

2025 KIF1A.ORG Family and Scientific Engagement Conference Agenda

Thursday, July 24:

5:00-8:30pm: Registration Desk Open

7:00-8:30pm: Milk and Cookies Dance Party

Friday July 25, 9am-5pm: Understanding KAND

Morning

KIF1A.ORG Updates: Angie Fuller, Dr. Dylan Verden, Dr. Dominique Lessard

#ThisisKIF1A Family Stories and Perspectives

Natural History Update: Dr. Wendy Chung, Boston Children's Hospital

Lunch Provided

Afternoon

Communication in KAND: Lottie Morison, Murdoch Children's Research Institute

Vision in KAND: Dr. Mary Whitman, Boston Children's Hospital

Movement in KAND: Dr. Darius Ebrahimi-Fakhari, Boston Children's Hospital

KAND Heterogeneity: Dr. Jayne Aiken, University of Pennsylvania

Dinner Provided

Saturday, July 26, 9am-5pm: Therapeutic Development

Morning

KIF1A.ORG Board Panel

Caregiver Perspectives on Therapeutic Development

ASO Journeys – Laurence Mignon, n-Lorem; Luke Rosen; Megan Hedstrom

KAND Models and Gene Editing: Dr. Markus Terrey, Jackson Laboratory

Noninvasive Neuromodulation: Dr. Parag Gad, SpineX

Lunch Provided

Afternoon

Australian Research Updates: Dr. Simran Kaur, Murdoch Children's Research Institute

Global Efforts: International KIF1A.ORG Ambassador Updates

Rare Disease Advocacy for KAND: Ashira Vantrees, J.D., Aimerd Alliance

What's next? Closing Remarks



Want to learn more about our speakers?
Visit www.kif1a.org/2025-kand-conference