



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.