# PANDAS/PANS Advisory Council Meeting November 9, 2022, Meeting Minutes

Via WebEx (Zoom) Event

**Present:** Elaine Gabovitch, MPA, PANDAS/PANS Advisory Council Chair; Margaret Chapman, RN, MSN, PMHCNS-BC; Karen Colwell, PTA; Sylvia Fogel, MD; John Gaitanis, MD; Sheilah Gauch, LICSW, Med; Melissa Glynn-Hyman, LICSW; Lisa Grisolia; Kathleen Maher, MS-PHCNS, RN; Mark Pasternack, MD; Michelle Pinto, MSN, RN; Blake Poggi, MA, CCC-SLP; Jennifer McCormack Vitelli, MBA; Kyle Williams, MD, PhD; Amy Benison, DPH; Nicole Roos, DPH; Casey Hall, CHTA

# Meeting Agenda

* Welcome: Roll Call & vote to approve September 14, 2022, meeting minutes
* Announcements: General and housekeeping
* Discussion: Year reflection & moving forward
* Present: No work group updates this month
* Vote: Work group meeting times
* Wrap Up: Next steps for work groups
* Next Meeting: Wednesday, January 11, 2022, 4-6 PM
* Vote: Adjourn

# Welcome, Agenda and Meeting Rules (slides 2)

Elaine Gabovitch, PANDAS/PANS Advisory Council Chair, called the meeting to order, welcomed the Advisory Council and reviewed the agenda.

# Open Roll Call & Vote on meeting minutes (slide 3)

Elaine Gabovitch managed the virtual open roll call and Amy Benison tracked this information for the meeting record. Elaine led the vote to approve the September 14, 2022, meeting minutes. There was a quorum with 11 Advisory Council members in attendance for the vote and two members joined shortly after the vote for a total of 13 members present.

# Meeting Rules & Statutory Authority (slide 4 & 5)

Elaine Gabovitch reviewed the meeting rules and shared the following with the Advisory Council:

**Statutory Authority**, Section 26 Chapter 260 of the Acts of 2020, of the Health Care Omnibus bill established 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).

1. **Aim Statement review (slide 6)**

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).

1. **General Announcements (slide 7)**

# Elaine Gabovitch invited Council members Jennifer Vitelli, Sheilah Gauch, and Dr. Mark Pasternack to summarize their meeting with the Deputy Commissioner of Insurance. They shared that they used the meeting to talk about frustrations the families and providers in Massachusetts are having with insurance. Medical providers are frustrated with being denied for IVIG and other procedures. Additionally, they discussed the list of providers, and lack thereof, that care for PANDAS/PANS patients, they felt the Deputy Commissioner of Insurance’s list was not accurate. They were advised to report back to the Deputy about inaccuracies on the list. The Deputy also instructed the Council members to keep a detailed list of IVIG requests that are being denied, so he can help improve compliance. Jennifer, Sheilah and Dr. Pasternack will meet again with the Deputy Commissioner of Insurance in a couple weeks.

# Elaine Gabovitch then discussed her visit to the Dearborn Academy where Sheilah Gauch and Peggy Chapman work. Elaine shared that she appreciated meeting families and hearing their stories about successes and struggles. Elaine expressed gratitude, as learning more about the needs for the PANDAS/PANS population will also serve the Division for Children & Youth with Special Health Needs.

# Sheilah shared that the Dearborn Academy is working to get more diagnostic clarity and ensure they have done medical rule outs. They are finding a lot of the students have neuro immune conditions.

# Meeting Schedule (slides 8 & 9)

# Elaine Gabovitch reviewed the past and upcoming meeting dates:

**2022**

|  |  |
| --- | --- |
| January 12 Wednesday | 4-6 PM |
| March 9 Wednesday | 4-6 PM |
| May 11 Wednesday | 4-6 PM |
| July 13 Wednesday | 4-6 PM |
| September 14 Wednesday | 4-6 PM |
| November 9 Wednesday | 4-6 PM |

**2023**

|  |  |
| --- | --- |
| January 11 Wednesday | 4-6 PM |
| March 8 Wednesday | 4-6 PM |
| May 10 Wednesday | 4-6 PM |
| July 12 Wednesday | 4-6 PM |
| September 13 Wednesday | 4-6 PM |
| November 8 Wednesday | 4-6 PM |

1. **Reflection Discussion (slide 10)**

Sheilah asked each Council member to spend two minutes sharing a reflection with the group about the past year including what worked, what didn’t work and what would they like to keep/discard/change etc.

