations were held during the Council meeting after to the vote regarding environmental scans, citations and reference pages created by work groups within the Council. Council member Michelle suggested that the research group and education group should have their environmental scans published on mass.gov as they would be hard to attach to the annual report. Specifically, she suggested using a scoping report.

Additionally, Council member Blake suggested using the database Zotero is a useful resource to view the workgroup citations and publications in a legible format. Furthermore, she also suggested to the Council the idea of creating a QR code that links to the Zotero file with the public if the Commonwealth will allow.

One member of the Council was wondering if we could include articles outside of the scope of work of PANDAS/PANS. Elaine Gabovitch suggested we split up resources into various categories to share information to the public. Jennifer Vitelli suggested that it could be the individual workgroups responsibility to update their specific database with resources on an annual basis to prevent links from becoming inactive. More discussion to come around the website creation and potential maintenance.

Discussion: Guest Speaker: DOI

- January Guest Speaker: Department of Public Health
 - Division for Children & Youth with Special Health Needs (DCYSHN)
 - If available, Bureau of Infectious Disease and Laboratory Sciences (BIDLS) and others related to final recommendations.
- March Guest Speaker: Division of Insurance (DOI)
 - Please pull up the Google Form survey and fill out now.

Jennifer announced that she has connected with a representative from the Division of Insurance (DOI) to present to the PANDAS/PANS Advisory Council at DPH. He agreed to join us and present to the Council in January.

Elaine Gabovitch shared information regarding the potential speakers affiliated with DPH that could be beneficial to speak with in January. Departments in DPH she mentioned included the Division for Children & Youth with Special Health Needs and Bureau of Infectious Disease and Laboratory Sciences (BIDLS). Furthermore, Elaine mentioned she is also going to find other bureaus and/or staff that may be willing to speak to the Council meeting in January.

Discussion: Guest Speaker Questions

Please provide the following general information about your agency as well as specific data about PANS and PANDAS:

- Brief agency description
- Overview of program and services
- Eligibility
- Data, statistics, and incidence related to PANS and PANDAS
- Case management and training
- Recent family support efforts
- Funding
- Gaps and challenges
- Future goals and initiatives

In addition:

- What experience/exposure do you/your organizations have to PANS and PANDAS?
- What knowledge or understanding do your staff and/or organization have about these illnesses?
- What professional development including training and informational resources have you and your staff had related to PANS and PANDAS?
- What additional trainings or resources do you need to understand PANS and PANDAS better?
- What kind of barriers do you experience when working with children & youth with PANS and PANDAS and their families?
- What are your hopes and goals for the quality of life and well-being of this community?

Elaine Gabovitch mentioned that the slide contains more broad and general questions to ask a stakeholder and adapt the questions as needed. Elaine asked the group to curate and share thoughts on the more generalized questions.

Wrap Up: Next Steps for Work Groups

Elaine Gabovitch shared the following information with the Advisory Council:

- First meeting of 2024
 - Wednesday, January 10th, 2023, 4-6 PM
 - Future meetings via WebEx Events
 - If you need help, please email Maddy Goskoski at madelyn.m.goskoski@mass.gov in advance who will find assistance.
- Next steps:
 - Set up for the new year and the third report.
 - Available DPH team to present to Council in January
 - Email madelyn.m.goskoski@mass.gov to get on the January agenda.
 - Anything else?
 - Vote to Adjourn
 - Anything else?

Motion to Adjourn

Elaine Gabovitch thanked everyone in attendance, led the vote to adjourn the meeting. Maddy Goskoski recorded votes.

All votes during this meeting obtained two motions and have been recorded.