**PANDAS/PANS Advisory Council Meeting** September 11th, 2024, 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, John Gaitanis, 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: 0

**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 July 10th, 2024 meeting minutes. There was a quorum with thirteen Advisory Council members in attendance for the vote, with five members joining later in the meeting for a total of twelve members.

# Agenda

Elaine Gabovitch reviewed the agenda:

* Welcome: Roll Call & Vote to Approve 7/10/2024 Minutes Announcements: General & Housekeeping
* Guest Speaker Presentation: Iraida Alvarez (DESE)
* Composite Cases Update: What progress has been made?
* 2024 Annual Report Update: What progress has been made?
* Reenrollment: Process for 2025
* Wrap Up: Next Steps
* Next Meeting: Wednesday, November 13, 2024, 4:00pm—6:00pm
* 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

* Look. Foundation is participating in World PANDAS/PANS Awareness Day. This is a worldwide effort to get landmarks lit up both locally and nationally. 105 landmarks will be lit up on October 9th including Massachusetts bridges lit up and billboards. The Look. Foundation is seeking connections to light up additional landmarks.
* The Alex Manful Symposium will be held on November 2nd in Portsmouth, NH. The symposium will have various speakers and a young adult panel.
* The Look. Foundation Walk is taking place on Saturday October 5th to honor PANDAS/PANS Awareness Day and fundraising. A few hundred people are registered to participate along with officials, community members, and Wally from the Boston Red Sox. Additionally, a banner can be located at Tremont Street on the route of the walk. If interested in participating the walk please click the link to register on the Look. Foundation website: www.givebutter/lookwalk.
* One Council member mentioned that she has moved to the Lyme and PANS Treatment Center in Hingham, MA. They are excited to focus on Neuroimmune Disorders through a new line of work.
* Another council member stated that school nurses have gotten update from DPH regarding strep throat protocols. DPH stated that there is a 12-hour return to school policy following strep throat. This council member asked medical providers sitting on the council if this policy is evidence-based and if they can provide the council with further studies on this topic. Another council member mentioned that he is not aware of change but offered to investigate it more and report back to the council with more information.

# Guest Speaker Presentation: Iraida Alvarez (DESE)

Iraida Alvarez, Executive Director, Special Education at The Department of Elementary

& Secondary Education (DESE) presented a power point presentation to the PANDAS/PANS Advisory Council. After the presentation, council members had an opportunity to ask Iraida Alvarez questions.

Group Discussion: DESE

**Question 1:** If a student misses school due to PANS, and the provider confirms it is likely due to PANS, does the school still need to involve DCF as a mandatory reporter?

* Iraida stated that if a student misses school, DCF should not be the first resort for the family. After Covid, the rates of student attendance have decreased, because of that, it has been an area of focus of the department. She informed the council that DESE provides guidance to school districts about mandated reporter information.
	+ **In response to this question,** one council member discussed a specific case that she experienced as a provider. They stated that they wrote a letter of medical excuse on behalf of a patient. The provider mentioned that the school district refused to acknowledge or accept the letter and DCF was informed. In response to the statement made by a council member, Iraida stated that if the family has not been able to reach a resolution, it would be important for the family to utilize the complaint resolution system. The DESE complaint resolution system that allows families to receive technical assistance and file a complaint. Also, Iradia stated that families can reach out to the Office of Civil Rights as another avenue for further support. Lastly, Iraida encouraged council members to reach out to her directly for further support if needed.

**Question 2:** What type of communication from providers could be the most helpful? We often provide a letter stating the diagnosis, possible accommodations needed. Sometimes we attach a link to the PANS related website.

