



KAND Family & Scientific Engagement Conference

Friday, August 16

Location	<p>Hammer Health Sciences Building – Columbia University Irving Medical Center 701 W. 168th St. New York City, NY 10032</p> <p><i>All sessions in 4th Floor Auditorium, unless noted otherwise</i></p>
7:00 a.m.	<p>Shuttle Departs Hyatt for Hammer Building (Boarding Starts at 6:45 a.m.) <i>Families staying at the Hyatt: be sure to enjoy complimentary breakfast before the shuttle leaves at 7 a.m.</i></p>
8:00 a.m. – 9:30 a.m.	<p>Registration at 4th Floor Auditorium & Social Time <i>Continental breakfast available for attendees not staying at the Hyatt</i></p>
9:30 a.m. – 10:00 a.m.	<p>Why We're Here & Introductions <i>Speaker: Luke Rosen</i></p>
10:00 a.m. – 10:45 a.m.	<p>Our True North: Family & Patient Impact on Research & Development <i>Speakers: Rickard Lundqvist & Dr. Wendy Chung</i></p>
10:45 a.m. – 11:45 a.m.	<p>What We've Learned from the KAND Natural History Study <i>Speaker: Lia Boyle</i></p>
11:45 a.m. – 1:00 p.m.	<p>Lunch <i>Pick up lunch in LL107 – Enjoy lunch across the hall in LL104 or outside</i></p>
1:00 p.m. – 2:30 p.m.	<p>The Latest in KIF1A Research <i>Speakers: Dominique Lessard (Univ. of Vermont), Dr. Richard Vallee (Columbia Univ.), Dr. Cat Lutz (The Jackson Laboratory)</i></p> <p><i>Each speaker will provide a 20-minute update, followed by 10 minutes for Q&A</i></p>
1:45 p.m. – 2:45 p.m.	<p>Children's Area: Musical Performance!</p>
2:30 p.m. – 3:00 p.m.	<p>Break & Social Time</p>
3:00 p.m. – 3:30 p.m.	<p>KAND & Neurology <i>Speaker: Dr. Cigdem Akman</i></p>
3:30 p.m. – 4:00 p.m.	<p>KAND & Ophthalmology <i>Speaker: Dr. Steven Kane</i></p>
4:00 p.m. – 4:30 p.m.	<p>A Team Approach to Special Education & Advocating for Your Child's Services <i>Speaker: Pam Wheeler-Civita</i></p>
4:30 p.m. – 5:00 p.m.	<p>Social Time & Wrap-Up</p>
5:00 p.m. & 6:00 p.m.	<p>Shuttle Departs Hammer Building for Hyatt (Select families who need to stay late will be assigned to the 6:00 p.m. shuttle)</p>

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Saturday, August 17

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7:00 a.m.	Shuttle Departs Hyatt for Hammer Building (Boarding Starts at 6:45 a.m.) <i>Families staying at the Hyatt: be sure to enjoy complimentary breakfast before the shuttle leaves at 7 a.m.</i>
8:00 a.m. – 9:00 a.m.	Check-In at 4 th Floor Auditorium & Social Time <i>Continental breakfast available for attendees not staying at the Hyatt</i>
9:00 a.m. – 9:30 a.m.	The Power of Your Story <i>Speaker: Erin Barker, The Story Collider</i>
9:30 a.m. – 10:00 a.m.	Patient Perspectives Activity <i>Facilitators: Shannon Scott & Kathryn Atchley</i>
10:00 a.m. – 10:45 a.m.	Children’s Area: Magic Show!
10:00 a.m. – 10:30 a.m.	Room Transition: Move to Rooms LL203/LL204/LL207/LL209 for Table Topics
10:30 a.m. – 11:30 a.m.	Table Topics: KAND Edition KAND in Adulthood – <i>Speakers: Janie & Betsy MacMichael (Room LL203)</i> Physical Therapy – <i>Speakers: Gay Rosenberg & Jim Harrison (Room LL204)</i> KAND at School – <i>Speaker: Pam Wheeler-Civita (Room LL207)</i> Medically Complex KAND – <i>Speaker: Dr. Wendy Chung (Room LL209A)</i>
11:30 a.m. – 12:30 p.m.	Lunch <i>Pick up lunch in LL107 – Enjoy lunch across the hall in LL104 or outside</i>
12:30 p.m. – 12:45 p.m.	Group Photo: Meet in Lobby at 12:30 (wear KIF1A.ORG t-shirt if you have one)
12:45 p.m. – 1:30 p.m.	Let’s Talk: Clinical Trial Readiness & Community Preparation <i>Speaker: Luke Rosen</i>
1:30 p.m. – 2:00 p.m.	Let’s Talk Therapeutics: How Urgency & Collaboration Leads to Therapeutic Strategies <i>Speaker: Hans Christinger, Ovid Therapeutics</i>
2:00 p.m. – 2:30 p.m.	Break & Social Time
2:30 p.m. – 4:00 p.m.	World Café: Advancing Progress in the KAND Community <i>Located in Rooms LL203/LL204</i>
4:00 p.m. – 4:15 p.m.	Room Transition: Move to Auditorium
4:15 p.m. – 4:30 p.m.	Where We Go from Here <i>Speaker: Luke Rosen</i>
4:30 p.m. – 5:00 p.m.	Social Time & Goodbyes
5:00 p.m. & 6:00 p.m.	Shuttle Departs Hammer Building for Hyatt (Select families who need to stay late will be assigned to the 6:00 p.m. shuttle)