

DPH PANDAS/PANS Advisory Council
RESEARCH WORKGROUP MEETING



Apr 28, 2022

ATTENDEES: Blake Poggi, Jennifer Vitelli, Dr. Mark Pasternack, Dr. Kyle Williams

LOCATION: VIRTUAL

AGENDA

1. Meeting called to order
2. Review & Discuss Baseline Environmental Scan on Research
3. Discuss the next steps of the workgroup
4. Adjournment

MINUTES

- **Meeting called to order:**
Ms. Poggi made a motion to call the meeting to order at 12:35 p.m.
Dr. Williams seconded the motion
- **Open Roll Call:**
Ms. Vitelli managed the virtual open roll call.
All workgroup members were in attendance.
- **Review & Discuss Baseline Environmental Scan on Research**
Ms. Vitelli, reminded group right now the workgroup's only objective is to compile PANDAS/PANS (& related) research to date (a baseline of the research) to bring back to the main Council.

For the next Council meeting on May 11, 2022, this work group should be prepared to make a 10 minute presentation on:
 - update on work group's progress:
 - the process the workgroup will use to gathering the research
 - and how workgroup will eventually share the research for the 2023 Annual Report
 - Dr. Pasternack offered to be the "Reporter" for the Council update

- **Discuss the next steps of the workgroup**

The research subcommittee members discussed the short term goals of classifying and understanding existing PANS/PANDAS research with a long term goal of identifying research areas that will be important for future investigation. The members focused on the processes that will be utilized in the course of the committee's work and discussed

classifying existing research efforts into three major domains: basic science, translational research, and clinical trials. Reported studies can be readily classified in this manner which will provide a framework for further investigation and research planning.

Basic science includes:

- laboratory-based investigations that address disease mechanisms, particularly autoimmunity
- animal studies that investigate these issues
- genetic studies that investigate possible heritable markers which convey an increased risk of PANS/PANDAS (and will also address sibling studies)

Translational science includes:

- investigations of epidemiology of PANS/PANDAS and possible triggers of the syndromes
- imaging studies including quantitative volumetric analysis of brain structures and investigation of the blood-brain barrier in children with PANS/PANDAS
- clinical investigations that develop and validate symptom scores and other clinical features of these illnesses

Clinical science includes:

- therapeutic trials of IVIG, steroid therapy, nonsteroidal anti-inflammatory therapy, therapeutic and prophylactic antibiotic therapies, and others.

Ms. Vitelli noted that the ASPIRE Foundation maintains a large annotated database of all research identified as related to PANS/PANDAS, which will facilitate sorting existing research into the above groups. This will serve as the committee's starting point, with inclusion of additional studies that might be known to committee members but not entered into the ASPIRE annotated bibliography. The committee members will work individually and in groups to populate the framework categories with relevant publications.

- **Motion to adjourn:**

Dr. Pasternack made a motion to adjourn the meeting at 1:22 p.m. and Dr. Williams seconded the motion