

Patient Perspectives Activity Discussion Guide

July 9 | 3:00 – 4:15 p.m. Eastern Time



No one knows KAND like patients and family members. In this session, we'll spend time in small groups discussing our hopes, worries and real-life experiences.

1 Before You Start

- The purpose of this session is to help inform researchers, doctors and others about what it's like to be a KAND patient or family member.
- Some tables have assigned Discussion Leaders. These volunteers will share anonymous highlights from your discussions during the next conference session "What Matters Most to KAND Families?"
- Feel free to share as much or as little as you would like. We all have unique experiences and perspectives. They are ALL valid.

2 Say Hello

- Spend 10 to 15 minutes getting to know each other. Go around the table and introduce yourselves. What is your connection to KIF1A? Are you a patient, a parent, a caregiver, etc.?

3 Personal Reflection: Fill in the Blank

- Spend about 5 minutes quietly thinking about how you would answer each of the questions below.
- You can use the digital Whiteboard at your table to add your notes using virtual sticky notes and text fields. Or simply use pen and paper to note your thoughts.
- You can (and probably do) have more than one answer to each question.
 - **What makes KAND so challenging is:** _____
 - **I worry about:** _____
 - **I hope treatment will help with:** _____
 - **What matters most to me is:** _____

4 Discuss

- Spend the remaining time going through these questions and discussing your answers together. Do any other responses resonate with you?
- If you're an assigned Discussion Leader, have the group help you answer the following question, which you'll have 2 minutes to share during the following session.
 - **One response that stood out during our discussion was _____, because _____.**

Thank you for your time and helping others understand the KAND patient and family perspective.