**DPH PANDAS/PANS Advisory Council**   
 **March 8, 2023**   
 **4:00 – 6:00 PM**   
   
 **Please stand by. The meeting will begin shortly.**

**Agenda**

* Welcome: Roll Call & Vote to Approve 1/11/2023 Minutes
* Announcements: General & Housekeeping
* Present: Work Group Report Outs & Recommendations
* Discussion: Writing Meeting in Person
* Discussion: Guest Speakers
* Discussion: Materials for Mass.gov
* Wrap Up: Next Steps for Work Groups
* Next Meeting: Wednesday, May 10, 2023, 4-6 pm
* Vote: Adjourn

**Opening Roll Call & Vote**

* Attendance **roll call**
* **Vote** to approve Meeting Minutes (January 11, 2023)

**Meeting Rules**

* Open Meeting Law applies:
  + Chat function disabled
  + Texting, emails, etc. are public records
  + Council member attendance taken to establish quorum
* Agenda pre-planned
* Cameras on during the meetings
* Mute your mic unless you are speaking
* Meeting not recorded
* “Raise your Hand” option to speak

**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 her 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).

**2023 Bi-Monthly Meeting Schedule**

Chart with meeting dates: 1/11, 3/8, 5/10, 7/12, 9/13, 11/8. Second Wednesday of the month from 4-6 PM

**General Announcements**

* Introducing Madelyn (“Maddy”) Goskoski!
* Neuroimmune CEU Conference
* Legislation Updates
* *Please contact* [*Elaine.Gabovitch@mass.gov*](mailto:Elaine.Gabovitch@mass.gov) *to add any other Advisory Council updates, announcements to future agendas.*

**2023 Timeline**

* Timeline for January through April
  + January: Discuss timeline and second report
  + February: Work groups meet to form recommendations and plan to present
  + March: Dr. Swedo presents, work groups present recommendations
  + April: Work groups finalize and send draft sections for report, first draft compiled and sent out

**2023 Timeline**

* Timeline for May through September
  + May: Review and discuss first draft as a Council, outreach to speakers for September-January
  + June: Work groups meet to make final edits on draft report
  + July: Vote on final second annual report
  + September: Guest speaker, start research for third annual report

**Annual Cycle**

* Chart showing the annual cycle by season
  + Winter:
    - December-February
    - Wrap up speakers for the year
    - Start writing first draft of report sections
  + Spring:
    - March-May
    - Brainstorm next round of speakers
    - Form recommendations
    - Compile first draft of report
  + Summer:
    - June-August
    - Extend invitations for next round of speakers
    - Finalize recommendations
    - Finalize and vote on report
  + Fall:
    - September-November
    - Bring in starting speakers
    - Start research for next report

**Guest Speakers for 2023**

* Speakers for September, November and January
  + 6 speakers (2 at each meeting)
  + 30-45 minutes per speaker
  + Allow for in depth conversations
  + Work groups can consider inviting speakers to their separate work group meetings
  + Before deciding on speakers, first identify your research questions. Then, determine which speaker can best address them.

**Guest Speakers for 2023**

* Do work groups have guest speakers to suggest?
* Six invited guest speakers will join us from September-January meetings
* Invitations to selected guest speakers should be sent following this meeting or May at the latest
* A standard list of questions and instructions for presenting to AC should be determined

**Work Groups Report Out**

* **High level reports/discussion** from work groups
* Timing: **15 minutes each to present and Q&A**

**Materials for mass.gov**

* PANDAS/PANS AC page on mass.gov can serve as a place for the Council to post resources and information
* Autism Commission website is an example of how done
* Announcements such as PANDAS/PANS Awareness Day could be posted on mass.gov

**Next Steps**

* Second meeting of 2023
  + **Wednesday, May 10, 2023, 4-6 PM**
  + Future meetings via WebEx Events
    - If you need help, please email Amy Benison in advance who will find assistance
* Next steps:
  + Distribute work group written sections (date TBD) and raise first draft questions for group consensus at May meeting
  + Email [madelyn.m.goskoski@mass.gov](mailto:madelyn.m.goskoski@mass.gov) to get on the May agenda
  + Anything else?

**Motion to Adjourn**

Thank You!