

**DPH PANDAS/PANS Advisory Council**

# November 8, 2023

**4:00 – 6:00 PM**

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

**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

**Opening Roll Call & Vote**

* Attendance **roll call**
* **Vote** to approve Meeting Minutes (September 13, 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**

* PANS/PANDAS Awareness Day Walk
* The Alex Manfull Fund participated in the Head of the Charles'
* JBC PANS & PANDAS Foundation hosted Dr. O'Hara presentation on "Demystifing PANS/PANDAS" for caregivers & providers.
* JBC coordinated a CME training on PANS/PANDAS South Shore Hospital as well as few pediatric practices; they also 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

JV/SG

**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

EG

**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

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

**Discussion: Guest Speaker Questions**

* + 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?

**Next Steps**

## First meeting of 2024

* + - **Wednesday, January 10, 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:

* + - 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](mailto:madelyn.m.goskoski@mass.gov) to get on the January agenda
    - Anything else?
    - Vote to Adjourn

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**Motion to Adjourn**

Thank You!