"Defining a Roadmap for SHANK3-related Epilepsy Research"

Meeting Logistics:

**Tuesday September 26th 5:30-8 pm** welcome dinner. Please join us at Punchbowl Restaurant (Emerald Room) in the Hilton Garden Inn (700 Brookline Avenue, Brookline, MA) for cocktails and dinner.

Hotel Accommodations: Hilton Garden Inn (next to 2 Brookline Place conference location). Please reach out to Geraldine Bliss if you need travel support.

**Wednesday September 27th 12-6 pm** (in person and virtual)

Meeting hosted by CureSHANK, the Rare Disease Clinical Research Network Developmental Synaptopathies Consortium and the Rosamund Stone Zander Translational Neuroscience Center.

Co-Chairs: Elizabeth Berry-Kravis, Jimmy Holder, and Mustafa Sahin

Conference Location: Boston Children’s Hospital Brain Mind Behavior Center, 2 Brookline Place, 5th Floor Conference room (Room 598), Brookline, MA.

Parking: There is a parking lot next door to the Brookline Place buildings on Pearl Street. We will provide parking vouchers.

Goals for Meeting:

- Identify the key gaps, needs, and challenges that hinder progress in epilepsy research for Phelan McDermid Syndrome

- Develop a set of research priorities along with specific recommendations for addressing the major challenges in each priority area. The new research plan will be organized around both short-term and long-term goals with the expectation that progress toward specific objectives. We will produce a white paper after the conference conclusion.

Agenda:

12:00: Welcome lunch

1:00: Family experiences (recorded/in person) (Moderated by Geraldine)

1:30: Clinical Overview (Jimmy Holder)

1:45: Basic Science Overview (Joe Buxbaum)

2:00: Brainstorming Sessions (5th and 8th floor conference rooms)

  a. Clinical Gaps, Needs and Challenges (Moderated by Jimmy Holder) Room 598
  b. Basic Science Gaps, Needs and Challenges (Moderated by Mustafa Sahin) Room 898

3:30: Brainstorming Session Reports

4:00-6:00: Setting Research Priorities and Plan (Moderated by Co-chairs)