**PANDAS/PANS Advisory Council Meeting**

March 12th, 2025, 4:00 – 6:00 PM

Via WebEx Event

**Present:** Elaine Gabovitch, DPH, PANDAS/PANS Chair, Amy Benison, DPH, Program Support Specialist, Casey Hall, CHTA, PANDAS/PANS Meeting Consultant, Nicole Roos, DPH, Technical Assistance and Coordinator, Madelyn Goskoski, DPH , Margaret Chapman, APRN, MSN, PNMHCNS, Karen Colwell, Sheilah Gauch, LICSW, MEd, Melissa Glynn-Hyman, LICSW, Lisa Grisolia, Kelli Kennedy,MD, FAAP, Mark Pasternack, MD, Michelle Pinto, RN, Blake Poggi, MA, CCC-SLP, Jennifer M. Vitelli, MBA,  Yujuan (Julia) Zhang, MD.

**Public Attendees:** 3

**Welcome, Open Roll Call & Vote on Meeting Minutes**

Elaine Gabovitch, PANDAS/PANS Advisory Council Chair, called the meeting to order, managed the virtual open roll call and Maddy Goskoski tracked this information for the meeting record. Elaine led the vote to approve the January 8, 2025 meeting minutes. There was a quorum with eleven Advisory Council members in attendance for the vote.

**Agenda**

Elaine Gabovitch reviewed the agenda:

* Welcome: Roll Call & Vote to Approve 1/8/2025 Minutes        ​
* Introductions: Welcome Kelli Kennedy, MD!                              ​
* Announcements: General & Housekeeping                               ​
* Discussion: Update on Report Process                                  ​
* Update: 2025 Guest Speakers (specific questions for DDS, MassHealth and DCF meetings from May through September)​
* Next Meeting: Wednesday, May 14th, 2025, 4-6PM​
* Vote: Adjourn

**Statutory Authority**

Elaine Gabovitch reviewed the following Statutory Authority statement with the Advisory Council.

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 his 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**

Elaine Gabovitch reviewed the following aim statement with the Advisory Council.

* 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).

**Welcome Kelli Kennedy, MD!**

Members of the Council went around to introduce themselves to our newest member, Kelli Kennedy, MD. Members of the council were asked to share their names, role on the council and why they are on the Council. In addition, Kelli Kennedy had an opportunity to share who she is and explain why she wanted to join the Advisory Council.

**Announcements: General & Housekeeping**

* A council member shared that the National Alliance for PANDAS/PANS Action (NAPA) will hold two days of advocacy on April 10 and 11, with a virtual option available. To participate in Capitol Hill advocacy for NAPA on April 10 and 11, please email info@napaaction.org for details and registration.
* A council member noted the Alex Manfull Fund will host a road race on Saturday, April 12 at Hains Point in Washington, DC, to support clinician education at Dartmouth.
* One council member reported that Lifting Voices met with national-level Medicare and Medicaid consultants and launched surveys on mental health system effectiveness; more info is at [liftingvoices.org](https://www.liftingvoices.org/).
* A council member shared that the Boston Marathon will feature a PANDAS/PANS runner promoted by the Look. Foundation. The runner will hit the roads to complete on Marathon Monday, or Monday April 2021.
* One council member reported the Look. Foundation recently distributed $11,000 in healing grants. These grants have been distributed to multiple families and children with PANDAS/PANS.
* A council member confirmed that the Massachusetts Coalition’s bills have been assigned numbers and committees:
* H1249 is assigned for screening.
* S1415 is with the Mental Health and Substance Use Committee.
* A member reported that the Title V program at the Department of Public Health is accepting applications for the federal block grant, which requires a five-year needs assessment and action plan; PANDAS/PANS is being proposed as a mental health priority.

**Update: Annual Report**

Council members, Michelle Pinto and Jennifer Vitelli had the ability to screen share the current version of the annual report with the council members and provide an overview of the annual report and where it currently stands.

