**PANDAS/PANS Advisory Council Meeting**

May 8th, 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, Sheilah Gauch, LICSW, MEd, Sylvia Fogel MD, Sheilah Gauch, LICSW, MEd, Melissa Glynn-Hyman, LICSW, Lisa Grisolia, Kathleen Maher, MS-PHCNS, RN (Kate), 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:** 5

**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 March 13th, 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 3/13/2024 Minutes
* Announcements: General & Housekeeping
* Discussion & Q&A: Kevin Beagan, Deputy Commissioner (DOI)
* March Reflections: Mary Beth Miotto, MD, President (MCAAP)
* Wrap Up: Next Steps
* Next Meeting: Wednesday, July 10, 2024, 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**

* JBC and New England PANDAS are hosting an event called “Let’s Get Real” on June 9th at the Real Theater in Scituate. The event will highlight individuals that will share experience with PANDAS and offer insights on their personal experiences.
* Sheilah Gauch, Council member, highlighted multiple presentations that she has completed recently including:
* Training presented to social workers in Massachusetts and Rhode Island
* Department of Public Health: Lunch and Learn Series
* Sheilah and Council member Jennifer presented for the Rare Disease Council through the Department of Public Health
* Sheilah and Council member Melissa presented at the Youth at Risk Conference
* JBC is participating in the Cohaset Triathalon on June 23, 2024, (Team JBC)
* JBC is hosting a benefit walk on October 5,2024, located at the Boston Common
* April 12, 2024, was Capitol Hill Advocacy Day. Over 80 participants joined from all over the United States to participate in the event.
* April 13, 2024, was the Alex Manful Fund 5k. Over 300 runners and walkers participated in the event and raised over $70,000. Meghan O’Rourke was the guest speaker at the event where she discussed her book “Untangling PANDAS & PANS”
* Recently, Susan Manful started a podcast where Council member, Kyle Williams, had an opportunity to make a guest appearance.
* Currently the University of California San Francisco is partaking in a study relating to PANDAS and PANS. The study enrolls individuals who have PANDAS/PANS and OCD. The study will provide a full gene scan for participants along with a partial genetic study.

**Discussion: Guest Speaker Presentation and Discussion**

Kevin Beagan, Deputy Commissioner, Division of Insurance reviewed his power point slides with the Advisory Council. Information shared from the power point slides is outlined below for reference. After Kevin presented, the group asked him questions and participated in a group discussion.

Group Discussion: Kevin Beagan, DOI:

* Council member asked Deputy Beagan who ultimately decides adequate decisions for care? Kevin states that at this time, DOI makes that decision though he described it as short-term. He mentioned that staff members from DOI spend a lot of time fixing the provider directory as it contains inaccurate information (ex. a provider may state that they treat a disorder and they do not). Additionally, Kevin mentioned that there is a lack of providers for PANDAS/PANS, especially in Western Massachusetts.
  + Council member asked a follow-up question to Kevin Beagan. He asked if there are other areas of medicine that include “carve outs”. Kevin stated that they hold insurance companies to the same standards including the overseeing of behavioral health companies. DOI needs to oversee all operations to assure that they are meeting proper standards of care. With that, Kevin reported that providers can only include treatments or disorders they have treated within the last two years into the directory, rather than including treatments that they do not treat or have not treated in a very long time.
* Council member wanted to know the average length of an appeal of someone who was denied care? Council member reported that she wanted to know the answer for this as delay of care is prominent in this population. She also reported that the earlier treatment, the better the care PANDAS/PANS will be. Kevin answered the question stating that The Office of Patient Protection is responsible for publishing an annual report. This report includes information on timing of appeals, denials, and withdrawals. Furthermore, he stated that there is a law requiring that appeals take place in a specific amount of time.
* Council member asked if Council members have families who do not have access to treaters in the Commonwealth, how do they connect with DOI. Kevin stated that there is a complaint function is available for consumers if they are not able to find access to care in their catchment area. Kevin encouraged providers and families to reach out to DOI for further assistance.
* Council member asked a question as it relates to insurance protection through employer insurance companies. Kevin reported that the bigger the employer (especially with headquarters in another state) the less likely the law will apply. If it is a smaller and located in Massachusetts, the more likely DOI laws will be covered.
* Council member asked if the insurance has authority to drop the coverage for an individual. Kevin reported that a letter of medical necessity can be provided by their doctor to validate that a particular treatment is medically necessary. He reported that if the letter gets denied, that the doctor can appeal and go through concurrent review to convince the insurance company through their notes that the treatment is medically necessary for the individuals treatment.

