**PANDAS/PANS Advisory Council Meeting**

January 12, 2022, 4:00 – 6:00 PM

Via WebEx Event

**Present:** Elaine Gabovitch, PANDAS/PANS Advisory Council Chair & DPH Ex-Officio Member; Margaret Chapman, RN, MSN, PMHCNS-BC; Karen Colwell, PTA; Sylvia Fogel, MD; Sheilah Gauch, LICSW; Melissa Glynn-Hyman, LICSW; Lisa Grisolia; Kate Maher,;Melissa McCormack, MD, PhD; Mark Pasternack, MD; Michelle Pinto, MSN, RN; Blake Poggi, MA, CCC-SLP; Jennifer McCormack Vitelli, MBA; Kyle Williams, MD, PhD; Yujuan Julia Zhang, MD; Nicole Roos; Betsy Day, CHTA; Casey Hall, CHTA; Amy Benison, DPH

**Meeting Agenda**

1. Welcome, Agenda and Meeting Rules
2. Roll Call: Attendance and Vote: November 29, 2021, meeting minutes approval
3. Introduction: Amy Benison, DPH Report Writer
4. Vote: Logic Model
5. Review/draft: Work plan/aim statement
6. Vote: Work Groups
7. Presentation: know resources for report content (time permitting)
8. Next meeting: Wednesday, March 9, 2022, 4-6 pm
9. Vote: Adjourn

**1.Welcome, Agenda and Meeting Rules (slides 2,4)**

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

**2. Open Roll Call & Vote (slide 3)**Elaine Gabovitch managed the virtual open roll call and Betsy Day tracked this information for the meeting record. Elaine led the vote to approve the 11/29/21 meeting minutes. There was a quorum with 14 Advisory Council members in attendance.

**3.Statutory Authority (slide 5)**

Elaine Gabovitch, Chair (designee of the Commissioner of DPH) shared the following with the Advisory Council:

**Statutory Authority**, Section 26 of Chapter 260 of the Acts of 2020, Advisory Council to advise the Commissioner on *research, diagnosis, treatment, and education* relating to pediatric autoimmune neuropsychiatric disorder associate with streptococcal infections and pediatric acute neuropsychiatric syndrome (PANDAS/PANS).

**4. EG reviewed 2022 Regular Bi- monthly Meeting schedule (slides 6)**

|  |  |  |
| --- | --- | --- |
| January 12 Wednesday | 4-6 PM | 2nd |
| March 9 Wednesday | 4-6 PM | 2nd |
| May 11 Wednesday | 4-6 PM | 2nd |
| July 13 Wednesday | 4-6 PM | 2nd |
| September 14 Wednesday | 4-6 PM | 2nd |
| November 9 Wednesday | 4-6 PM | 2nd |

**5. Other notes: Amy Benison Introduction, COVID Community Impact Survey, and EG meeting with Executive Director of the Autism Commission**

* Amy Benison, DPH intern, will be the Report Writer for the Advisory Council. She is experienced and her role will be sponsored by the CDC at this time.
* EG announced the COVID Community Impact Survey meeting on 1/13/22, where she will present the findings of the impact of COVID on families with special health needs. A brief overview was provided, including how this information could be valuable to the work of the PANDAS/PANS Advisory Council.
* Some key points from meeting with Executive Director of the Autism Commission regarding running Advisory Council meetings – OML, by-laws, publishing meeting announcements, including volunteers, chairperson for each work group, etc.

Question from Jennifer McCormack Vitelli: do we need (Nicole for tech support) at every meeting? Sheilah Gauch inquired about quorum.

EG, Chairperson, will contact legal counsel for advice.

**6. Aim Statement/work plan development (slide 7)**

* During today’s meeting, the Council will:
	+ Review **logic model** draft
	+ Review **aim statement & work plan** draft
		- Determine goals, scope, timeline, etc.
	+ Determine Council **member roles** based on skills & experience
	+ Determine **next steps** for documents to complete & implement

**7. Aim statement/work plan development (slide 8 and 9)**

Elaine Gabovitch reviewed the drafts of the logic model, aim statement and workplan drafts based on updates from last meeting on 11/29/21. In real time council members commented with suggestions, changes, and appropriate wording. The drafts were updated at once. There was a council vote facilitated with a Yea response to approve the model, statement and workplan. More work is to be done on all documents. For now the work that has been identified is approved.

Reminder for clarification purpose:

* These documents are working documents and should be changed as needed to keep things on target.
* Getting consensus is part of the process, reviewing terms and concepts are also part of the process.

AIM Statement generated lots of discussion with ideas, opinions in the Because and Why sections. The by When section will be revisited in the next meeting.

How will we Achieve section – council agrees with the content.

Workplan will require some re-work. The options include Elaine Gabovitch do it and present, or others can get together to work on the plan and update.

Option two was chosen and a number of council members will work on the work plan revisions. They are: *I think it is Jennifer, Sheilah, Blake and Elaine*

**8. Work Group Poll Results and Setting Up the Work Groups (Slide 10-12)**Poll results were shared with all. Elaine Gabovitch shared an example of how the groups might look based on responses and needs.

Below is an initial composition of the Four Work Groups.

|  |  |  |  |
| --- | --- | --- | --- |
| **Diagnosis** | **Education** | **Research** | **Treatment** |
| Sylvia Fogel, *Chair*Melissa McCormackJulia ZhangJohn Gaitanis  | Lisa Grisolia, *Chair*Kate MaherMichelle PintoKaren Colwell | Blake PoggiKyle WilliamsMark Pasternack, *Chair* | Peggy ChapmanMelissa Glynn-Hyman,*Chair*Melissa McCormack |

An interactive discussion took place to organize the work groups as indicated above. Council Members did move around.

Each group has a chairperson. Melissa McCormack has volunteered to participate with two groups (diagnosis and treatment).

**9 Jennifer McCormack Vitelli** presented a Timeline that she and Sheilah Gauch prepared to share with the Advisory Council. She also discussed more about environmental scans and shared an example of the Research scan.

More time needs to be dedicated here to review and discuss.

Meeting was running over so a Vote was taken to extend the meeting time by 5 minutes to finish the meetings’ business. All agreed to the extension.

**Next Steps (slide 13)**

Second bi-monthly meeting for 2022 will held on March 9, 2022, 4-6 PM using MS Teams

General Agenda topics include: reviewing update aim statement, logic model and work plan;

Elaine Gabovitch thanked everyone in attendance, lead the vote to adjourn the meeting. Motions 1 and 2 obtained and voting roll call (Yea or Nay) was completed.

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