

PANDAS/PANS Advisory Council Meeting May 10, 2023 Meeting Minutes

Via WebEx (Zoom) Event

Present: Elaine Gabovitch, PANDAS/PANS Chair, Madelyn Goskoski, CHTA, PANDAS/PANS Meeting Consultant, 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, John Gaitanis, MD, Sheilah Gauch, LICSW, MEd, Melissa Glynn-Hyman, LICSW, Lisa Grisolia, Kathleen Maher, MS-PHCNS, RN, Melissa McCormack, MD, PhD, Mark Pasternack, MD, Michelle Pinto, RN, Blake Poggi, MA, CCC-SLP, Jennifer M. Vitelli, MBA, Kyle Williams, MD, PhD, Yajuan (Julia) Zhang, MD.

Public Attendees: 1

Welcome and Agenda

Elaine Gabovitch, PANDAS/PANS Advisory Council Chair, called the meeting to order, welcomed the Advisory Council and reviewed the agenda.

Open Roll Call & Vote on Meeting Minutes

Elaine Gabovitch managed the virtual open roll call and Maddy Goskoski tracked this information for the meeting record. Elaine led the vote to approve the March 8, 2023, meeting minutes. There was a quorum with 15 Advisory Council members in attendance.

Announcements: General & Housekeeping

Jennifer and Sheilah to lead general and housekeeping section. Lisa shared an update from NE PANS. NE PANS is hosting an awareness walk on October 1st. Additional information for the walk is to come.

Blake Poggi – Refer to pages 31-32 of the FY 2024 Congressional Justification. There is a PANS/PANDAS action from 2020-2023. This federal appropriation bill is searching for funding for PANDAS/PANS. Ultimately, their ask was 5 million dollars for NIH funding studies that directly looks at PANDAS/PANS, and trainings for doctors so they recognize it early. Refer to this link for more information:

<file:///Users/blakepoggi/Downloads/NIH%20FY%202024%20CJ%20Significant%20Items%20Volume%20final.pdf>

Blake also suggested viewing Amanda Peel Crowley's testimony, see link below:

https://youtu.be/ftU_L_qo_ow

Sheilah mentioned that NAPA collaborating with the Alex Manfull fund to put on a 5k race. Additional information can be accessed here for reference [The Alex Manfull Fund 5K June 3, 2023.](#)

Jennifer explained that the JBC PANDAS/PANS organization was chosen as one of the charitable partners at the Cohasset Triathlon. There will be more information to come.

Present: 2023 Timeline

The timeline for Council activities was shared.

Work Group Report Outs & Recommendations

Elaine led the work group report out portion of the meeting. Each workgroup reported out current findings and recommendations to include within the annual report.

1. Research Group- high-level report out led by Kyle Williams

The PANDAS/PANS diagnosis originated from the National Institute of Mental Health. In time, there were increased reports of OCD Sydenham's chorea (SC), with side effects of strep infection and rapid onset condition (OCD). However, these individuals did not have SC, which is how the diagnosis was developed.

Since 2016, publications by year have continued to increase. The research workgroup has reviewed research that has been published about PANDAS/PANS. In addition, the research work group has classified research publications by category including clinical research, case report, basic science, review, and treatment research.

Kyle noted that his work group discovered clinical research is the highest rate of publications. Second, is research review articles because they do not cost much to publish. Kyle noted this could be due to lack of funding and cost effectiveness. Furthermore, only 6% of publications look at treatment and efficacy which may be due to lack of patient populations for research or lack of funding. It was noted that these publications still need time, funding, and research.

Kyle and the research workgroup noted that people need to advocate for treatment as it is hard to advocate for treatment with lack of evidence to prove that treatment is needed.

Members from other work groups suggested the following:

- Consider looking into diagnostic codes to see what practitioners are billing for.

2. Treatment- high level report out by Peggy Chapman

Peggy noted that the treatment group's findings did not reflect the state of Massachusetts because many treatments are national. The treatment group noted that they do not know how insurance is being enforced and carried out.

