**PANDAS/PANS Advisory Council Meeting**

March 13th, 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, Margaret Chapman, APRN, MSN, PNMHCNS, Karen Colwell, Sheilah Gauch, LICSW, MEd, Melissa Glynn-Hyman, LICSW, Lisa Grisolia, Kathleen Maher, MS-PHCNS, RN (Kate), 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 Amy Benison tracked this information for the meeting record. Elaine led the vote to approve the January 10, 2023 meeting minutes. There was a quorum with nine Advisory Council members in attendance for the vote, with three members joining later in the meeting for a total of twelve members.

**Agenda**

Elaine Gabovitch reviewed the agenda:

* Welcome: Roll Call & Vote to Approve 1/8/2024 Minutes
* Announcements: General & Housekeeping
* Discussion: Guest Speaker Presentation & Discussion
* Discussion: Guest Speaker Reflection
* Wrap Up: Next Steps
* Next Meeting: Wednesday, May 8, 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**

* Jennifer to share- Neuroimmune Institure Events– Conference in June
  + First time member
  + Neuroimmuneintistute.org
* Lisa from ANYPANS and JBC are collaborating for an event on June 9th looking for answers on PANDAS/PANS questions
* Michelle Pinto from JBC Foundation
  + 1) Secured a bid for Boston Marathon and raising money to support PANDAS/PANS
  + 2) Mentioned that there are team slots available for Cohasset Triathlon taking place on June 23rd
* Blake shared an update from the National Alliance for PANS/PANDAS for Action teamed up with the Alex Mandull Fund for an advocacy day in Washington DC on April 12th
* Sheilah shared that Alex Mandfull Fund is hosting a 5k in Washington DC in April
* Sheilah shared that the Alex Mandfull is funding a position at Dartmouth Medical Center for a PANS/PANDAS clinician
* Sheilah shared that the Alex Mandfull Fund teamed together with the Louisa Madeline fund to fund a research project at MGH in Eating Disorder and Clinical program to fund a study they are currently working on
* Kate shared that a group of nurses reached out from the state of MA looking for more information on PANDAS/PANS. This event is taking place on June 25 from 8:30am-3:30pm. They are looking for speakers to fill 60-90 minute slots. Kate encouraged board members to attend and speak if possible.

**Report status:**

Diagnosis, Treatment, and Education Work Groups are complete eff. 3/8

Still need Research Work Group's citations and bar chart; uncited references and incomplete graphics will be removed 3/14

**Discussion: Guest Speaker Presentation and Discussion**

Welcome Mary Beth Miotto, MD, MPH, FAAP

* President, MA Chapter American Academy of Pediatrics
  + Pediatrician, Mattapan Community Health Center
  + Assistant Professor of Pediatrics, UMass Chan Medical School
* Discussion Format
  + 15 minutes: Dr. Miotto to present background and thoughts
  + 30 minutes: Questions and Answers
  + Raise hand
  + Be mindful of the space and time you are taking
  + Foster an open discussion focused on group learning and problem solving

Dr. Miotto presented a set of power point slides on behalf of the Massachusetts Chapter of the American Academy of Pediatrics (MCAAP). At the beginning of the presentation, Dr. Miotto reviewed the Mission statement of the Massachusetts Chapter of the American Academy of Pediatrics as she finds it important to reflect upon. Dr. Miotto shared information on the Massachusetts Chapter of the American Academy of Pediatrics and reported it is comprised of 1600 members including primary care, pediatric specialists and surgical subspecialists. Of this, a majority of Chapter members are Fellows of the American Academy of Pediatrics. She reported that this diverse background of providers cultivates important and vigorous conversations among providers.

Dr. Miotto shared the MCAAP chapter vision which states that the MCAAP is a leading voice for child health advocacy and high-value equitable care for all youth in the Commonwealth of Massachusetts. Furthermore, she reported that the MCAAP built on Foundational stability which includes:

1. Child Health programming
   1. Education for Child Health Professionals and other child advocates
2. Advocacy
   1. Aligned with National AAP Goals an
3. JEDI: Justice, Equity, Diversity and Inclusion
   1. Specific Focus on Vulnerable Communities and Children/Youth with Special Health Needs

Dr. Miotto reported that the MCAAP programming strives to improve the level of quality care that families receive. This chapter does a lot of work to think through creating and implementing programming to improve the quality of care that children and their families receive.

Dr. Miotto shared that The Massachusetts Chapter of the American Academy of Pediatrics is not typically a clinical policymaking organization. The MCAAP Board, officers, and Chapter committees utilize the best evidence and policies published by the national AAP and other national specialty societies to disseminate best practices to Chapter members, nonmember pediatric professionals, child health advocates, and policymakers in the Commonwealth.

Group Discussion

Jennifer Vitelli has shared that it is frustrating for the PANDAS/PANS community not being in the curated gateway. She asked if there would be an opportunity to have and present information on PANDAS/PANS to make it more accessible to pediatricians in the Commonwealth. Dr. Miotto stated that she would have to go directly to the board and have a discussion on this together. Dr. Miotto states that it is worth having conversations with the board because they want people to be aware however she stated that it is “controversial”. Dr. Miotto stated that is it “controversial” or “a gap” because of a lack of evidence-based research in the community.

In response to Dr. Miotto’s comment, Peggy stated that there is a lot of research and data discovered by big institutions. Peggy reported that the PANDAS Physician Network does exist and has evidence however it appears to be overlooked. She reported that the counter argument seems to be disregarded due to outdated and old data, however, much newer data exists and is readily accessible to families and providers. Dr. Miotto stated that she has reviewed the PANDAS Physician Network website and tries to stay up to date on the newest information. Dr. Miotto also mentioned that the systems are very slow and “their hands are tied”. Dr. Miotto mentioned to the Council that the MCAAP is not a policymaking board. Dr. Miotto reported that she understands the frustration of the Council members who do the work relating to PANDAS/PANS.

