**DPH PANDAS/PANS Advisory Council  
  
January 11, 2023  
4:00 – 6:00 PM**  
  
*Please stand by. The meeting will begin shortly.*

**Agenda**

* Welcome: Roll call & vote to approve 11/9/22 minutes
* Announcements: General & Housekeeping
* Share: Family Story
* Present: Illinois PANDAS/PANS Council
* Update: 2023 Timeline and Annual Cycle
* Discussion: Guest Speakers for 2023
* Present: Work Groups
* Wrap Up: Next steps for work groups
* Next Meeting: Wednesday, March 8, 2023, 4-6 pm
* Vote: Adjourn

**Opening Roll Call & Vote**

* Attendance **roll call**
* **Vote** to approve Meeting Minutes (November 9, 2022)

**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**

* Legislation updates from Sheilah and Jennifer
* Work group votes, attendance and minutes
* *Please contact* [*Elaine.Gabovitch@mass.gov*](mailto:Elaine.Gabovitch@mass.gov) *to add any other Advisory Council updates, announcements to future agendas.*

**Family Story**

* Bryanne Wainford
  + Bureau of Community Health and Prevention (BCHAP)
    - Operations Manager, Massachusetts Sexual Assault Nurse Examiner Program
  + Parent of a child with PANDAS/PANS

**Welcome Illinois**

* Wendy Nawara, MSW
  + Board Certified Patient Advocate and Consultant
  + Member of Illinois PANDAS/PANS Advisory Council

**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**

* Suggested speakers from the November meeting:
  + Wendy Nawara, MSW, BCPA, Illinois Council
  + Dr. Swedo
  + Dr. Silva
  + Marybeth Miotto, MA, President of MCAAP
  + Russell Johnston, DESE
  + Cody Meissner, MD
  + Dept of Mental Health
  + Dept of Elementary and Secondary Education (DESE)
  + Dept of Developmental Services
  + Dept of Children & Families
  + Dept of Youth Services
  + Children’s Hospital
  + Committee on Rights of People with Disabilities
  + Teachers Union

**Work Groups Report Out**

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

1. Treatment: to present environmental scan
2. Diagnosis: to discuss report writing and approach

**Next Steps**

* Second meeting of 2023
  + **Wednesday, March 8, 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:
  + Work groups to present their starting recommendations for discussion
  + Invite Dr. Swedo to speak in March
  + Email Elaine.Gabovitch@mass.gov to get on the March agenda
  + Anything else?

**Motion to Adjourn**

Thank You!