Some of the thoughts are recorded below:

* + Frustration with working within a government body and things being slow
  + Hard to find time to meet with work groups
  + Level of need for the PANDAS/PANS community is rising and the urgency is rising
  + How can we raise more awareness going forward?
  + Grateful to be part of a group of like-minded people and thankful for DPH
  + Can see the wheels are moving slowly and setting up for future change
  + Hopeful that over time the Council can set up frameworks for much needed clinical research. Need research in order to quote stats to advocate for treatment. Need etiology research and broad research into why our community is getting so sick. COVID may open doors and minds for more research.
  + Trouble mobilizing generally because many people still don’t think PANDAS/PANS exists
  + Empowering for parents to see people and physicians come together and fight for this cause, physicians for a long time have been dismissing parents/moms
  + Insurances are only worried about saving money which makes it convenient that PANDAS/PANS is not widely recognized
  + Would be great to get PANDAS/PANS into medical school curriculum to target the upcoming physicians of the world
  + Need to put more pressure on providers and insurance. How can we educate providers and speak insurance company languages (money)?
  + Hopefully Massachusetts can lead the way in making change
  + Worried as parents with children who are still struggling, and about other children being missed
  + Want to push for testing for strep in schools
  + How can DPH help more from the top down?
  + Whiplash working in this care
  + Need to simplify and disseminate testing and treatment
  + The Council is doing great things, and everyone is excited to continue to move forward

1. **Future Discussion (slide 11)**

Jennifer Vitelli led an open discussion with the Council about the possible approaches for the Council’s 2023 meetings, including what questions do members want answered over the next year, who does the Council want to invite to meetings, and would the Council be open to inviting a family to speak at the start of each meeting to ground the Council.

* People to bring in:
  + Dr. Swedo
  + Dr. Silva
  + Chair of Illinois Advisory Council
  + Mass Child Psych Chair
  + President of MCAAP
  + Committee on Child Mental Health and Committee on Disability
  + Boston Children’s Hospital
  + Cody Meisner (editor and chief Redbook, does not support PANDAS/PANS)
  + Teacher’s Union
  + Russell Johnston, Department of Elementary & Secondary Education (DESE)
  + Department of Mental Health, DESE, DDS, DCF, DYS,

Elaine suggested for members to look at Autism Commission website at <https://www.mass.gov/orgs/autism-commission> and how they provide information, guidelines,

and resources. Our Council is not an advocacy group, but can acquire information.

1. **Subject Matter Experts Workspace (slide 12)**

Elaine Gabovitch skipped past this slide for time.

1. **Work Group Report Outs (slide 13)**

Elaine Gabovitch skipped past this slide because there were no work group updates.

1. **Work Group Meeting Times (slide 14)**

Elaine Gabovitch explained to the Council the meeting options for work groups. Elaine detailed that the Council work groups should try to meet bi-monthly outside of the regular Council meetings and that all work group meetings should be set up in advance for 2023. Elaine explained that she and Amy would follow up individually to finalize work group meeting times.

1. **Next Steps (slide 15)**

Elaine Gabovitch shared the following information:

First meeting of 2023

Wednesday, January 11, 2023, 4-6PM

Future meetings via WebEx Events

If you need help, please email [amy.benison@mass.gov](mailto:amy.benison@mass.gov) in advance who will find assistance

Next steps

Continue to work on baselines from work groups through January

Amy will reach out to all work groups for missing documents

Invite a family member to tell their story and/or invite subject matter experts

Email [elaine.gabovitch@mass.gov](mailto:elaine.gabovitch@mass.gov) to get on the January agenda

Anything else?

1. **Vote to Adjourn (slide 16)**

Elaine Gabovitch thanked everyone in attendance, led the vote to adjourn the meeting. Amy Benison recorded votes. All votes during this meeting obtained two motions and have been recorded.