World Café Round 1: Research & Clinical Care

1. Quick Introductions (4 Minutes)
   - Your name
   - What brings you to the KAND Conference
   - Where you’re from

2. Pick a Scribe & Timekeeper (1 Minute)
   - The Scribe will document important insights, concerns, questions, themes, etc. in the notebook provided

3. Discuss (20 Minutes)
   - What can researchers & clinicians do to help families improve the daily care & wellbeing of their loved ones now?
   - How can families help researchers keep a patient-centered approach to their work?
   - What questions or concerns do families have about drug/therapy development for KIF1A?

4. Document Takeaways & Action Items (5 Minutes)
   - For individuals: What can I do to advance progress in research & clinical care for KIF1A families?
   - For the group: What can the KIF1A.ORG community (as a whole or specific individuals) do to advance progress in research & clinical care for KIF1A families?

5. Patient Advisory Board
   - Families: Are you interested in joining a KIF1A.ORG Patient Advisory Board to help provide guidance & feedback on this topic? Write your name in the Scribe’s notebook to let us know you’re interested.