



Table Topics: Medically Complex KAND

1

Introductions

- Your name & where you're from
- Families: Tell us about your child

2

Pick a Scribe

- The Scribe will document important insights, concerns, questions, themes, etc. in the notebook provided

3

Discuss

- What are your biggest health-related challenges?
- How do you educate your child's clinicians and caregivers about KAND? What challenges do you face?
- How do you look after your own well-being?
- What advice do you have for other families in similar situations?

4

Document Takeaways & Action Items (Last 5 Minutes)

- For individuals: What are your biggest takeaways from this conversation? What will you do with this information?
- For the group: How can the KIF1A.ORG community (as a whole or specific individuals) provide more support for families related to this topic?