**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* *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!