**PANDAS/PANS Advisory Council Meeting**

July 10th, 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, 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, Yujuan (Julia) Zhang, MD.

**Public Attendees:** 2

**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 5/8/2024 Minutes
* Announcements: General & Housekeeping
* May Reflections: Kevin Beagan, Deputy Commissioner (DOI)
* Case Review: How do we want to use case reviews?
* Discussion: How will we approach the next report?
* Wrap Up: Next Steps
* Next Meeting: Wednesday, September 11, 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**

* The LOOK Foundation is participating in a Global PANDAS/PANS awareness project where monuments to be lit up across the globe. The Global Landmark Lighting will occur on October 9th. Council members are asking if anyone has any connections to highway billboards or personally know of someone who can provide a landmark.
* The Alex Manfull Fund: partaking in the Global Landmark Lighting
* Announcement was shared that ANYPANS and JBC merged and rebranded to become the Look Foundation. The purpose of the merge was to change the trajectory of PANDAS/PANS for children and adults within the Commonwealth.
* An announcement was shared that the PANS Center is hiring a Nurse Practioner and social worker. If interested, the application can be found on Indeed.com.
* Council member Sheilah is traveling to Orlando, FL for the National OCD Conference to present on PANDAS/PANS. Two young adults will be joining Sheilah’s presentation to share their lived experiences with PANDAS/PANS.
* In addition, Council member Sheilah is hosting a support group in Orlando,FL with her daughter based on her lived experiences

**May Reflections: Kevin Beagan, Deputy Commissioner (DOI)**

* Guest speaker: Deputy Commissioner Kevin Beagan, DOI
* Related to the 2023 report, was there anything he shared:
  + 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 asked the group if they want to include Kevin Beagon’s power point slides within the report, ask him to put together a one-page document regarding insurance coverage for PANDAS/PANS and ask for an updated list of PANDAS/PANS providers located within the Commonwealth.
* One council member asked the board how we can make sure that the list of providers are vetted as PANS/PANDAS specialist. They also wondered how to find out what providers are actually vetted. Another Council member stated that the insurance mandate states that they have to give the list, and if not it can be a violation. Law requires DOI to identify who is an active PANDAS/PANS clinician.
* A Council member stated that some providers are self reporting meaning that they do not know if the providers are vetted or not.
* One Council member stated that they felt the one-page document created by DOI should include information of practicing clinicians and where someone can call if their is a violation. Another member stated the one-pager should also contain the denial process and how it works, the DOI updated list of providers and contact information. A third Council member informed the Council that MA GIC plans are exempt as they are self-funded due to unions. The member stated that someone might not know whether one’s employer will be covered for working a state job. Informing one to contact their employer was suggested to be included within the one-pager.
* A Council member suggested creating a “help guide” for out of network providers while utilizing their insurance to provide to families. Another Council member stated that the law states that if a provider is out of one’s network, that a individual has access to treatment if an in-network provider does not exist.
* A Councul member asked if Kevin was to get us all of this information, can this be put on the DPH website. Elaine Gabovitch suggested that the Council provide him with a list of questions for clarification including: Can there be a one-pager informing individual’s on how insurance works, can DOI share an updated list of providers who serve families and individuals with PANDAS/PANS and request to share this document on the DPH landing page. Lastly, ask Kevin for a guide that would benefit families who are out of network with step-by-step instructions on where and how to locate a provider. Council members Melissa Glynn Hyman and Jennifer Vitelli offered to draft and send an email to Kevin with a list of questions. Melissa and Jennifer were asked to share a finished product to Maddy Goskoski. Other Council members were encouraged to connect with Jennifer and Melissa to add more questions.
* Another Council member suggested that Melissa and Jennifer also reach out to Dr. Miotto with questions as well with the following questions: Is Dr. Miotto willing to put up the publication MCAAP that the AAP put out on long covid? Also is she willing to publish our cases on her website for review? Elaine Gabovitch informed the Council that she must speak to the DPH legal team about a release and protections.

