

Conference Agenda: Day 1

Thursday, July 24:

- 6:00-8:30pm: Registration Desk Open
7:00-8:30pm: Milk and Cookies Dance Party

Friday, July 25:

- 7:45-9:30am: Registration table check-in
8:00am-5:30pm: Childcare available
9:00-9:30am: Welcome and KIF1A.ORG Updates
Angie Fuller, Dr. Dylan Verden, Dr. Dominique Lessard, KIF1A.ORG
9:30-10:15am: #ThisisKIF1A with Patient Families
10:15-10:30am: Break
10:30-11:30am: KAND Clinical Research Updates
Dr. Wendy Chung, Boston Children's Hospital
11:30-11:50am: Group Photo
11:50am-1:00pm: Lunch
1:15-2:15pm: Susannah and Sloane's ASO Journey
Dr. Jennifer Bain, Columbia University
2:15-3:00pm: Clinical Conversations: Speech in KAND
Lottie Morison, Murdoch Children's Research Institute
3:00-3:15pm: Break
3:15-3:55pm: Clinical Conversations: Vision in KAND
Dr. Mary Whitman, Boston Children's Hospital
3:55-4:25pm: Clinical Conversations: Movement in KAND
Dr. Darius Ebrahimi-Fakhari, Boston Children's Hospital
4:25-5:00pm: KAND Neuromodulation Pilot Study
Dr. Parag Gad, SpineX
5:00-5:15pm: Day 1 Closing Remarks
Luke Rosen, KIF1A.ORG
5:30-7:00pm: Dinner



Conference Agenda: Day 2

Saturday, July 26

- 7:45-9:30am: Registration table check-in
- 8:30am-5:30pm: Childcare available
- 9:00-9:50am: KIF1A.ORG Board Roundtable
- 9:50-10:30am: n-of-1 studies for KIF1A
Dr. Laurence Mignon, n-lorem Foundation
- 10:30-10:50am: Break
- 10:50-11:10am: Heterogeneity in KIF1A Variants
Dr. Jayne Aiken, University of Pennsylvania
- 11:10-11:40am: KAND Animal Models and Prime Gene Editing
Dr. Markus Terrey, Jackson Laboratory
- 11:40am-12:30pm: Leveraging KIF1A Research Tools
Dr. Dylan Verden, Dr. Dominique Lessard, KIF1A.ORG
- 12:30-2:00pm: Lunch
- 2:00-2:45pm: KIF1A Australia Research Updates
Dr. Simran Kaur, Murdoch Childrens Research Institute
- 2:45-3:25pm: Global Efforts: KIF1A.ORG International Ambassador Updates
Salima Shivji, KIF1A Canada
Pierre Goaziou, KIF1A France
- 3:25-3:45pm: Break
- 3:45-4:30pm: Advocacy for KAND – Sponsored by Novartis
Ashira Vantrees, Aimed Alliance
- 4:30-5:00pm: Closing Remarks

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