

**DPH PANDAS/PANS Advisory Council**

**January 10, 2024**

**4:00 – 6:00 PM**

***Please stand by. The meeting will begin shortly.***

**Agenda**

* Welcome: Roll Call & Vote to Approve 11/8/2023 Minutes
* Announcements: General & Housekeeping
* Discussion: Guest Speaker Presentation & Discussion
* Discussion: Guest Speaker Reflection
* Discussion: Future Speakers
* Wrap Up: Next Steps
* Next Meeting: Wednesday, March 13, 2024, 4-6PM
* Vote: Adjourn

**Opening Roll Call & Vote**

* Attendance **roll call**

# **Vote** to approve Meeting Minutes (November 8, 2023)

**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 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**

The DPH PANDAS/PANS Advisory Council aims to **advise the DPH Commissioner on research, diagnosis, treatment, and education** relating to pediatric autoimmune neuropsychiatric discovered 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).

**General Announcements**

# Jennifer and Sheilah to make announcements

JV/SG

**Guest Speaker: Karen Robitaille**

* Welcome Karen Robitaille, MSN, MBA, RN, NCSN
  + Director of School Health Services at DPH
* Discussion Format
  + 15 minutes: Karen to present background and thoughts
  + 30 minutes: Questions and Answers
    - Raise hand
    - Be mindful of the space and time you are taking
    - Foster an open discussion focused on group learning and problem solving

**Guest Speaker Reflection**

* What are people's immediate reactions?
* Do we have follow-up items or questions?
* How will we incorporate what we heard into the next report?
* DOI to join us in March, what DOI specific questions do we have?

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

**Future Guest Speakers**

* 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?

**Future Guest Speakers**

* Who should join us later this year?

|  |  |
| --- | --- |
| **Person/Organization** | **Type of Speaker** |
| Department of Mental Health | State Agencies or Affiliates |
| Department of Children & Families |
| Bureau of Public Health Hospital - Fatima Watt |
| Department of Health & Human Services |
| Disabled Persons Protection Committee (new addition) |
| Department of Elementary & Secondary Ed - Russel Johnston |
| Mass General Hospital | MA Hospitals |
| Franciscans Hospital |
| Boston Children's Hospital |
| East Boston Neighborhood Health Center - Behavioral Health Unit |
| President of child/adolescent psych unit |
| Susan Swedo, MD, Aspire Chair | PANDAS/PANS Network |
| Marybeth Miotto, MA, President of MCAAP | Physicians Network |
| Cody Meissner, MD, Tufts | Individuals |
| Michael Danes, MD, U Arizona |
| James Giodano, Georgetown |

**Next Steps**

* Second meeting of 2024
  + **Wednesday, March 13, 2024, 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:
  + DOI to join us in March
  + Invite future guest speakers
  + Email [madelyn.m.goskoski@mass.gov](mailto:madelyn.m.goskoski@mass.gov) to get on the March agenda
  + Anything else?
  + Vote to Adjourn

EG

**Motion to Adjourn**

Thank You!