**PANDAS/PANS Advisory Council Meeting**

January 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, Margaret Chapman, APRN, MSN, PNMHCNS, Karen Colwell, Sylvia Fogel MD, Sheilah Gauch, LICSW, MEd, Melissa Glynn-Hyman, LICSW, 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 Amy Benison tracked this information for the meeting record. Elaine led the vote to approve the November 8, 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 11/8/2023 Minutes
* Announcements: General & Housekeeping
* Discussion: Guest Speaker Presentation & Discussion
* Discussion: Guest Speaker Reflection
* Discussion: Future Speakers
* Wrap Up: Next Steps
* Next Meeting: Wednesday, March 13, 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 Vitelli encouraged the Council going forward to bring announcements to these meetings and any updates coming from the field.

Jennifer shared that the JBC PANS & PANDAS Foundation is participating in the Cohasset Triathlon.  JBC is welcoming members to their team to compete & raise funds. For more information visit: [https://www.jbcfund.org/volunteer-1](https://urldefense.com/v3/__https:/www.jbcfund.org/volunteer-1__;!!CPANwP4y!VjcmsTDBz9iipX_hSbgVUFZyaaIYKMsxxZyhngg0vedA7hEdEj0qqAwn0x_4nYNEQN0W9G74aajRHta5HYLzv1w$)

Sheilah Gauch shared that the Alex Manfull Fund has awarded a substantial grant to Dr. Kyle Williams at the Pediatric Neuropsychiatry and Immunology Program at Massachusetts General Hospital to study the correlation between cytokines IL-17 and il-23 and OCD symptoms in patients with autoimmune conditions receiving monoclonal antibody therapies. This research could possibly validate investigations into the immune system’s role in conditions like PANDAS/PANS.

The Alex Manfull Fund will also be having a 5k in Washington D.C. on April 13th. On April 12th, there will be a capital hill day where advocates from the PANDAS/PANS community will come together to voice the need for policy change. This is a great opportunity to raise money and support.  For more information:  [https://thealexmanfullfund.org/advocacy-day-on-capitol-hill-2024/](https://urldefense.com/v3/__https:/thealexmanfullfund.org/advocacy-day-on-capitol-hill-2024/__;!!CPANwP4y!VjcmsTDBz9iipX_hSbgVUFZyaaIYKMsxxZyhngg0vedA7hEdEj0qqAwn0x_4nYNEQN0W9G74aajRHta5oAcaJQQ$)

Peggy said there is a trial starting today of a PANS family against Childrens. They are suing. Child and mother were held against their will

Example of national publication speaking against PANDAS. Peggy will ask someone to formally respond. She is going to see if PPN can write their own article to counter

**Discussion: Guest Speaker Presentation and Discussion**

Elaine Gabovitch introduced Karen Robitaille, MSN, MBA, RN, NCSN, the Director of School Health Services at DPH. Karen has 30 years of pediatric nursing experience. She has worked in various roles in school nursing and is now at DPH. She has lived experience as a patient and parent of children with rare conditions.

Karen presented a series of slides reviewing the structure and scope of services of School Health Services in Massachusetts, reviewed pertinent regulations and regulatory procedures, services available to students with acute and chronic health conditions and discussed that impact of PANDAS/PANS on students experiences in school. (Refer to Karen’s slides for more specific information)

Karen explained the numbers of school nurses across the state, the budget the School Health Services program has and their role of data collection and consultation. Some important points are included below:

* Schools nurses are not employed by DPH they are employed by local municipalities
* DPH is only required to collect data from public school nurses based on a couple statues or schools that receive funding from DPH
* Only data required for data collection by statues/regulations is height, weight, BMI, and screening, brief intervention & referral to treatment (SBIRT)
* Some other non-mandatory data is collected around asthma and diabetes prevalence in children 5-14 and immunizations for pre-kindergarten, kindergarten, seventh and eleventh grade
* Data collected from Comprehensive School Health Services Grantees includes monthly reports about office visits, dispositions, concussions, medication and case management
  + They also collect yearly reports about rates for common chronic illnesses, medical technology & procedures, IHPs/AAPs/504s/DNRs, health services utilization by demographic, health insurance type, screening results, health services staffing and grant performance measures

Karen noted that nurses are already required to take a number of mandatory trainings and have a variety of other optional leadership trainings and resources at their disposal.

Karen then briefly explained the CMC-SHARE; Children with Medical Complexity School Health Resources & Education Project. Some students with PANDAS/PANS may be touched by this project. This project allows nurses to learn and practice skills, it includes an online resource library with rare uncommon procedures, a podcast that in part focuses on parent engagement and other helpful skill based learning.