Sheilah mentioned that AAP came out with an article on long-term COVID-19 complications that referenced PANDAS/PANS. She was wondering could that be vetted and uploaded to the website. Dr. Miotto was apart of a task force from COVID and return to school. As a chapter, they have not been very involved with long-term COVID. Sheilah mentioned that this is especially important in Massachusetts DEI efforts are prioritized especially in minority populations.

Julia stated that as a physician herself that high-level evidence is important but with this population it is very hard to get information. However, due to the condition it is hard to acquire that high level evidence. Julia mentioned that it is important to review case studies and information if providers are exposed to PANDAS/PANS in their training. She believes that we should give providers open access to that information even if the provider does not believe that PANDAS/PANS is real. Julia believes that having access to this information comes before policy. Dr. Miotto stated that she opportunistic in terms of symptoms for PANDAS/PANS and related conditions to hopefully drive evidence forward.

Additionally, Michelle reported that one the most recent publications on PANDAS/PANS reviewed medical records of individuals for individuals who have PANDAS/PANS even though there was no ICD code to reference. The conclusion of the study she referenced was that PANDAS/PANS is a rare disorder and she believes that the study did not to justice to this disorder.

Melissa G reported that a large subset of children are being missed and have never received a diagnosis due to lack of knowledge on this topic. Melissa G also stated that many families are struggling financially to afford treatment. Because of this, Melissa asked Dr. Miotto how we should advocate or support these children when families are being told there is not enough research or that this is controversial. Dr. Miotto shared that she does not have a specific answer for Melissa’s question. She stated that even though the AAP does not fully recognize PANDAS/PANS thay it does not mean that a culture shift isn’t possible especially if pediatricians can get “one foot in the door” and do more to have better access.

**Discussion: Guest Speaker Reflection**

We will send the slides to Council members to read through and digest for further reflection at a future meeting. For now, what is your initial response to what you heard:

* Re: the last report, was there anything:
  + That supports it?
  + That contradicts it?
* What was the takeaway message?
* What will the Council’s next steps be?
  + Do you have follow-up questions for Dr. Miotto?
  + How will you incorporate what you heard into the next report?

Group Discussion:

Jennifer suggested that the Council should send follow up questions to Dr. Miotto by sending an official email from the Council. Dr. Miotto stated that local chapters of the AAP support PANDAS/PANS but the Council agreed that they would like the national chapter of the MACAAP should support and recognize PANDAS/PANS. Jennifer suggested that the Council should advocate and present to their board or for their lunch and learn program by presenting case reports. Dr. Miotto mentioned that she wanted to collaborate further with the Council.

Michelle stated to the Council that it was useful for Dr. Miotto to share that PANDAS/PANS knowledge at the state-level is not where it should be considering research supports PANDAS/PANS is present in children and youth. Furthermore, Michelle presented the idea that the Council should send the report to Dr. Miotto and hope that she disseminates it to her colleagues. The Council discussed that “big change” will come if they get to present or share information at the national level of the AAP.

Sheilah stated that she is disappointed by the MCAAP as the state of Massachusetts claims to be a state that is very progressive in treatment and healthcare opportunities. Sheilah believes that workarounds could be done as physicians are currently treating PANDAS/PANS in the state. Sheilah is saying that treatment of PANDAS/PANS comes with economic privilege for a child to be supported long-term in the state of Massachusetts. She asked Dr. Miotto if there is there an opportunity for case studies or stories to be presented at the AAP. Melissa Glynn-Hyman agreed with Sheilah’s statement. Melissa thinks they are hiding behind the research to continue marginalizing kids with PANDAS/PANS and death rates are continuing to increase in this subset of children. In response to this, Elaine had reiterated to Sheilah, Melissa and the Council that Dr. Miotto did not have a chance to “hear the stories”. Elaine asked if sharing a story might be useful when speaking to new guest speakers that can set the tone for the meeting. Karen shared that instead of creating an entire power point presentation of stories we could put short synopses in the slides for guest speakers to view. Julia stated that she was happy to write five short stories based on her work as she reported that “every patient has a story” and suggested that we show the guest speaker ahead of time rather than at the meeting. In response to this, Blake said that she is worried about doctors who do want to help and treat children with PANDAS/PANS especially if their institution is not allowing them to treat or check for PANDAS/PANS.

**Discussion: Future Speakers**

* Future Guest Speakers for the rest of 2024-5 questions needed for each.

1. DOI, Deputy Cmr. Kevin Beagan
2. DESE
3. DMH
4. DCF
5. Bureau of Public Health Hospitals
6. EOHHS

* Process moving forward

Group Discussion

* Jennifer stated that Kevin Beagan from DOI will be the guest speaker for the Advisory Council meeting May 8th
* Jennifer asked if we want to stick to state agencies for this year and in the coming years to outside organizations. The Council agreed that we should continue to speak with state agencies for the remainder of this year and that next year we should invite outside organizations to speak with the Council
* Sheilah stated that DMH and DESE would be key guest speakers as they can disseminate information to various families. For a backup option the group said they would prefer to EOHHS.
* The Council agreed with the process moving forward and decided to start to write report in September and have our last guest speaker in September rather than over the summer

**Wrap Up: Next Steps**

* Third meeting of 2024
* Wednesday, May 8, 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 May agenda
* Anything else?

**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.