**PANDAS/PANS Inaugural Advisory Council Meeting**

October 25, 2021, 9:00 – 11:00 AM

Via WebEx Event

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

**Meeting Agenda**

1. Welcome, Agenda and Meeting Rules
2. Roll Call: Attendance
3. Vote: September 29, 2021, inaugural meeting minutes approval
4. Vote: Regular bi-monthly 2022 Council meeting schedule
5. PANDAS/PANS advisory council exchange (5-minute presentations)
6. Plans and preparation for meeting on November 29, 2021 (9-11 AM)
7. Vote: Adjourn

**1.Welcome, Agenda and Meeting Rules (slides 1-3)**

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 4)**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 Inaugural Meeting (9/29/21) minutes. There was a quorum with 13 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. Vote: 2022 Regular Bi- monthly Meeting schedule (slides 6-8)**

Elaine Gabovitch led this process:

* deliberate on best day, time, week of the month
* Narrow to top two choices
* Vote

Slide #7 contained the bi-monthly deliberation meeting choices. It was displayed for all to see and respond to.

**Vote outcome** for 2022 bi-monthly meeting schedule resulted in these days, time, and week of the month:

  **Month and Day**   **Time**  **Week of Month**

|  |  |  |
| --- | --- | --- |
| 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. Getting to Know the Council Exchange (slide 9)**

* 14 Council Members including the co-facilitators and Elaine Gabovitch participated in the exchange.
* Each person was allowed up to 5 minutes to answer these three questions:
1. What is your connection to PANDAS/PANS, and what brought you here?
2. What skills and experience will you contribute to the Council?
3. What do you hope to achieve?

Betsy Day kept track of the time and delivered a 1-minute warning at 4 minutes, which the Council was prepared for this to occur ahead of time.
* There were many themes, commonalities, skill sets, and challenges mentioned. Below are some:
- Many council members are not only parents but providers and professionals such as clinicians,
 business, finance, facilitators, trainers, social workers, educators, traditional and holistic
 treatment providers for example.

- Some key *hopes to achieve*:

 1. Training/education of professionals to recognize symptoms (earlier the better)
 2. Treatments and availability
 3. Address skepticism in medical community and bring disciplines together
 4. Parent/provider collaboration
 5. Overcome challenges of insurance coverage
 6. Change conversation to life saving and treatment
 7. Education of medical community – every pediatrician understands it
 8. Getting the right treatment to the right child … everyone presents differently
 9. Change language to *it’s all medical, and not medical and psychiatric.*
 10. Need more evidence, research, data, and treatments

**6. The Work Ahead: November 29, 2021 (slide 10)**

Elaine reviewed what material the Council members will receive prior to the 11/29 meeting, what will happen during the meeting, along with a vote to be taken during the January 12 meeting to discuss further work on the Aim Statement and Charter and determine next steps to get these documents to completion.

**7. Vote to Adjourn the Meeting (slide 11)** Elaine Gabovitch thanked everyone in attendance, led the vote to adjourn the meeting. Motions 1
 and 2 obtained and voting roll call (Yea or Nay) was completed.

**Some notes**
1. Attendance was high with 13 Council members in attendance. Quorum was met.

2. The meeting started at 9 AM and ended at 11 AM.

3. Three-votes were successfully completed. Another vote for the 2022 meeting schedule was successful
 and resulted with a confirmed schedule.