



2021 KAND FAMILY & SCIENTIFIC ENGAGEMENT CONFERENCE

All times are in Eastern Daylight Time, New York City, UTC-04:00

FRIDAY, JULY 9			
NEW! 11:00 a.m. – Noon	Pre-Conference Networking & Technical Assistance <i>Join us early for open networking & technical assistance from our tech team if needed!</i>		
12:00 – 12:15 p.m.	Welcome & Why We're Here <ul style="list-style-type: none"> • <i>Luke Rosen, Co-Founder & Board Chair – KIF1A.ORG</i> • <i>Kathryn Atchley, President – KIF1A.ORG (How to Use the Conference Platform)</i> 		
12:15 – 12:45 p.m.	Let's Connect: Ice Breaker		
12:45 – 12:55 p.m.	A Message from Lhasa's Mom & We Remember <ul style="list-style-type: none"> • <i>Anouk Lanouette Turgeon, Lhasa's mom – KIF1A.ORG Advocate</i> 		
1:00 – 1:45 p.m.	KIF1A.ORG's Therapeutic Development Strategy <ul style="list-style-type: none"> • <i>Dominique Lessard, PhD, Chief Science Officer – KIF1A.ORG</i> • <i>Hans Christinger, MBA, Board Member – KIF1A.ORG</i> • <i>Kathryn Atchley, President – KIF1A.ORG</i> 		
1:45 – 2:45 p.m.	What We've Learned from the KAND Natural History Study <ul style="list-style-type: none"> • <i>Wendy Chung, MD, PhD, Chief of Clinical Genetics Division in Pediatrics & Principal Investigator – Columbia University Irving Medical Center (CUIMC)</i> • <i>Lia Boyle, PhD, Researcher, Chung Lab – CUIMC</i> 		
2:45 – 3:00 p.m.	Break & Networking		
3:00 – 4:15 p.m.	<table border="0" style="width: 100%;"> <tr> <td style="width: 50%; vertical-align: top;"> Family Track Patient Perspectives Activity <ul style="list-style-type: none"> • <i>Small breakout groups led by KAND patient advocates to discuss what matters most to KAND families</i> </td> <td style="width: 50%; vertical-align: top;"> Scientist & Clinician Track Short Talks <ul style="list-style-type: none"> • <i>Michael Silverman, PhD, Principal Investigator & Troy Collins, PhD Student & Lab Member, Silverman Lab – Simon Fraser University</i> • <i>Ajay Chitnis, MBBS, PhD, Senior Investigator & Head of Section on Neural Developmental Dynamics – National Institutes of Health, Division of Intramural Research</i> • <i>Jayne Aiken, PhD, Postdoctoral Scientist, Holzbaur Lab – Perelman School of Medicine, University of Pennsylvania</i> • <i>Douglas Chapnick, PhD, CEO & Founder – BioLoomics</i> </td> </tr> </table>	Family Track Patient Perspectives Activity <ul style="list-style-type: none"> • <i>Small breakout groups led by KAND patient advocates to discuss what matters most to KAND families</i> 	Scientist & Clinician Track Short Talks <ul style="list-style-type: none"> • <i>Michael Silverman, PhD, Principal Investigator & Troy Collins, PhD Student & Lab Member, Silverman Lab – Simon Fraser University</i> • <i>Ajay Chitnis, MBBS, PhD, Senior Investigator & Head of Section on Neural Developmental Dynamics – National Institutes of Health, Division of Intramural Research</i> • <i>Jayne Aiken, PhD, Postdoctoral Scientist, Holzbaur Lab – Perelman School of Medicine, University of Pennsylvania</i> • <i>Douglas Chapnick, PhD, CEO & Founder – BioLoomics</i>
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4:15 – 4:45 p.m.	What Matters Most to KAND Families? <ul style="list-style-type: none"> • <i>Shannon Dennis, Alejandro Duval, Avantika Fraser, Charisma Freeman, Audrey Guilmatre, Charlotte Klinepeter, Ennio Lamari, Anouk Lanouette Turgeon, Kassondra Lambert, Joshua Metz, Megan Rockwell, & Maribel Saez – KIF1A.ORG Advocates</i> • <i>Moderated by: Kathryn Atchley, President – KIF1A.ORG</i> 		
4:45 – 5:00 p.m.	Day 1 Closing <ul style="list-style-type: none"> • <i>Dominique Lessard, PhD, Chief Science Officer – KIF1A.ORG</i> 		

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SATURDAY, JULY 10	
NEW! 12:30 – 1:00 p.m.	Pre-Conference Networking & Technical Assistance <i>Join us early for open networking & technical assistance from our tech team if needed!</i>
1:00 – 1:05 p.m.	Welcome to Day Two <ul style="list-style-type: none"> Kathryn Atchley, President, KIF1A.ORG
1:05 – 1:35 p.m.	Care Guidelines: What We Have & What We Need <ul style="list-style-type: none"> Wendy Chung, MD, PhD, Chief of Clinical Genetics Division in Pediatrics & Principal Investigator – Columbia University Irving Medical Center Shannon Dennis, DNP, Chief Patient Officer – KIF1A.ORG
1:35 – 1:45 p.m.	Break & Networking
1:45 – 2:45 p.m.	KAND Symptoms Q&A <ul style="list-style-type: none"> Wendy Chung, MD, PhD, Chief of Clinical Genetics Division in Pediatrics & Principal Investigator – Columbia University Irving Medical Center (CUIMC) Lia Boyle, PhD, Researcher, Chung Lab – CUIMC Jennifer Bain, MD, PhD, Assistant Professor of Neurology – CUIMC Moderated by: Shannon Dennis, DNP, Chief Patient Officer – KIF1A.ORG
2:45 – 2:50 p.m.	Treatment Accelerator Program (TAP) Update <ul style="list-style-type: none"> Dominique Lessard, PhD, Chief Science Officer – KIF1A.ORG
2:50 – 3:00 p.m.	Introducing Good Dogg Beverage <ul style="list-style-type: none"> Luke Rosen, Co-Founder & Board Chair – KIF1A.ORG Andrew Parry, Director, Marketing and Communications – Good Dogg Beverage
3:00 – 3:45 p.m.	Break & Networking
<p>Before the KAND Conference, view recorded presentations with updates from our therapeutic development collaborators. During the next hour, collaborators will take questions from the audience, moderated by Luke Rosen.</p>	
3:45 – 4:00 p.m.	Rarebase Update Q&A <ul style="list-style-type: none"> Omid Karkouti, MS, Co-Founder & COO – Rarebase
4:00 – 4:15 p.m.	Ovid Therapeutics Update Q&A <ul style="list-style-type: none"> Patrick Sarmiere, PhD, Senior Director, Molecular Pharmacology – Ovid Therapeutics
4:15 – 4:30 p.m.	BioLoomics Update Q&A <ul style="list-style-type: none"> Douglas Chapnick, PhD, CEO & Founder – BioLoomics
4:30 – 4:45 p.m.	Murdoch Children's Research Institute Update Q&A <ul style="list-style-type: none"> John Christodoulou, PhD, Director, Genetics Theme – Murdoch Children's Research Institute (MCRI) Simran Kaur, PhD, Research Officer & Research Fellow – MCRI
4:45 – 5:00 p.m.	Closing Remarks <ul style="list-style-type: none"> Kathryn Atchley, President – KIF1A.ORG
5:00 – 5:30 p.m.	Networking