# PANDAS/PANS Advisory Council Meeting

January 8th, 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, Sylvia Fogel MD, Sheilah Gauch, LICSW, MEd, Melissa Glynn-Hyman, LICSW, Lisa Grisolia, Kathleen Maher, MS-PHCNS, RN (Kate), Melissa McCormack, MD, PhD, Mark Pasternack, MD, Michelle Pinto, RN, Blake Poggi, MA, CCC-SLP, Jennifer M. Vitelli,

MBA, Kyle Williams, MD, PhD, Yujuan (Julia) Zhang, MD.

# Public Attendees: 4

**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.

# Agenda

Elaine Gabovitch reviewed the agenda:

* Welcome: Roll Call & Vote to Approve 1/8/2025 Minutes
* Announcements: General & Housekeeping
* Guest Speakers: Department of Mental Health Panel
* Guest Speakers: Reflection of Guest Speakers
* Guest Speakers: Future Guest Speakers Update
* Discussion: Update on Report Process
* Discussion: American Academy of Pediatrics
* Wrap Up: Next Steps
* Next Meeting: Wednesday, March 12th, 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).

# Announcements: General & Housekeeping

* NAPA: The NAPA Steering Committee is working on new legislation in regard to the congressional appropriations bill to be included within the 2025 fiscal year
* NAPA: Recently, NAPA partnered with Alex Manful Fund and spent two full-days meeting with law makers at the US capital advocating for PANDAS/PANS
* Alex Manful Fund: On April 12, 2025, the Alex Manful Fund will host a 5k walk and run in Washington DC for anyone to join
* Open seat on the council (pediatrician) posting can be found on DPH PANDAS/PANS - deadline to apply 2/5/2025
* AAP :The American Academy of Pediatrics (AAP) has officially recognized PANS as a valid, serious diagnosis in their preliminary report, and this meaningful step forward. However, there is work to be done and we are going to address this later in our agenda.
* Claimable: a new FREE software tool (just launched last month) to help PANS/PANDAS patients fight denials and secure treatment. For more information, visit [www.getclaimable.com/pans-pandas](https://www.getclaimable.com/pans-pandas)
* “Inflammatory Brain Disorders Conference”: Neuroimmune Institute open their early bird registration for the May 15 &16 2025. There are 500 free fee waivers for clinicians who it’s their first time attending. For more information: [www.neuroimunneinstitute.org](http://www.neuroimunneinstitute.org/)

# Department of Mental Health Pannel

Elaine Gabovitch provided a brief introduction of our Department of Mental Health Speakers.

* Carol Murphy, LICSW, Director of Programs and Practice, DMH Child, Youth and Family Services
* Mi-Haita James, LCSW, Assistant Commissioner, DMH Child, Youth and Family Services
* Nandini Talwar, M.D., Child Psychiatrist and Medical Director, DMH Child, Youth and Family Services

Elaine then asked the council to consider the following points as the personnel of DMH speak:

* Discussion Format
	+ 15 minutes: DMH presentation
	+ 30 minutes: Questions & Answers
* Update your name and role in Webex for our speakers
* Raise hand
* Presentation and Q&A will end promptly by 5 pm
* Be mindful of the space and time you are taking
* Foster an open discussion focused on group learning and problem solving

Carol Murphy, Director of Programs and Practice, DMH Child, Youth and Family Services, shared a power point slide where they presented information to the council on the role and purpoe of DMH, services offered and how to access these services at DMH. In addition, they identified what are the qualifying diagnoses that an individual must possess to be supported at DMH, treatments they offer or connect families to (including community-based and facility-based), programs that DMH offers which do not require DMH Service Authorization in order for an individual to access, and how DMH works closely with school systems to bridge mental health leaves and returning back to school.

After the presentation, the team at the Department of Mental Health led a question-and- answer session with the Council.

* Nandini Talwar answered the background question “Are there any available data/stats related to PANDAS/PANS”. To answer this question, she stated that DMH does not have any formal data on PANDAS/PANS, however, they received polling from the five cases per year they have served. She also answered a second background question “Are there any relevant case management or training”. She stated that they do not typically serve this population due to children oftentimes needing additional medical interventions. While they do not serve many/if any children with PANDAS/PANS each area office have their own child psychiatrist doing research and special projects and they are aware of the diagnosis. Furthermore, she stated that within DMH parameters, PANDAS/PANS would fall under mental disorder due to another medical condition. Because of this, they do not serve the individual unless they have another qualifying condition. She informed the council that DMH is always available for consultation. Lastly, she answered the final background question “Does DMH have funding to support PANDAS/PANS” to which she responded that DMH does not have any specific funding to support those with PANDAS/PANS.
* Nandini Talwar answered the question “What experience/exposure do you/your organization have with PANDAS/PANS?”. Nandini stated that DMH has minimal experience working with individuals who have PANDAS/PANS as it is not a qualifying diagnosis for enrollment at DMH.
* Nandini Talwar answered the question “What professional development including

training/information resources have you and your staff had related to PANDAS/PANS?” She stated that DMH staff personnel receive minimal trainings on PANDAS/PANS. Furthermore, she stated that the trainings cannot be mandatory due to regulations, however, they are open to allowing optional training opportunities to staff to encourage continuing education opportunities

