

**PANDAS/PANS Advisory Council Meeting
January 11, 2023 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; 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; Amy Benison, DPH; Nicole Roos, DPH; Casey Hall, CHTA

Meeting Agenda

- Welcome: Roll Call & vote to approve November 9, 2022, meeting 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

1. Welcome and Agenda (slides 2)

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

2. 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 November 9, 2022, meeting minutes. There was a quorum with 10 Advisory Council members in attendance and 2 joining late for a total of 12 members.

3. 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).

4. 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).

5. Meeting Schedule (slides 7)

Elaine Gabovitch reviewed the upcoming meeting dates:

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

6. General Announcements (slide 8)

Jennifer V. and Sheilah G. informed the Council that they are going to try to put legislation into this legislative session and will come back to the group with updates.

Elaine reminded the group that work groups need to vote on meeting minutes at every meeting and should be sending separate voting and attendance records for DPH to store.

7. Family Story (slide 9)

Bryanne Wainford shared a personal story about her son who has PANDAS/PANS and what she considers to be a success story. Following her story, the Council members provided comments and asked questions about her personal experience.

8. Illinois PANDAS/PANS Presentation (slide 10)

Jennifer V. introduced Wendy Nawara, MSW, a board-certified patient advocate and consultant and former member of Illinois PANDAS/PANS Advisory Council.

Wendy shared a presentation about the history of PANDAS/PANS Advisory Council in Illinois and the legislation instituting an insurance mandate. Illinois's Council goals were to write a yearly report, increase awareness amongst pediatricians, regularly attend AAP Chapter conferences, present to mental health providers, schools and more. They also held a yearly Summit meeting, created and disseminated information, provided information to the State Board of Ed and school nursing, became a free Speakers Bureau to answer all call for more information on PANDAS/PANS, and developed an IDPH webpage dedicated to PANDAS.

Wendy explained they had no funding through Illinois, but instead used local non-profit money for supplies and conference fees and got sponsorships from specialty pharmacy for yearly summit.

Some of the successes, barriers and advice Wendy shared are listed below:

Successes:

- Acceptance and an expectation from the APP that their group would attend chapter conferences
- Positive relationship with ILGA, hospitals, and schools

- Increased physician awareness and some new providers
- Yearly increased attendance at their Summits
- Access to legislators and new bill developments
- Very trustful group process

Barriers:

- Lack of funding
- Diminished interest
- Loss of key members
- COVID-19

Ways to do it better:

- Obtain funding
- Change legislation to allow for alteration of goals based on present need
- Focus on education and recruitment
 - Med schools
 - Psychology and social work programs
 - Teacher education
- Alter co-chairs yearly for fresh perspectives and to avoid burnout

Jennifer and Sheilah then facilitated a question-and-answer session with Wendy. A summary is listed below:

- How did you decide on treatment protocols?
 - They stuck closely with PANDAS network and consortium protocols. Moving outside of evidence-based leads to controversy, especially if different states are doing and recommending different things.
- How long did the first report take to write?
 - One year, they tried to divvy up the work and fit it together.
- What is the success rate for IVIG for the patients in Illinois?
 - Illinois is facing issues. When Wendy has worked directly with families to try to get their insurance needs met, she is having an 80% success rate.
- What was the continuing legislation about?
 - Illinois tried to streamline the insurance procedures and put additional parameters on the law. They were not asking more, but just clarifying the language. The state does not have a lot of resources for IVIG.
- How many more PANDAS/PANS treating physicians did they gain through the years?
 - The numbers subtly increased, but they did see some pediatricians initially treating PANDAS/PANS and then handing their patients to current treating providers.
- Did you have Open Meeting Law and how did you work around it?
 - They were also under Open Meeting Law, they did everything in their meetings. People would write their individual sections and bring them to the meetings.
- Were there specific annual summits or conferences they were able to present at?

- They attended local AAP (American Academy of Pediatrics) meetings and school events on Autism.
- Did the local AAP give push back?
 - They weren't allowed to present, but they attended the local AAP chapter meetings without much issue.
- Did they hold summits?
 - They did host their own conference/summit, with their own speakers. They hosted it at agency rooms (state fairgrounds, public health offices, etc.).

9. 2023 Timeline (slide 11 & 12)

Elaine discussed the 2023 timeline including upcoming presenters, what work groups should plan to do over their upcoming meetings and how we should go about writing and voting on the second annual report.

10. Annual Cycle (slide 13)

Elaine discussed the annual cycle that she hopes the Council can follow year after year to provide a flow and consistency to their work.

11. Guest Speakers (slide 14 & 15)

Amy explained that the Council should bring in two speakers per meeting during September, November and January. Work groups should consider the list of speakers provided and prioritize which speakers should be brought in during the next fiscal year to answer their questions.

The Council discussed and agreed that prior to bringing in guest speakers, members should prepare questions. The Council can require state agencies to bring data to their meetings and the Council members thought it would be useful to provide a questionnaire to any state agency that is presenting. Council members noted they may also need to present to some guest speakers or state agencies.

Elaine suggested that the Council looks at the Autism Commission's report. Also, that the Council should consider what needs to be in the report this year and what should wait for following years. She noted that not all domains need to be represented or represented equally if the Council is not ready.

12. Work Group Report Outs (slide 16)

Sylvia F. led a discussion regarding the report around who is the audience, what is the reading level and format logistics. The Council agreed that aside from the general court, their broader audience includes providers, state agencies, and insurance companies.

In regard to language, the Council thinks the report should use plain language and while they do not want to oversimplify the medical research, they do not want to lose their audience with an abundance of technical language.

Elaine suggested that DPH can handle all formatting and that Michelle Pinto can assist with citations.

13. Next Steps (slide 17)

Elaine Gabovitch shared the following information:

Second meeting of 2023

Wednesday, March 8, 2023, 4-6PM

Future meetings via WebEx Events

If you need help, please email amy.benison@mass.gov 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 January agenda

Anything else?

14. Vote to Adjourn (slide 18)

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.