

“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)