* Nandini Talwar answered the question “What kind of barriers do you experience when working with children & youth with PANDAS/PANS and their families?” She stated that specific programs within DMH would benefit from more information especially if treatment courses are not improving. In these cases, the clinician may want to consider other diagnoses or impacts. Furthermore, Mi-Haita James stated that even though DMH has limited experience working with this population, they always are happy to be invited and sit at tables to learn the behavioral health needs of individuals. She went on to explain that DMH wants to build a partnership where continued learning is always welcomed. She feels that DMH hold the responsibility of helping families navigate systems even if individuals are not authorized within DMH. She encouraged the council to reach out whenever necessary and be a long-standing partner with DMH.
* Carol and Nandini answered the question “Would DMH staff be open to an educational presentation on PANDAS/PANS? (Specifically, their Mass Child Access Psychiatry Program)” and stated that yes, they would be interested in ongoing training opportunities. They stated that they would never want to withhold medical care from someone who needs it. Additionally, if an individual cannot receive treatment within a DMH facility, the staff personnel would partner with a facility that is equipped to provide a certain treatment(s) that the individual would require.
	+ One council l member stated that PANDAS/PANS is derived from a three-pronged approach to treatment: one being mental health. This member stated that individuals with PANDAS/PANS oftentimes need mental health providers for their treatment. Because of this, she asked how families, members of the council, and providers could advocate for change and understanding at the state-level to access support for children who need services? Nandini Talwar stated that service authorization criteria are within DMH regulations. Because of this, council members would need take a change with DMH regulations. However, Nandini is unsure how to go about changing those regulations—she thinks advocacy would help in supporting greater change and creating more specialized services to support those with PANDAS/PANS. In addition, Mi-Haita James added that CYF area offices support children and families daily so if a comorbid diagnosis exists than the individual can access services and treatment at DMH. She stated that if the individual l has a comorbid diagnosis to make sure that is clearly documented for the authorization process. Lastly, Nandini stated to look at acuity, she explained that the most ill children are in tertiary care so many of the services established at DMH are aimed to serve that subset of children.

# Guest Speakers: Reflection of DMH

* Related to the 2024 report, did the speaker share anything:
	+ That supports it?
	+ That contradicts it?
* Do you have follow-up questions for DMH?
* Do you have any recommendations for the next report yet?

Co-Facilitator, Sheilah Guach read aloud the questions that the group did not have an opportunity to ask DMH. Elaine Gabovitch informed the council that they can collect these questions and follow up with DMH via email.

* One council member shared that there is a clear line for individuals who are ineligible to qualify for DMH regulations; specifically, those with a medical illness do not qualify. She mentioned that individuals she has worked closely with were initially denied, but after

providing proof and navigating the system, they were eventually accepted. She then asked the council how do regulations in DMH get changed? Can the council have an impact on changing the regulations? Elaine Gabovitch followed up and addressed that people come up against challenges within the systems in terms of changing regulations. She stressed the importance of the legislation as regulations can be encoded within the law. Elaine offered to talk to colleagues about how to go about this to determine if this can be done.

* Another council member felt that the DMH panel does not understand PANDAS/PANS and thinks that training and education can benefit DMH staff. All council members agreed to this sentiment.
* A third member asked the council how they can gain DMH's support for this initiative. They noted that securing DMH's backing could be beneficial in advancing the legislative process. In response to this, another council member noted that she feels some staff at other area offices do understand the diagnosis, while other offices do not necessarily understand the diagnosis leading to a discrepancy in information.
* A council member mentioned that many individuals reject IVIG and frequently dismiss the value of administering more than 10 days of antibiotics, suggesting instead that the treatment should be handled by a psychiatrist. In response, another council member wants to know if these are in the regulations and what are the disqualifying factors? In addition, she would like to know how to does DMH define equity especially for those who desperately need support

# 2025 Guest Speaker Update

Elaine Gabovitch shared an update regarding the upcoming guest speakers with Council members.

