**DPH PANDAS/PANS Advisory Council September 13, 2023 4:00 – 6:00 PM**

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

**Agenda**

* Welcome: Roll Call & Vote to Approve 7/12/2023 Minutes

•Announcements: General & Housekeeping

•Discussion: Annual Report

•Discussion: Questions for Guest Speakers

•Wrap Up: Next Steps

•Next Meeting: Wednesday, November 8, 2023, 4-6PM

•Vote: Adjourn

# Opening Roll Call & Vote

Attendance **roll call**

**Vote** to approve Meeting Minutes (July 12, 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

•Rep. Cutler's office is in the process of getting the PANS/PANDAS Awareness Day Proclamation from the Gov. 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/)

•Please contact [Madelyn.M.Goskoski@mass.gov](mailto:Madelyn.M.Goskoski@mass.gov) to add any other Advisory Council updates, announcements to future agendas.

# Discussion: Annual Report

•Update on annual report

* + The co-facilitators will summarize work groups sections 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

# Discussion: Questions for Guest Speakers

•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

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# Next Steps

* + 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 September agenda
    - Anything else?

# Motion to Adjourn

Thank you!