Recommendations:

1. Explore the insurance commission what they learn and how they can find out. Determine what they are doing.
2. Need to create contact with all state agencies who have interventions for children with PANDAS/PANS. The PANDAS/PANS AC Council do not have documents from state agencies in terms of treatment.

3. Survey current treaters. This is because we do not have anything as a base to tell us what is happening in the state for treatment.
 - a. Can the insurance companies tell us who is billing for PANDAS/PANS treatment?
4. Determining the index for caregiver burden. Determine what are the state agencies' understanding and plan to support these caregivers.
 - a. Do they have the ability to survey providers to see if they are treating PANDAS/PANS or do they just see a case within their practice (What are they doing? Are they available?)

Identified Gaps:

1. Working PPM. The guidelines are so old within the existing PPM, and so little written for psychiatry.

Education

- The Education work group shared the following recommendations:
 - Insurance companies will ensure patient access to coverage for both diagnosis and treatment of PANS/PANDAS
 - DOI/EOHHS will reach out to insurance companies to educate them about the insurance law, billing codes and the importance of covering diagnosis and treatment for patients with PANS/PANDAS
 - The Council noted that it is important to know what the billing codes are we should be looking for to identify PANS/PANDAS diagnosis or treatment
 - Providers remain up to date on recommended guidelines for diagnosis and treatment of PANS/PANDAS and any new science research and protocols
 - EOHHS reach out to MCAAP to disseminate guidelines
- The Education group asked who may be the appropriate agencies to list for each recommendation and asked the chair, Elaine Gabovitch to attend their next work group meeting on May 16th from 5-7 PM

Diagnosis I

- The Diagnosis work group shared the following thoughts:
 - They hope to address the delay of diagnosis and misdiagnosis
 - Want to provide recommendations regarding initial work ups for primary care providers and address inconsistency in diagnosis criteria
 - The Council needs to consider what they want the average physician to be able to do. The work group wants to encourage physicians to consider PANS with any sudden OCD or tics and consider treatment
 - Physicians should also consider PANS in people who are acutely hospitalized for psych symptoms
 - They hope to educate physicians regarding clinical utility of NSAIDs, corticosteroids, and antimicrobials
 - When bringing in guest speakers, they want to ask
 - "What is your knowledge of PANS/PANDAS?"

- “Are there any instructional or training requirement for your agency?”
 - Hope to request department leadership to provide a particular number of hours of course work per year for trainees or to hold grand rounds
- The Diagnosis work group believes this could be an opportunity to create and disseminate continuing medical education hours
 - They questioned whether DPH could create an educational tool to be disseminated or disseminate current recommendations/guidelines
- The group feels it is important to define what abrupt or sudden onset of symptoms are and acknowledge that not all PANS/PANDAS symptoms are abrupt
 - They also noted that strep is not required for a diagnosis
- They suggested the Council consider the weight of symptoms where some things are more important than others for a certain Diagnosis
- They proposed creating a working diagnosis criteria that is more inclusive and does not explicitly say abrupt patients or strep and includes people with minor symptoms
 - If the criteria becomes too inclusive however, the Council can always adjust it in the future
- The work group asked the Council “What kind of diagnostic work up will we recommend?”
 - There are not reliable diagnostic tests
 - Providers will not like to hear that they have to diagnose without clear guidelines of how to diagnose
 - Lack of clinical evidence should not negate diagnosis
 - Supportive history is important to include to look at possible autoimmune conditions
 - History drives a work up and testing is not perfect
 - Need to make clear guidelines that strep is not required and acute onset is not required, should use established guidelines for reference but eventually have the Council make their own

Wrap Up: Next Steps for Work Groups

Elaine Gabovitch shared the following information:

Third meeting of 2023

- Wednesday, July 12, 2023, 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

- Distribute work group written sections by May 30 and raise first draft questions for group consensus at July meeting
- Email Madelyn.m.goskoski@mass.gov to get on the July agenda
- Anything else?

Next Meeting: Wednesday, July 14, 2023, 4-6PM

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.