



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

# Massachusetts Department of Public Health

## 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 disorder 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

Meeting #	Month and Day		Time	Week of Month
1	<b>January 11</b>	Wednesday	4-6 PM	2 <sup>nd</sup> Pending
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>

EG

# 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.*



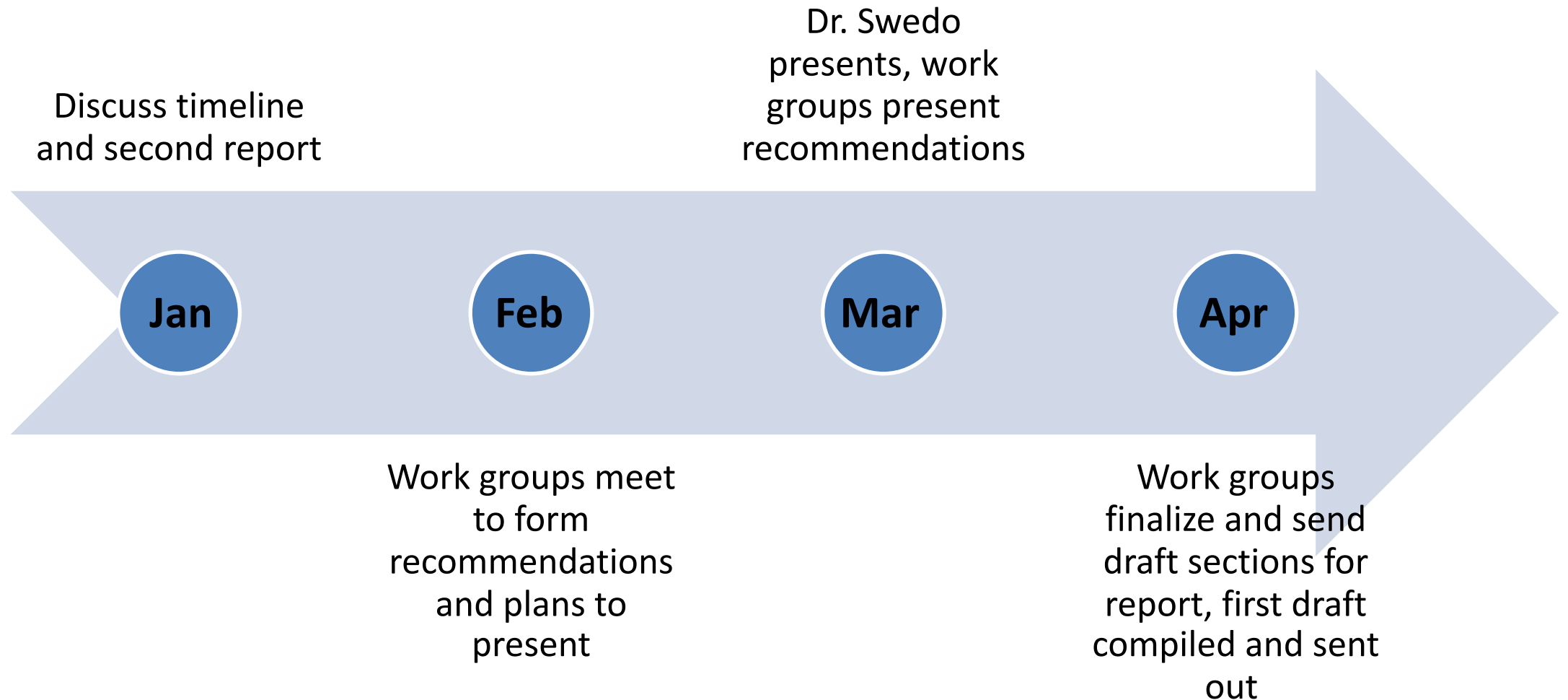
# Family Story

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

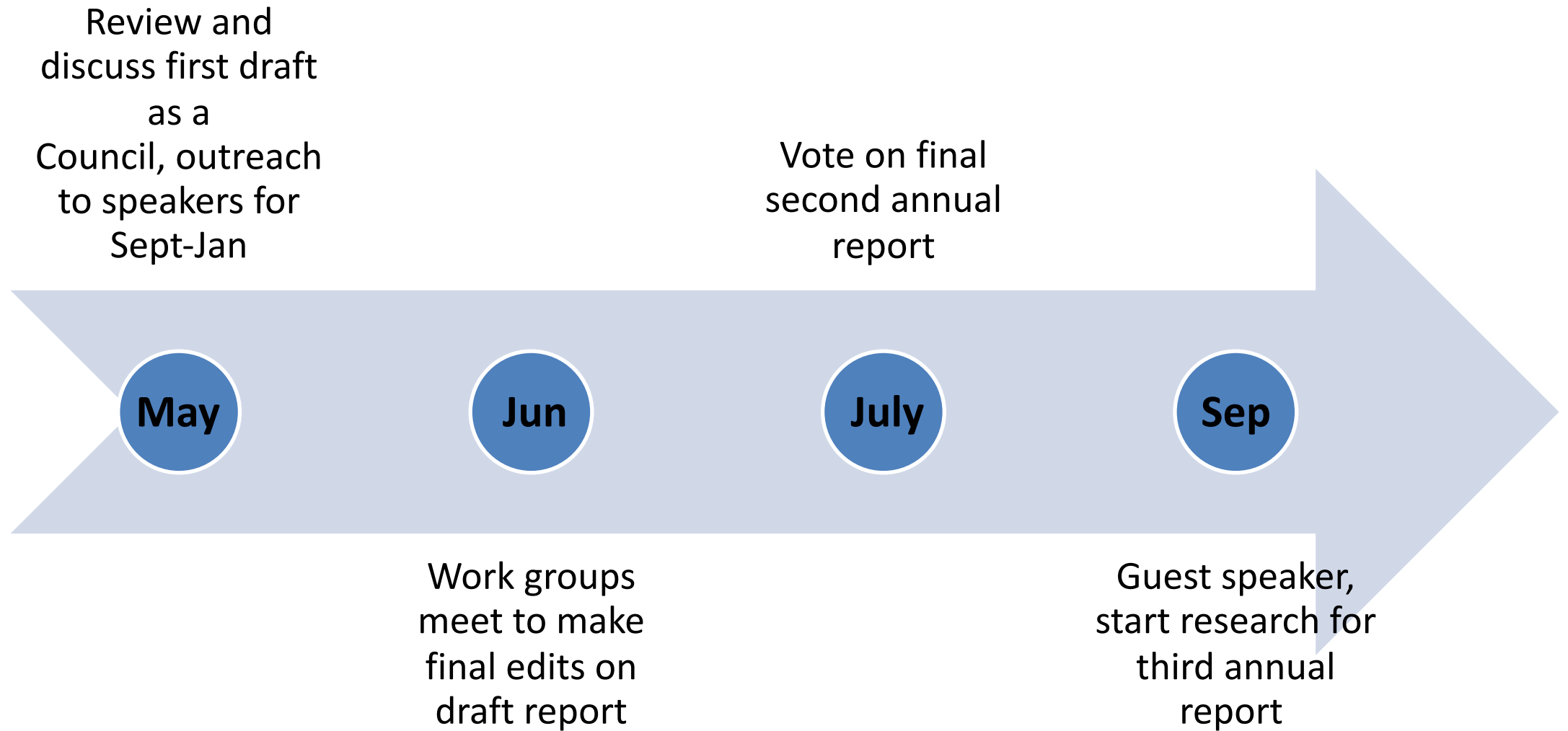
# Welcome Illinois

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