* + A council member stated that children with PANS/PANDAS tend to miss school compared to other students to protect themselves from getting sick or miss school if they are in a flare. The council asked if there a way to get the message Office of Family Support as attendance is one of their main priorities. In addition, the council member also asked how can we educate staff members at DESE along with the school districts to have information spread? Iraida stated that her current role at DESE does not include educating and training of school staff. In addition, she stated that for students that do not have an IEP, there should be communications between parents and the school to provide an understanding of the health condition. While Iraida hopes the school would understand, not everyone would react the same way. Furthermore, Iraida felt that education and trainings for her staff would be helpful to meet the needs of the students. In response to this statement, a council member asked if we could provide education to Iraida and pass the information?
	+ Another council member asked Iraida about what kinds of recommendations around policies exist around medical or psychiatric needs? She also asked if there are any accommodations for students if medical issues arise? Iraida stated that there is a public document posted on the DESE website that provides guidance around attendance policies. However, Iraida said that this document is not around specific medical conditions.
	+ One council member shared with the council that through his work as a medical provider that he experiences differences between various schools and districts. He reported that some schools have been supportive of his patients and others have been hostile. He noted that in this case patients oftentimes get support from educational advocates or community supports. In addition, he reported that students using IVIG miss approximately 12-28 days a year for treatment. Because of this, the council member believes school districts should be educated on PANDAS/PANS. Iraida noted that this is unfortunate news to hear, but important to identify where the need is, and educate the districts.
	+ Another council member noted that since there is not a lot of awareness around this disorder, they are not diagnosing many children, especially those of marginalized populations. This council member was wondering how we can start to get information out there so children are not moved to a restricted learning environment. Iraida stated that DESE receives a monthly special education leader webinar. She explained that this could be a communication avenue for presentation on PANSAS/PANS. Iraida also stated that there are newsletters for special education and various other networks to share information on this diagnosis. In response to Iraida, another council member agreed

that members of the Council should speak with special education directors to make it less antagonistic when working with families

**Question 3:** If we want to learn more about infection exposure in school (for example exposure to strep), is it possible the teacher informs the PANS family there is a positive strep case in a specific classroom?

* + Iraida stated that students have privacy protections broader than one might assume. She explained that the FERPA law restricts health conditions to be shared apart from a few conditions (e.g. head lice and COVID-19). The Department of Public Health outlines what can and cannot be shared and DESE follows the rules. In response to Iraida, a council member agreed as she has experience working in the school system.

**Question 4:** What is the usual procedure before a school district can approve and pay for a therapeutic school program for a student?

* + Iraida noted that an IEP is a multi-tiered system which includes the creation process, once it has been developed, and implements the determined needs and services of that specific student. Also, she reported that a discussion occurs among the IEP team around where is the best place for this student to learn (ex. general education classroom, special ed classroom, hybrid, out of district placement). Ultimately, the IEP team decides a student’s classroom placement. Additionally, for an out of district placement various interviews and an admission process occurs.
	+ **Question 5:** Would DESE consider an educational endorsement of PANDAS/PANS as part of their approved courses of study as they do for Autism?
	+ Iraida stated that of course they are willing to consider it, however, legislative action would have to occur externally. In addition, it would have to go through own regulatory rules and ask the board, becomes part of the process. In response to Iraida’s answer, a council member stated that a Bill would be passed. Elaine Gabovitch posed a question to the group regarding how they could go about getting a bill moving forward to recognize PANDAS/PANS?

Once Iraida concluded her presentation, the Council had an open discussion considering what she had shared with the group.