* We will work to invite these three agencies for 2025:
* Department of Developmental Services (DDS)
* Department of Children and Families (DCF)
* Department of Youth Services (DYS)
* We will send out a poll for people to submit questions once we have confirmations from the speakers
* The Council should consider previous recommendations/activities that were noted in past report

# Report Timeline

Michelle Pinto shared the report timeline with the council. The timeline and significant updates are as follows:



# American Academy of Pediatrics

Jennifer Vitelli and Sheilah Gauch led a conversation relating to the new article published by the American Academy of Pediatrics (AAP). Jennifer and Sheilah asked the council to consider the following questions:

* What are your thoughts about the AAP’s clinical report?
* How could we follow up with the MA chapter?
* One council member stated when the AAP first came out, she was happy that they acknowledged PANDAS/PANS as an actual diagnosis. However, one of the insurance companies used the paper to deny IVIG to one of her patients. Because of this, she is very concerned that other insurance companies might follow and start to deny IVIG. She stated that she wonders if council needs to react to the AAP report as it is a concern to families. Another council member agreed that he was happy that PANDS/PANS was recognized and deemed a formal diagnosis. However, he felt that the AAP provided incorrect the details throughout the paper that do not make sense in his opinion. One detail that did not make sense to him was the fact that the AAP alluded that screening and antibiotics are not valid to treat PANDAS/PANS.
* In addition, one council member stated that it seems like the report was written by people who are not familiar with this area or working with patients. Within the last few years, a lot of research has been emerging however, this member felt that those who treat the disorder or participate in research endeavors were not included as authors

within the report. In response, another member pointed out that the citations included within the report are not the most up to date research. Furthermore, another member chimed in and stated that the AAP had access to newer research and chose to “cherry pick” and ignore the data that was presented to them.

* Another council member pointed out that the Oregon Medicaid group has already attempted to figure out if IVIG is still encouraged and covered by insurance companies. In addition, she stated that she feels very confused by the article.
* Another council member mentioned that if we had to run a clinical trial for Kawasaki, we wouldn’t go that route. IVIG started being used, and it worked for many people, so doing a trial would be unethical at this point. He stated that the outlook isn’t great right now because they plan to rely on the AAP and a recent failed trial. He suggested that the council needs to draft a letter and respond to the AAP especially since IVIG

treatment is so expensive, it’s unlikely another study will be funded anytime soon. He also pointed out that with similar pediatric epilepsy conditions, IVIG is used without much pushback. NIH-funded research now shows they won’t be funding clinical trials in this area, which raises the question of what comes next for finding evidence-based treatments for these conditions. In response to this, another council member stated that many students she works with have greatly improved from IVIG. She was wondering how this can be quantified as IVIG does make an impact to many.

* Another council member described the AAP article as a “kick in the gut”. In response, a clinician stated that the collection of symptoms includes difficulty sleeping at night without a parent and daytime urination episodes, representing an “umbrella” of symptoms that are unique and differ from what the paper described.
* One council member informed the council that she thinks the Massachusetts PANDAS/PANS Advisory Council is the only active council in the United States at this time. Elaine Gabovitch stated that she consulted with Stephanie Doyle, Deputy Director of Strategy and Implementation, Bureau of Family Health and Nutrition at the Department of Public Health to understand the role of DPH. Elaine stated that our annual report is required, and annual bulletins should be more aligned with advocacy organizations due to their relationship with DPH. In response, a council member mentioned that if the council informs the DPH commissioner about the concern, it could help bring it to their attention.
* Another member stated that the council will likely see more families enroll into Mass Health Secondary asmany private insurance companies will likely not cover IVIG treatments going forward. In response, a member stated that she likes idea of drafting a letter to the commissioner regarding the AAP article. In addition, she was wondering why it is not possible for the council to write a letter to the AAP on behalf of the DPH council. Elaine Gabovitch informed the council that she will talk to the DPH legal team for further answers. As a response, the council member asked if she or other council

members choose write letters individually to the commissioner can they state affiliation with the council? Elaine Gabovitch stated that it is okay to mention that they are participants of the Council. In addition, Amy Benison wants to consult with legal to make sure a group of DPH council members can write letters to avoid issues with a quorum and open meeting laws. In addition to sharing letters, one member suggested sending the Massachusetts annual reports to the AAP just so they can understand the work.

Elaine Gabovitch informed the council members that the reports cannot be shared at this time, but once the reports are finalized and it can be publicly posted and shared.

* One council member wanted to remind the council that we are a “pocket of hope” and we will keep pushing on and driving forward because all members of the council are strong advocates involved with the work. Elaine Gabovitch agreed with this council members sentiment as they are up against an entire system. In response, a council member was wondering if we can create a poll or data to collect and share with the AAP? One example she gave was informing the AAP of how many children were impacted by treatment. She informed the council that the AAP is open to comments. Another council member stated that the that Look. Foundation has that type of data already readily to share with the AAP if interested.

# Wrap Up: Next Steps

Elaine Gabovitch shared wrap and next steps with the council Second meeting of 2025

* Wednesday, March 12th, 2024, 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 March 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.