**PANDAS/PANS Advisory Council Meeting**

September 13, 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, John Gaitanis, MD, Sheilah Gauch, LICSW, MEd, Melissa Glynn-Hyman, LICSW, Lisa Grisolia, Kathleen Maher, MS-PHCNS, RN, Mark Pasternack, MD, Michelle Pinto, RN, Blake Poggi, MA, CCC-SLP, Kyle Williams, MD, PhD, Yujuan (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.

**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 July 12, 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 Sheilah Gauch presented the following information and updates to the Advisory Council:

* Representative Cutler's office is in the process of getting the PANS/PANDAS Awareness Day Proclamation from Governor Healy
* Sunday, 10/1: NEPANS will be hosting the "Annual PANS/PANDAS Awareness Day" walk in Hull, MA
* The Weekend of 10/21 & 10/22: The Alex Manfull Fund will have a tent and boat in the Head of the Charles
* Saturday, 10/21: The Massachusetts Rare Disease Council will be hosting a virtual Town Hall Meeting
* Tuesday, 10/24: JBC PANS & PANDAS Foundation is hosting an Evening with Dr. Nancy O'Hara, author of Demystifying PANS/PANDAS. For more information, please visit [www.jbcfund.org](http://www.jbcfund.org).
* Friday, 11/3: JBC will be hosting their Second Annual JBC Fest, a night of hope, health & support for children with PANS & PANDAS. To learn more, please visit [www.jbcfund.org](http://www.jbcfund.org).

**Discussion: Annual Report**

* Elaine Gabovitch provided an update to the members on the annual Advisory Council report and suggested that more work needs to be done before a final vote. Casey Hall then shared her experience working with multiple advisory councils and the process of writing an annual report and how to think through approaches and recommendations. Finally, Council member Sheilah Gauch explained the work that her and Jennifer Vitelli plan to do to make the final version of the Advisory Council report cohesive.
* Update on annual report:
  + The co-facilitators will summarize work groups section for a cohesive succinct section to be in the body of the report.
  + Work groups’ reports will be included as appendices.
  + Next step will be editing the full report with help from the Council and DPH team.
  + Individuals will review the full report, with a focus on the summary, priorities, and recommendations in preparation for a vote.
  + We will plan to vote in November, if need be, we can hold a short meeting in December for a vote only.

**Discussion: Annual Report**

* Best practice for most council reports is to recommend the most strategic priorities at a high level with room for progress.
* Propose four domains as the priorities:
  + Research
  + Diagnosis
  + Treatment
  + Education
* High level and complementary of each other

The Advisory Council members asked for clarification on how changes in the report process came to be, and what direction they are supposed to be taking next. Elaine explained that the Council has never had a global discussion as a group and could really benefit from reading it through thoroughly prior to a vote. Council member Sheilah then explained that all four sections written by the four work groups do not tie together well, so it is important to put together a clear and concise report for the legislator.

**Discussion: Questions for Guest Speakers**

Elaine led a discussion about upcoming guest speakers and presented the following questions:

* What is the goal of inviting these agencies?
* What questions will we ask?
  + Provide brief agency description.
  + Overview of program and services
  + Data, stats, and incidence related to PANDAS/PANS
  + Eligibility
  + Case management and training
  + Recent family support efforts
  + Funding
  + Gaps and challenges
  + Future goals and initiatives

Advisory Council Members brainstormed the following questions to ask guest speakers at upcoming Council meetings:

1. What professional development have you had related to PANDAS/PANS?
2. What do your staff and/or organization know about these illnesses?
3. What training and information does your staff have?
4. What exposure do you/your organizations have to PANDAS/PANS?
5. What additional resources or trainings do you think you need to understand this better?
6. What kind of barriers do you experience when working with this population?

Elaine asked the Advisory Council to focus on the goals for each guest speaker or in other words “what do you want to get out of this?” She then shared the following notes:

1. Share a dialog.
   1. What could be their role and what are resources they can use within the community?
2. Creating a sense of comfort
   1. Getting providers comfortable with treating individuals with P/P
3. Opportunity to offer resources.
   1. What can the AC give to providers/agencies that they might not already have?
4. Great to leave conversations with stakeholders and have them be “champions.”

Elaine then asked the Council to share their thoughts and opinions and come up with a list of entities they would like to invite to upcoming meetings to speak to the entire Council. The Council decided they would benefit most from speaking with state agencies. Furthermore, the group would like to reach out to stakeholders from large medical facilities and hospitals. They concluded that they would prefer to request specific guest speakers from hospitals to come speak rather than asking the hospital to choose who comes to speak. The Advisory Council brainstormed a list of guest speakers that could potentially join an upcoming meeting, that list is as follows:

1. DMH
2. DPH
3. Dr. Sue Swedo
4. Boston Children’s Hospital
5. DOI (possibly extend invitation for January)
6. President child adolescent psych
7. Mass Chapter of pediatrics
8. Epidemiologist at Harvard (Kyle can reach out to him)
   1. Focus on anxiety and depression.
9. James Giodano from Georgetown
10. Bureau of Public Health Hospital
11. Dawn Caputa – Bureau of infectious disease and laboratory sciences at DPH
12. Fatima Watt-DPH public hospital
13. East Boston Neighborhood Health Center- new Behavioral Health unit

Once this list was curated, members from the Council agreed to start with the DOI because because multiple members have already engaged with DOI and established a working relationship. They believe this could be a good first step as they are targeting someone who understands this specific issue.

Also, the Council discussed that inviting and speaking with the Mass Chapter of American Academy of Pediatrics could be beneficial. Next steps for the Council are to determine what is the angle and/or approach to inviting the Mass Chapter of American Academy of Pediatrics to foster a respectful and open dialogue.

Council members determined that inviting speakers from the Bureau of Public Health Hospital could be helpful because they deal with people who have chronic illnesses. The Council also decided DPH should be invited to the second meeting of 2024 because the Council could engage openly with various epidemiologists or personnel from the Bureau of Infectious Disease and Laboratory Sciences.

**Wrap Up: Next Steps for Work Groups**

Elaine Gabovitch shared the following information with the Advisory Council:

* Sixth meeting of 2023
  + Wednesday, November 8th, 2023, 4-6 PM
  + Future meetings via WebEx Events
  + If you need help, please email Maddy Goskoski at [madelyn.m.goskoski@mass.gov](mailto:madelyn.m.goskoski@mass.gov) in advance who will find assistance.
* Next steps:
  + Discuss and possibly vote on report
  + Email [madelyn.m.goskoski@mass.gov](mailto:madelyn.m.goskoski@mass.gov) to get on the November agenda.
  + 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.