# PANDAS/PANS Advisory Council

# Diagnosis Workgroup

# Meeting May 2, 2022 Approved Meeting Minutes

Via Zoom

**Present:** Sylvia Fogel MD; Melissa McCormack MD; John Gaitanis MD; Julia (YuJuan) Zhang MD

# Meeting Agenda

1. Meeting called to order
2. Review and discuss research review
3. Create broad outline for our report—subject to change over time
4. Discuss next steps of work group
5. Set date and time for next meeting
6. Adjourn

# Group Discussed Several Broad Themes Related to Diagnosis

Presentation of neuro-inflammatory symptoms is widely variable and currently recognized criteria may obscure this clinical reality

* + Onset may be sub-acute as opposed to acute
  + Worsening of pre-existing neuropsychiatric symptoms should be emphasized as part of diagnostic evaluation (as opposed to focus on new-onset sx.s). More inclusive of individuals with pre-existing neuro-psychiatric illness or developmental delay.
  + Variability may be due to age, sex, pre-existing neurological or developmental issues, pre-existing immune dysfunction. Pre-existing neuropsychiatric illness does not exclude PANS.
  + Non-response or sub-optimal response to traditional therapies should prompt consideration of PANS.
  + Potential re-conceptualization of the way criteria are organized among different clinical guidelines and other state reports. “Major criteria” vs. “Minor criteria” as noted in the Illinois report may not reflect the variety /reality of clinical presentations.
  + Continue to emphasize that this is CLINICAL diagnosis. Laboratory and imaging studies are not diagnostic. No single diagnostic marker. Purpose of Initial Work-up is to characterize the nature of immune dysfunction, identify a potential trigger and provide a potential future framework to evaluate immunomodulatory therapies. Aspire Website has good initial list of potential lab work-up.
  + Importance of early diagnosis and initiation of initial work-up. Emphasis on simplifying diagnostic criteria and initial work-up in order to facilitate early diagnosis and prompt initiation of treatment by community pediatricians, family practice physicians and other PCPs.
  + Early diagnosis/treatment imperative not only for patient but for entire family system, as behavioral symptoms and functional decline represent an enormous stress on all family members, which may in turn increase risk for secondary medical and psychiatric symptoms in non-affected family members.

**Group Proposed Initial Outline of Tasks/Topics for Literature Review forIndividual Members to Focus On**

1. Emerging evidence of immune function impact on brain-John & Melissa
2. Acute versus subacute/evolving/worsening-Julia
3. Historical Context-Evolving definition of PANS-John
4. Variation in presentation-Sylvia
5. Covid related evidence-Melissa
6. Traditional psychiatric patients who responded to anti-inflammatory approaches-Sylvia

OCD

Schizophrenia

Tics

**Next Meeting 6/20/22**

**Meeting Adjourned**