Karen noted that there are already a number of existing resources available for school health staff about PANDAS/PANS. Karen believes many school nurses are aware of PANDAS/PANS but may not have had a student/patient with it.

**\*Discussion**

Jennifer Vitelli and Sheilah Gauch facilitated and question and answer session with Karen. Some important points are included below:

* Mark noted that a majority of Karen’s budget comes from and Karen explained that because of that their current goal is to expand resources and capacity
* Melissa asked about Karen’s knowledge of home bound instructed students and Karen noted that those students are most closely followed by DESE. The only responsibility that school nursing has is if that student comes to school for any reason temporarily or permanently, and supporting that transition back to school.
* Karen and Peggy noted that the BRYT program can be very helpful will children transition back to school.
* Sheilah asked what the best way is to disseminate info to school nurses. Karen believes that school nurses are well educated and that an important focus might be other school staff and admin. Perhaps schools nurses could help bridge that gap with the larger school system. Karen noted that the Council could work with her to post and add into newsletters the trainings that already exists to promote education around PANDAS/PANS. Karen could also host experts on PANDAS/PANS to talk directly to school nurses. Talking to directly to school nurses could be beneficial because that are often the ones that can help families get a diagnosis and care if they suspect a child of having a given diagnosis like PANDAS/PANS. Sylvia notes that school nurses could also help educate families about the possibility PANDAS/PANS to potentially help reduce delay in diagnosis.
* Elaine asked Karen about her thoughts on prevalence data and studies and Karen shared that unfortunately federal support is so important. It takes years to get national support, but you need to work with national institutes of health. MCAAP may be a great partner, they have a website, newsletter and professional development. Karen also noted that when consider that larger picture we cannot forget the importance of equity and those with limited resources or in areas of the state with less access are facing increased barriers.
* Karen answered a final question from Jennifer, noting that the data collected from school nurses is reliant on diagnoses given by providers or medications listed in the child’s medical records.

**Discussion: Guest Speaker Reflection**

At this time Karen left the meeting and Elaine Gabovitch led a reflection discussion with the Council based on what Karen said. Some key points are listed below:

* The Council noted the importance of talking to the broader school system, not only school nurses.
* There needs to be a push for standardization among school districts in their response to PANS/PANDAS. Parents within the same districts are having very different experiences with their children.
* The Council wants to investigate whether they can provide resources to be posted on the NEUSHA website if there are not already PANDAS/PANS resources available.
* It is important to ensure the Council is providing information that is consistent with what other organizations are saying. When there is inconsistencies people begin to distrust what they are hearing.
* The Council wants to reinforce with school nurses that they can be strong advocates for families that feel intimidated by the medical community and feel they do not have a voice.

Elaine then helped the Council identify the following action steps:

* The Council should identify what content they want to share with school nurses and if a training can be created or a presentation can be recorded and distributed. If trainings already exist, then the Council should work to make the trainings known
* The Council should identify what content they want to share with the wider school system
* The Council should discuss a possible future recommendation to standardized protocols for nurses or schools to respond to students with PANDAS/PANS
* The Council should follow up with Karen to see if schools could voluntarily provide PANDAS/PANS data

**Discussion: Future Speakers**

Elaine Gabovitch reminded the Council that a representative from the Division of Insurance (DOI) is scheduled to speak to the Council at the March meeting. The Council reviewed the standard questions to be sent and added the following questions to be shared with DOI:

* Are you hearing of instances of insurance denials?
* What diagnostic codes should providers be using to ensure coverage?
* How do you assist families who have been denied insurance coverage for PANDAS/PANS?
* What does the process entail for families to receive out-of-network coverage if there are no in-network providers for PANDAS/PANS?
* Many families have MassHealth as a secondary insurance and claims are often bumped to MassHealth when the primary insurance company denies a claim. What do you know about this process and is there an advocate or ombudsman person that can support families?
* Can you speak to the law as it currently stands and how it does not cover families who are self-insured, have federal coverage, or out of state plans?
* What can the DOI do to train/educate insurance carriers about these laws?
* Is there a way to put together a bulletin about these laws to help educate families?

Elaine then led a discussion to determine future guest speakers after March. The Council decided to invite a representative from DESE (Russel Johnston), DMH and the Department of Health & Human Services.

**Wrap Up: Next Steps**

Elaine Gabovitch shared the following information with the Advisory Council:

* Second meeting of 2024
  + Wednesday, March 13th, 2023, 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:
  + DOI to join us in March
  + Invite future guest speakers
  + Email madelyn.m.goskoski@mass.gov to get on the March agenda
  + Anything else?

**Motion to Adjourn**

Elaine Gabovitch thanked everyone in attendance, led the vote to adjourn the meeting. Amy Benison recorded votes.

All votes during this meeting obtained two motions and have been recorded.