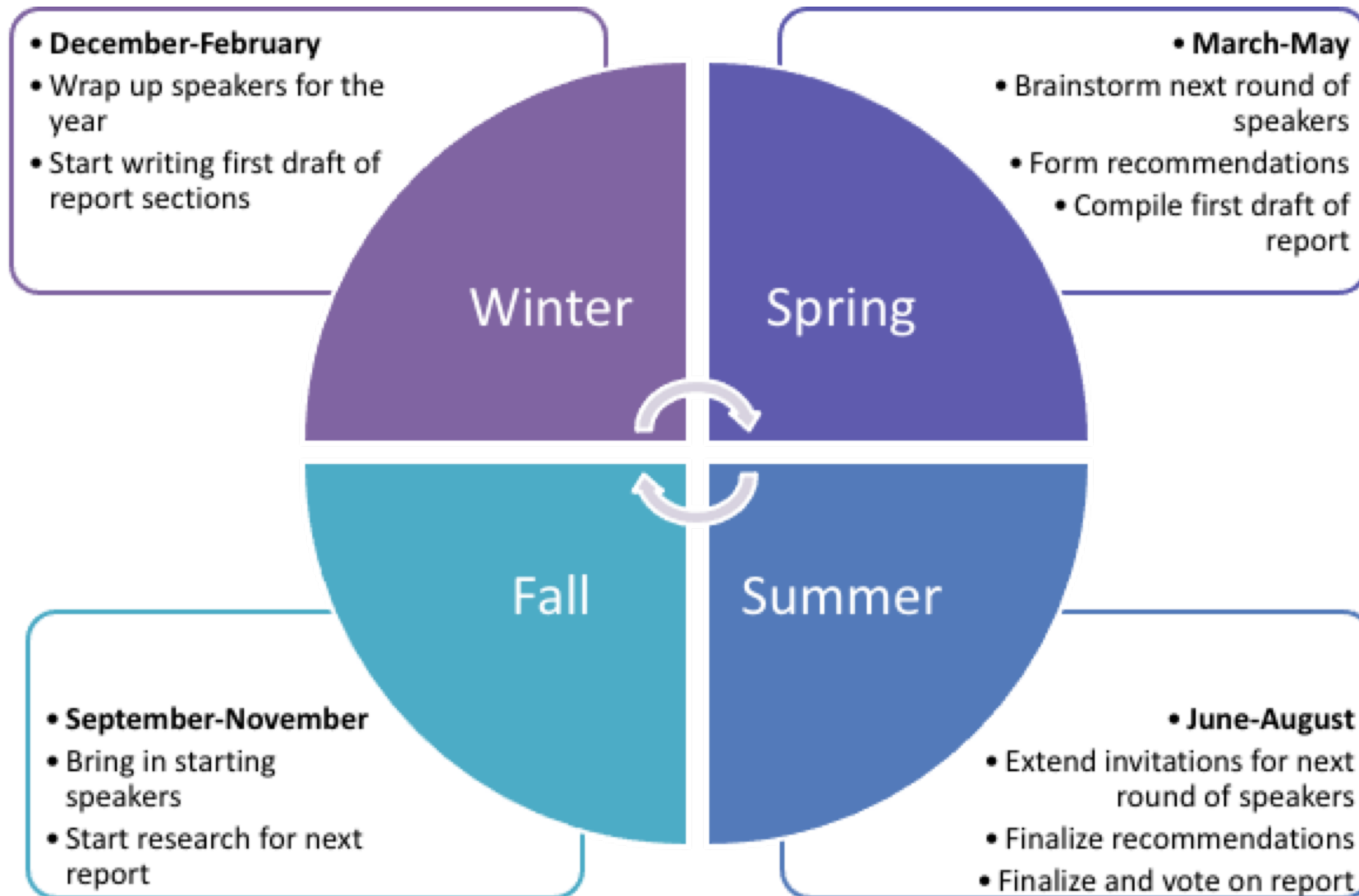
# 2023 Timeline



# 2023 Timeline



# Annual Cycle



# 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 groups 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](mailto:Elaine.Gabovitch@mass.gov) to get on the March agenda
  - Anything else?

# Motion to Adjourn

Thank You!