



**150 YEARS**  
OF ADVANCING  
**PUBLIC  
HEALTH**

# Massachusetts Department of Public Health

## 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 disorder 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](mailto: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 2<sup>nd</sup> 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

Meeting #	Month and Day		Time	Week of Month
1	January 12	Wednesday	4-6 PM	2nd Complete
2	March 9	Wednesday	4-6 PM	2nd Complete
3	May 11	Wednesday	4-6 PM	2nd Complete
4	July 13	Wednesday	4-6 PM	2nd Complete
5	September 14	Wednesday	4-6 PM	2nd Pending
6	November 9	Wednesday	4-6 PM	2nd

# 2023 Bi-Monthly Meeting Schedule (Vote)

Meeting #	Month and Day		Time	Week of Month
1	<b>January 11</b>	Wednesday	4-6 PM	2 <sup>nd</sup>
2	<b>March 8</b>	Wednesday	4-6 PM	2 <sup>nd</sup>
3	<b>May 10</b>	Wednesday	4-6 PM	2 <sup>nd</sup>
4	<b>July 12</b>	Wednesday	4-6 PM	2 <sup>nd</sup>
5	<b>September 13</b>	Wednesday	4-6 PM	2 <sup>nd</sup>
6	<b>November 8</b>	Wednesday	4-6 PM	2 <sup>nd</sup>

# 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
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# Education for School Personnel

## Audiences

- A. Special Educators / Special Education Administrators / Special Education Advocates
- B. School Nurses / School Consulting Physicians
- C. Teachers / Paraprofessionals
- D. Related Service Providers: Speech Language Pathologists, Occupational Therapists,  
Physical Therapists
- E. School Counselors / School Psychologists / Neuropsychologist
- F. Early Intervention / Head Start

# Sources for Education for School Personnel

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- 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 (part 1)

- 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 (part 2)

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- 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

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

# Education for Medical Professionals (part 1)

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## 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 (part 2)

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- 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 (part 3)

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- 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

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- 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](mailto:Elaine.Gabovitch@mass.gov) to get on Nov. agenda for updates
  - Anything else?



# Motion to Adjourn

Thank You!