

## **PANDAS/PANS Advisory Council Meeting**

July 12, 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, Jennifer M. Vitelli, MBA, 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 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**

- Jennifer shared with the Advisory Council that PANDAS/PANS Awareness Day takes place in October.
  - NEPANS is hosting a walk on October 1<sup>st</sup> to celebrate.
  - Coalition of the Mass chapter is discussing a celebration for PANDAS/PANS Awareness Day in October. Jennifer will share more details when applicable.
  - JBC PANDAS/PANS participated at the Cohasset Triathlon a few weeks ago and mentioned that it was a successful event for a great cause.
- Sylvia announced she is no longer affiliated with the Lurie Center for Autism and is transitioning to private practice work.
- Sheilah shared The Alex Manfull Fund had their 5k in Washington DC
  - With a goal to receive joint funding for PANDAS/PANS
  - Legislation day occurred the day before

### **Discussion Annual Report- Process**

- Elaine led a discussion regarding the updated process for the annual report with corresponding due dates for the final version.
- Today (July 12<sup>th</sup>)
  - Review priorities and recommendations
  - Identify one or two guest speakers (TBD) for 9/13 and standard questions.
  - Report follow-up: DPH team will format report for flow and consistency.
    - Maddy will send final draft to Advisory Council by August 11th.
    - Council sends any edits to Maddy by August 25th.
    - Maddy will send final report to Advisory Council for review by September 6th.
  - September 13 meeting:
    - Vote on each priority and recommendation
    - Engage guest speaker(s)
    - Determine future guest speakers.

### **Discussion Annual Report- Legislation**

- Jennifer and Sheilah led a conversation considering the following bills to be listed as recommendations in the annual report
  - S1266 & H1975: Study of Pediatric Adolescent Psychiatric Settings (DMH & DESE)

- H3920: Screening in Medical/Clinical Settings (DPH)
- The Council will decide whether to include these legislative recommendations in the report after we review all drafted/proposed priorities & recommendations.
- Council members expressed concern that there could be pushback or resistance from providers to do an additional annual screening

### **Discussion Annual Report- Recommendations**

Elaine Gabovitch led the discussion on the recommendations to include in the annual report and the need to edit for consistency. Elaine mentioned the formatting of individual work group sections to include priorities, findings/methods, and recommendations.

Elaine noted that the Council should review the recommendations for the following items:

1. Review for appropriate recommendations
2. Eliminate duplication.
3. Organize based on priority.

### **Draft Priorities**

The Advisory Council had an opportunity to review the proposed priorities for the 2023 PANDAS/PANS annual report and to share thoughts and opinions with one another regarding what should and/or should not be included in the report. Elaine Gabovitch reviewed the eight drafted priorities with the Advisory Council. The priorities proposed are as follows:

1. **Priority 1:** Improve understanding of the prevalence of PANS/PANDAS within the Commonwealth of Massachusetts
2. **Priority 2:** Decrease delays in the diagnosis of Pediatric Acute Onset Neuropsychiatric Syndrome (PANS) and Pediatric Autoimmune Neuropsychiatric Disorders Associated with Streptococcal Infections (PANDAS) in Massachusetts.
3. **Priority 3:** Report on missed diagnoses.
4. **Priority 4:** Improve the working diagnostic criteria for PANS and PANDAS
5. **Priority 5:** Assess and evaluate current diagnosis and/or treatment of PAN/PANDAS in the Commonwealth of Massachusetts
6. **Priority 6:** Review insurers compliance with current PANDAS/PANS insurance coverage laws
7. **Priority 7:** Use mechanisms to increase clinical awareness and education regarding the disorder and syndrome among health care providers including physicians, pediatricians, school-based health centers and providers of mental health services.
8. **Priority 8:** Conduct outreach to educators and parents to increase awareness of the disorder and the syndrome.

### **Discussion: Guest Speakers**

Elaine led a conversation on guest speakers to invite to upcoming meetings. The group agreed that inviting a representative from DPH would be a good idea.

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

Elaine Gabovitch shared the following information with the Advisory Council:

- Fifth meeting of 2023
  - Wednesday, September 13, 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:
  - Maddy will send final draft by August 11th.
  - P/P Council members send edits to Maddy by August 25th.
  - Maddy will send final report to review and vote on by September 6th.
  - Email [madelyn.m.goskoski@mass.gov](mailto:madelyn.m.goskoski@mass.gov) to get on the September 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.