**Immediate Reflection: DOI**

* Related to the 2023 report, did the speaker share anything:
* That supports it?
* That contradicts it?
* Do you have follow-up questions for Deputy Commissioner Beagan?
* Do you have any recommendations for the next report yet?
* Please come prepared with recommendations for the July meeting.

Group Discussion:

* Council member commented that based on treatment, many patients are probably trying to change their insurance to receive their treatment or medication covered.
* Council member was curious about IVIG, especially what procedures they cover and what they do not based on the laws regarding coverage.
* Another Council member asked the group if they can think about where there can be a landing page to help families navigate insurance. Her thought was to create or implement resources to help families understand their out of state insurance.
  + Council member replied that most insurance plans approve the treatment quickly, but some plans can take weeks to get approval for treatment implying that some plans are better than others.
* Council member commented that sometimes have having a specialty doctor(s) does matter in terms of accessing care, compared to an order being placed from another type of specialist.
* A Council member was wondering if it is feasible to ask DOI to create an informational one-page handout that we can put on the landing page of mass.gov and include within the report. She commented that she feels that the Council should guide families how to go about insurance coverage.
  + One Council member agreed with this statement. She felt that there are not many provider options, but she feels that we can help direct families to DOI to determine whether the provider in Massachusetts is within their network. Another Council member stated that a PANDAS/PANS provider directory exists, but many names were unfamiliar to people within the local PANDAS/PANS community. Because of this, providers listed in the directory may not be treating PANDAS/PANS on a regular basis, or at all.

**Discussion: March Meeting Reflection: MCAAP**

* Related to the 2023 report, was there anything:
  + That supports it?
  + That contradicts it?
* What will the Council’s next steps be?
* How will you incorporate what you heard into the 2024 report?
* Do you have any recommendations for the 2024 report?

Group Discussion

* One Council member felt that the AAP has not fully accepted or acknowledged PANDAS/PANS to be real or true. Because of this, she felt that the Massachusetts Chapter of the AAP does not believe it is real either. Council member had the idea to ask our guest speaker to share stories (complied by the Council) to the Massachusetts chapter.
* A Council member recalled that Dr. Miotto previously mentioned that people must be involved to move the needle in terms of change. Dr. Miotto stated that the more advocacy that gets pushed, the more likely it will be accepted into MCAAP or AAP.
  + Another Council member stated that current research being deemed as unreliable is false. This Council member reported that there aren’t enough funding or opportunities for individuals to participate studies. She had also stated that she feels that other specialists are hesitant to jump on board and support PANDAS/PANS and in time she hopes that providers and researchers will be able to start to participate in studying and researching.
* A Council member asked the group if there was an opportunity to present in a MCAAP to share stories and advocate for PANDAS/PANS if Council members would participate.
  + Elaine Gabovitch informed the Council that their voices and advocacy matters to move the needle and make changes at the state-level.

**2024 Timeline**

Elaine Gabovitch reviewed the 2024 timeline including what has been accomplished, and what is to be accomplished in the months to come.

**Discussion: Questions for DESE and DMH**

* What questions do people have specific to DESE or DMH?
* Please scan the QR code to share your questions by May 15th.

**Wrap Up: Next Steps**

* Fourth meeting of 2024
* Wednesday, July 10, 2024, 4-6 PM
* Future meetings via WebEx Events
* If you need help, please email Maddy Goskoski at [madelyn.m.goskoski@mass.gov](mailto:madelyn.m.goskoski@mass.gov) in advance who will find assistance.

Next steps:

* DESE or DMH to speak in July
* Submit your questions for July guest speaker by May 15th.
* Email [madelyn.m.goskoski@mass.gov](mailto: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.