Jennifer informed the council of what changes the writing group made to this year’s annual report and what looks different compared to years past. According to Jennifer, the group expanded the background section of the report to provide greater context for understanding the diagnosis and treatment methods, they included a new section highlighting research developments and studies that have occurred since the 2023 report. In addition, the writing group added a section detailing the current state of PANDAS/PANS in Massachusetts, which included information on burden, prevalence, diagnostic and treatment barriers, and the absence of diagnostic codes. Lastly, in the appendix, they incorporated a summary of recent announcements to showcase ongoing activity and progress within the PANDAS/PANS community.

Michelle informed the council members regarding the structure of the new report. According to Michelle, that the report will include an executive summary, following a background section, diagnosing PANDAS/PANS, treatment of PANDAS/PANS, recent research, an assessment of the current state of PANDAS/PANS in Massachusetts which contains two sub headers: the burden of PANDAS/PANS in Massachusetts and prevalence and lack of diagnostic codes. After those sub-headers, the next section following is barriers to diagnosis and treatment, followed by lack of parity among medical institutions, methods, summary of guest presentations, gaps and the report will be completed with it’s final header, recommendations.

Michelle also discussed the proposed “Gap” section will entail in detail. From there, Council members gave feedback and thoughts regarding the proposed section. Council members had very minimal feedback on proposed gaps as they agreed with what the writing group identified to be gaps. Furthermore, Michelle discussed “recommendation” section in detail. Council members gave feedback regarding the recommendation section. Council members added a recommendation to the proposed list for DESE. The Council would like for the school districts to consider PANDAS/PANS to qualify for special education services. In addition, they would like for each district to consider how they recognize PANDAS/PANS and if so, what IEP category would PANDAS/PANS qualify for.

After discussing the proposed gaps and recommendations, the council had a conversation regarding general DESE regulations and rules. One council member stated that children in some districts receive accommodations for having PANDAS/PANS-but accommodations are not universal. The council began to consider adding a recommendation into the annual report mandating DESE to ask each school district across the Commonwealth about how they support students with PANDAS/PANS. Another council member stated that they feel there are inequities present within the various school systems; another member followed up stating that PANDAS/PANS is an unequitable diagnosis, so action must be taken by the council. Another council member mentioned that she feels it is important to teach parents how to advocate for their child. In addition, she mentioned that this could include teaching them specific language to be able to advocate.

In response to this discussion, Elaine Gabovitch highlighted the Section 504 of the Rehabilitation Act. According to this act, students could receive an education plan for diabetes, asthma, etc. as these medical conditions can have an impact education. A council member stated that after speaking with many PANDAS/PANS families a common opinion is that 504 plans are not as effective as an IEP for these students as it does not always monitor progress as strictly as an IEP. Another council member who works in a school district stated that she has difficulty navigating with other schools because some districts have supports for students, while others do not. The council stated that a proposed recommendation could include the importance of increasing staffing in the school due to PANDAS/PANS. The council feels that school districts are understaffed and not fully equipped to assist the needs of some students with complex health and/or medical needs.

As the report takes a while to finalize and publish, one council member was wondering if a subset of the council could reach out to DESE and discuss this further. Elaine Gabovitch suggested asking for a meeting and/or sending a letter to spark a conversation. Council members understood.

**Questions for DDS**

* What specific questions do we have for DDS?

Due to prolonged discussions, the council did not have time to discuss and brainstorm questions for DDS as they are joining the council meeting in May. Jennifer and Sheilah stated that they plan to follow up with council to obtain questions from the council over email.

**Wrap Up: Next Steps**

* Third Meeting of 2025!​
	+ Wednesday, May 14th, 2025, 4-6 PM​
	+ Future meetings via WebEx Events ​
	+ If you need help, please email Maddy Goskoski at madelyn.m.goskoski@mass.gov in advance who will find assistance. ​
	 ​
* Next steps:​
	+ Email madelyn.m.goskoski@mass.gov to get on the May agenda ​
	+ Anything else?​
	+ Vote to Adjourn

**Motion to Adjourn**

Elaine Gabovitch thanked everyone in attendance, led the vote to adjourn the meeting. Maddy Goskoski recorded votes.

All votes during this meeting obtained two motions and have been recorded.