**DPH PANDAS/PANS Advisory Council
September 14, 2022
4:00 – 6:00 PM**
*Please stand by. The meeting will begin shortly.*

**Agenda**

* Welcome: Roll call & vote to approve 7/13/22 minutes
* Announcements: General and housekeeping
* Vote: 2023 Bi-Monthly Meetings
* Present: Work group reports (10 min to present, 5 Q&A)
	+ Treatment
	+ Research
	+ Diagnosis
	+ Education
* Wrap Up: Next steps for work groups
* Next meeting: Wednesday, November 9, 2022, 4-6 pm
* Vote: Adjourn

**Opening Roll Call & Vote**

* Attendance **roll call**
* **Vote** to approve Meeting Minutes (July 13, 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).

**General Announcements**

* P/P updates and general announcements will take place at the start of each meeting
* Use November meeting to reflect, take stock & plan
	+ Share professional updates from AC members
	+ Listen to stories from the P/P community to learn about their experiences & needs and what matters most
	+ Discuss how/when to complete the next annual report that will set baseline of what’s known
	+ Create & schedule a list of subject matter expert guest speakers for future interviews/exchanges
* Please contact Elaine.Gabovitch@mass.gov to add any other Advisory Council updates, announcements to future agendas.

**Work Group Contact/Public Access Changes**

* DPH requires a secure DPH email contact and video link
	+ DPH also requires that a DPH representative is available during work group meetings to assist the public as needed
* Work Group scheduling:
	+ Could work groups set 2023 calendars now?
	+ Options to meet are bimonthly (preferred), flex or in-person
		- Limited capacity for increased DPH meeting support
			* Ideally 2nd Wed 4-6 pm bi-monthly between full AC meetings and use breakout rooms
			* Could combine four workgroups into two
		- Should be scheduled between 8am-6pm
		- To secure DPH support, scheduling meetings a minimum of one month in advance is requested.

**2022 Bi-Monthly Meeting Schedule**Chart with dates: 1/12, 3/9, 5/11, 7/13, 9/14, 11/9. Second Wednesday from 4-6 PM

**2023 Bi-Monthly Meeting Schedule (Vote)**Chart with dates: 1/11, 3/8, 5/10, 7/12, 9/13, 11/8. Second Wednesday from 4-6 PM

**Work Group Reporting Guidelines**

* **High level reports** from each work group reporter
* Timing: ***15 minutes***
* Share:
	+ Each group’s **process**
	+ General **topics** team discussed
	+ Each team’s **plans** moving forward
	+ Engage Council with **questions**
* No need to vote on content until Council is ready to do so.

**Work Group Reports (10 min share & 5 Q&A)**

* **Treatment**
	+ Sheilah Gauch, Reporter; Melissa Glynn-Hyman, Facilitator
* **Research**
	+ Kyle Williams, Reporter; Mark Pasternack, Facilitator
* **Diagnosis**
	+ John Gaitanis, Reporter; Sylvia Fogel, Facilitator
	+ **Education**
	+ Michelle Pinto, Reporter; Lisa Grisolia, Facilitator

**Education Workgroup Environmental Scan**

* MA DPH PANS/PANDAS Advisory Council
* 9/14/22

**Education Workgroup Target Audiences:**

* + School Personnel
	+ Families
	+ Medical Providers
	+ Public Service Departments

**Education for School Personnel**

Audiences

1. Special Educators / Special Education Administrators / Special Education Advocates
2. School Nurses / School Consulting Physicians
3. Teachers / Paraprofessionals
4. Related Service Providers: Speech Language Pathologists, Occupational Therapists, Physical Therapists
5. School Counselors / School Psychologists / Neuropsychologist
6. Early Intervention / Head Start

**Sources for Education for School Personnel**

* Aspire
* Journal of Child and Adolescent Psychiatry
* Moleculera
* New England PANS/PANDAS Association
* Northwest PANDAS/Pans Network
* National Institute for Mental Health
* Neuroimmune.org
* PANDAS Physician Network
* PANDAS Network
* Southeastern PANS/PANDAS Association
* Published books ie: Doran’s PANS/PANDAS in the School Setting

**Education for Parents & Families**

* Online resources from websites such as:
	+ PANDAS Network
	+ Aspire
	+ NEPans
	+ SEPPA/NWPPN
	+ Neuroimmune Foundation
	+ PANS/PANDAS UK
* Books
	+ 16 books for parents and families
	+ Multiple books for children specifically
* Documentaries
	+ MKINC, Stolen Childhood, A Childhood Mystery, 20/20

**Education for Parents & Families (continued)**

* Parents may attend conferences ie: IOCD conference, Neuroimmune.org (2022 IOCD hosted a conference for families and children with OCD)
* Online Support groups and social media are a common source for parents/families (but this is unedited/non-medical advice)
* Local support groups
* Are parents/kids/siblings getting education from providers? How can we improve the education provided?
* How can we support siblings?

**Types of Media for Family Education**

* Brochures
* Fact Sheets/FAQs
* Books
* Webinars
* Documentaries
* News Articles
* Research studies

**Education for Medical Professionals**

Audiences

* Pediatricians/Urgent Care/ER (Includes: MD, PA, NP, RN, MA)
* Specialties: Neuro, GI/GU, Derm
* Psych Practitioners/Social Workers/Counselors/Therapists
* EMT/Paramedics/Police/Fire
* Outpatient Services PT/OT/Speech
* Dentists/Hygienists/Orthodontists
* Functional Medicine
* Infusion Center Staff

**Education for Medical Professionals (continued)**

* Peer-reviewed Journals & Published research
	+ How can we make these more readily available to pediatricians, ER doctors, etc?
* Grand Rounds
* Conferences/CMEs
	+ Inflammatory Brain Disorders Conference
	+ Manfull Foundation Conference
	+ PANDAS Network Conferences/Webinars
	+ IOCD Conference

**Education for Medical Professionals (continued)**

* Online Resources for Providers
	+ PPN
	+ NWPPN
	+ Moleculera
	+ PANDAS Network
	+ SEPPA
	+ Aspire
	+ IOCDF
	+ Neuroimmune.org
* Dissemination of New Research
	+ Stanford
	+ Columbia
	+ PANDAS Physician Network Research Library

**Education for Public Services/Departments**

* Social Services
* Department of Youth & Families
* Division of Children & Youth with Special Needs
	+ Annual Special Needs Conference
* Disability Services
* Department of Mental Health
* Judicial
	+ Opportunity has been given in past/potential future educational possibility
* Youth with Behavioral/Juvenile Detention
* Education for Insurance Companies

 **Next Steps**

* Sixth and final bi-monthly meeting for 2022
	+ **Wednesday, November 9, 2022, 4-6 PM**
	+ Future meetings via WebEx Events
		- If you need help, please email Betsy Day in advance who will find assistance
* Next steps:
	+ **Continue to work on baselines** from work groups through January, tbd
	+ Use November to reflect, listen and plan (see Gen’l Announcements)
	+ Invite family to tell their story
	+ Email Elaine.Gabovitch@mass.gov to get on Nov. agenda for updates
	+ Anything else?

**Motion to Adjourn**

Thank You!