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?