* A council member mentioned that a cohort of the council should educate staff through school committees. A second council member noted that Special Education Directors and Superintendents do not have this information. As they do not have this information, she stated that they would be good people to target first. Additionally, this council member noted that Iraida can make a lot of policy change at DESE, but each district can have power to make their own choices.
* In addition, a council member also informed the council that if a student is out for 10 days consecutively, they are required to have tutoring. A second council member reported that a tutor is required after 14 days if it not consecutive. A third council member noted that it seems like each district has their own policies, but she is unsure if there is an actual written policy. A fourth council member chimed in and stated that she feels that every school system seems to “play a different game” when working with these kids. She feels that it seems that some schools give pushback at every turn while others are great and understanding. She asked the group if there are people in the school district that we can reach out to before filing a complaint? **In response to the question asked,** a council member who has experience working in the school system said yes. She informed the council that one can reach out to superintendent. She also noted that every district interprets DESE policy and DESE home health form differently. Another council member stated she felt that “there is no rhyme or reason” one district may accept it, another may not. She also stated that it is likely relating to the resources available within that district.
* **In response to the group discussion, one** member asked the council what we can do as DESE can only give recommendations. She also expressed that she feels as it is not fair for families who are being reported on. She posed two questions to the group, what recommendations do we want to think about for the next report? What changes do we want to make? In response to the two posed questions, a council member stated that she feels educating superintendents and special education directors would be a good start. Furthermore, she stated that its behavior/psychiatric presentation that schools acknowledge, not just a medical issue such as chemotherapy viewed as a medical concern. Another council member stated that we can’t target everyone right away, but this is a diagnosis that has a medical component and behavioral component. Elaine Gabovitch then informed the group that the Insurance Resource Center through UMass Medical Center has expanded into behavioral health, and they help families to obtain coverage for various diagnoses. In addition, Elaine informed the group that it might be worth speaking with them. Another council member reported that she has an upcoming meeting with regional consultants. She stated that she will hopefully be educating them in lesion to special education directors. She mentioned that this could be helpful especially by targeting school nurse directors working with special education directors.

# Composite Cases Update: What progress has been made?

Elaine Gabovitch and Jennifer Vitelli shared information and updates regarding composite cases and optional WHY statements.

* Update
	+ We will be using composite cases for this report and can explore specific cases in the future
	+ People also have the option to submit *Why Statements*
* Next Steps
	+ People need to submit items to Maddy by Wednesday October 9th
* One council member wants the group to consider whether including WHY statements within the next annual are necessary or not. This individual feels that the former report expressed the “why”?. In response to this, a council member further elaborated stating that the Writing Group did an in-depth review of the Autism Commission Report and shared that they had beautiful quotes throughout the report which they felt was a nice personal touch. The council member thinks we must be careful when publishing “WHY” statements for privacy reasons. In response to the concern, Elaine Gabovitch informed the council that we need more time as a council to deliberate this conversation. Another council member asked facilitators Sheilah and Jennifer to share examples with the council of examples of what the “WHY” statement could include. Jennifer and Sheilah to share examples with the Council for review.

# Composite Cases Template

Elaine Gabovitch shared the case example with the Council and reviewed the outline and format of what these cases should look like. The format reviewed is as follows:

* Clinical Presentation (with lab findings if applicable)
* Family experience
* Current Outcome
* Suggested Applications for the Field

# 2024 Annual Report Update: What progress has been made?

* Format:
* Keep the background
* Remove current appendices
* Add appendices related to this year's speakers
* Adjust recommendations and summary based on this year's speakers- if necessary

Writing Progress Update

* The Annual Report Writing Group shared with the Council that they are currently reviewing materials to determine what to focus on and include within the report. The writing group has met once, and have another meeting scheduled very soon. The Annual Report Writing Group shared that it seems like a fluid process thus far. They also mentioned that they are missing May and January meeting minutes as they are not

located on the website. Maddy Goskoski provided update to the writing group and informed members that she will email the missing documents for their reference.

# Reenrollment: Process for 2025

Elaine Gabovitch reviewed the slide and information regarding the reenrollment process for January 2025 through December 2027.

* Complete reenrollment application for Council term Jan 2025- Dec 2027
	+ Send application to Elaine by October 9th
	+ In the application we will ask people for their *Why Statements*
* Policies for reenrollment
	+ To be enrolled for the next 3 years, Jan 2025-Dec 2027
	+ To attend 4 out of 6 yearly meetings moving forward
	+ To review Open Meeting Law policies yearly

# 2024 Timeline:

Elaine Gabovitch reviewed the updated 2024 timeline with the Council.

# Wrap Up: Next Steps

Sixth meeting of 2024

* Wednesday, November 13th, 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 November 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.