Council members came up with a list of recommendations for the report:

* Having a DPH landing page
* If Kevin Beagan can create the resources that we discussed, those can be implemented as recommendations to include within the report
* Incorporate Kevin Beagon’s power point slides into the report

**Case Reviews**

* Julia to provide background on her cases
* Elaine to share MCH lens and how DPH uses story telling, family engagement and racial equity

* How do we want to use these cases?
* Who else wants to put together cases?

**Group conversation**

* Elaine Gabovitch asked the Council if they wanted to share case reports with future guest speakers or include within the next Annual report. One member suggested that if we have any medical professionals in the target audience there might be a place to put in a header “Laboratory Findings”. Elaine Gabovitch stated that if would be possible to add another header to the case reviews titled “Laboratory Findings”. A second Council member suggested adding key diagnostic features under the “Laboratory Findings” section.
* Council member suggested that it might be a good idea to include a case review where IVIG was not very helpful, and the individual had to seek other forms of treatment
* A Council member asked if we can we reword “functional disorder” to something else because “functional disorder” can be triggering to families and/or the individual. Another Council member stated that people need to see and be informed that the medical community is diagnosing incorrectly. Council member and Medical Doctor stared that there is no known reason as why FND is caused. Another Council member mentioned that FND is a phenomena to many, and in the medical community to some.
* Another member stated that FND is sometimes going to be relevant to a particular patient and their medical history. They illuded that it may open the door to more conversations on this topic. Elaine Gabovitch asked the Council if a small group wants to get together to write and discuss some of the cases. One Council member stated that they felt that it was not necessary to vote on case examples for credibility as they are Julia’s cases based on her experiences as a clinical provider. Together, the group wondered if there is a way to highlight the significance of each board member and their role/career. Furthermore, the Council agreed that it is crucial to be able to trust board members and there knowledge within their specialty.
* Two board members suggested that the Council votes on format of cases, not necessarily the content of the cases. Another Council member agreed with the idea that case reports should highlight the various clinical and community perspectives of board members. In addition, a Council member stated that they would love to see this project completed and suggested to include these case reports within the next annual report as the stories are powerful. Lastly, another Council member stated the importance of having these case reports on the website could be helpful to families as many parents often Google search symptoms their child is experiencing.
* Together, the Council members thought that case reports could be included within the next annual report; specifically, implementing quotes throughout the report. Also, sending copies of the case reports to guest speakers and having these on the website. Elaine Gabovitch added that the Council could start with implementing case reports in these areas and in time the usage of case reports can expand.
* Elaine Gabovitch then asked the Council who else wants to put together a case report or multiple. Council members Mark, Sheilah, Melissa Glynn-Hyman, Jennifer, Michelle volunteered to write up one or more case reports. Maddy Goskoski is to reach out to volunteers regarding the next steps in the writing process. Council members were directed to send case reports with Maddy Goskoski once they are completed.

**2024 Timeline**

Elaine reviewed 2024 timeline including information on upcoming guest speakers and report recommendations and writing process.

**Discussion: How will we approach the next report?**

Group discussion

* Council member suggested that inviting DMH to speak at a future Council meeting from an advocacy lens is very important. This Council member felt that if we do not ask them to meet in a timely manner, that it can delay the process. Other Council members agree to vote for the FY24 Annual Report in December and ask DMH join a Council meeting in September
* Elaine Gabovitch asked the Council who would be interested in writing the upcoming annual report. Council members volunteered to be apart of the writing group for the report. Members writing the report include Jennifer, Sylvia, Sheilah, Blake, Melissa Glynn-Hyman. Elaine Gabovitch encouraged the volunteers to connect as a workgroup to write the report together.

**Wrap Up: Next Steps**

Fifth meeting of 2024

* Wednesday, September 11, 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 September 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.