PANDAS/PANS Advisory Council Meeting
 Approved on July 13, 2022

May 11, 2022, 4-6 PM

Via WebEx Event

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

# Meeting Agenda

1. Welcome, Agenda and Meeting Rules
2. Roll Call: Attendance and Vote: March 9, 2022, meeting minutes approval
3. Work Group Presentations: Treatment, Research, Diagnosis, Education
4. Share Gap Analysis tools
5. Logic Model, Aim Statement & work plan review, edits and voted
6. Discuss Annual Report Draft
7. Next Meeting: Wednesday, July 13, 2022, 4-6 PM
8. Vote: Adjourn

# Welcome, Agenda and Meeting Rules (slides 2)

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

# Open Roll Call & Vote and meeting rules (slide 3 and 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 3/9/22 meeting minutes. There was a quorum with 13 Advisory Council members in attendance.

# 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).

# EG reviewed 2022 Regular Bi- monthly Meeting schedule (slides 6)

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

1. **Aim Statement review (slide 7)
The DPH PANDAS/PANS Advisory Council aims to advise the DPH Commissioner on research,** diagnosis, treatment, and education relating to pediatric autoimmune neuropsychiatric discovered associated with streptococcal infections and pediatric acute neuropsychiatric syndrome (PANDAS/PANS).
2. **Work Group Report Guidelines (slide 8)**High level reports from each work group reporter

Timing: *10 min + 5 Q&A*

 Share: each group’s process, general topics team discussed and each team’s plans moving forward

1. **Work group Reporting Order (slide 9)**Please note that each presentation was interactive with Q&A taking 10 or more minutes for discussion. **Treatment** Sheilah Gauch, Reporter; Melissa Glynn-Hyman, Facilitator
 Key points: complexity of healing and physical and mental health
 1. Initial meeting focus: need for mental health and need to explore research
 2. Actions: review baseline treatment (psychiatry, gut health, detox, brain,
 inflammation) and infection date
 3. Need to explore (limited available) research, gaps, and other areas, i.e., meds

**Research** Mark Pasternack, Reporter/Facilitator
 Focus – on a process to do the investigation
 Three key items: Basic Science, Translational Research and Clinical Studies
 - includes autoimmune studies, genetic studies, and developing clinical tools
 - can use other research and analyze it along with our own (i.e., lots of things
 championed in COVID are also being done with PANDAS/PANS
 - develop a framework for Research Team going forward

**Diagnosis** John Gaitanis, Reporter; Sylvia Fogel, Facilitator
 Three key items: Clinical Source, Core Symptoms, and Support of Evidence
 - (each team member has specific areas to work on)
 - Question: How acute is acute?
 Focus areas:
 - explore how other diagnoses were organized & established (Illinois Report)
 - More PANS focus (but want to be broad)
 - There is emerging literature that would be used introduction (clinical decisions,
 lumping versus splitting)

**Education** Michelle Pinto, Reporter; Lisa Grisolia, Facilitator
 Meeting 1 focused on Baseline of Education
 - created an outline
 - divided into 4 groups:
 Schools (Kate M)
 Parents & Families (Karen C)
 Medical Professionals (Michele P)
 Court System (Lisa G)
 Other
 - what’s available now - books, web-sites, support groups, new research, conferences,
 continuing education. What needs to be expanded? What else needs to be done?
 Next meeting will be June 6, 2022

1. **Review simple and complex Gaps Analysis Tools (slides 11 and 12)** Elaine Gabovitch provided an overview of this tool as a resource for the Work Groups.

# Review of Draft Annual Report and Next Steps (slides 13 and 14)Amy Benison shared the draft for all to review and discuss.- questions: What else would you want in this section? Do you want to leave as is? Do Work Groups  want to write their own section?- conclusion section: What would people like to suggest here?- Brainstormed wording for clarity and description example: from “lost their lives” to “lost their childhood”- Amy invited additional edits along with asking for general comments.- Final deduction… the report is in great share.10.Next Steps (slide 15)Fourth bi-monthly meeting for 2022

# Wednesday, July 13, 2022, 4-6 PM

# Future meetings via WebEx Events

# If you need help, please email Betsy Day in advance who will find assistance

# Agenda for next time:

# Final vote on the first annual report

# Report outs from work groups

# Possible future meeting agenda items for Council consideration

# Anything else?

# 11. Vote to Adjourn the Meeting (slide 11)

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.