



2021 KAND FAMILY & SCIENTIFIC ENGAGEMENT CONFERENCE

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

| FRIDAY, JULY 9 | | | |
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| 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</i> | | |
| 12:15 – 12:45 p.m. | Let's Connect: Ice Breaker | | |
| 12:45 – 12:55 p.m. | 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</i> • <i>Lia Boyle, MD, PhD Candidate, Researcher, Chung Lab – Columbia University Irving Medical Center</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>Alejandro Duval, Avantika Fraser, Charisma Freeman, Audrey Guilmatre, Charlotte Klinepeter, Ennio Lamari, Kassondra Lambert, Joshua Metz, Megan Rockwell, & Maribel Saez – KIF1A Patient and Family Community Members</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 | |
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| 1:00 – 1:05 p.m. | <p>Welcome to Day Two</p> <ul style="list-style-type: none"> <i>Kathryn Atchley, President, KIF1A.ORG</i> |
| 1:05 – 1:35 p.m. | <p>Care Guidelines: What We Have & What We Need</p> <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</i> <i>Shannon Dennis, DNP, Chief Patient Officer – KIF1A.ORG</i> |
| 1:35 – 1:45 p.m. | <p>Break & Networking</p> |
| 1:45 – 2:45 p.m. | <p>KAND Symptoms Q&A</p> <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</i> <i>Lia Boyle, MD, PhD Candidate, Researcher, Chung Lab – Columbia University Irving Medical Center</i> <i>Jennifer Bain, MD, PhD, Assistant Professor of Neurology – Columbia University Irving Medical Center</i> <i>Moderated by: Shannon Dennis, DNP, Chief Patient Officer – KIF1A.ORG</i> |
| 2:45 – 2:50 p.m. | <p>Treatment Accelerator Program (TAP) Update</p> <ul style="list-style-type: none"> <i>Dominique Lessard, PhD, Chief Science Officer – KIF1A.ORG</i> |
| 2:50 – 3:00 p.m. | <p>Introducing Good Dogg Beverage</p> <ul style="list-style-type: none"> <i>Luke Rosen, Co-Founder & Board Chair – KIF1A.ORG</i> <i>Andrew Parry, Director, Marketing and Communications – Good Dogg Beverage</i> |
| 3:00 – 3:45 p.m. | <p>Break & Networking</p> |
| <p><i>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.</i></p> | |
| 3:45 – 4:00 p.m. | <p>Rarebase Update Q&A</p> <ul style="list-style-type: none"> <i>Omid Karkouti, MS, Co-Founder & COO – Rarebase</i> |
| 4:00 – 4:15 p.m. | <p>Ovid Therapeutics Update Q&A</p> <ul style="list-style-type: none"> <i>Patrick Sarmiere, PhD, Senior Director, Molecular Pharmacology – Ovid Therapeutics</i> |
| 4:15 – 4:30 p.m. | <p>BioLoomics Update Q&A</p> <ul style="list-style-type: none"> <i>Douglas Chapnick, PhD, CEO & Founder – BioLoomics</i> |
| 4:30 – 4:45 p.m. | <p>Murdoch Children's Research Institute Update Q&A</p> <ul style="list-style-type: none"> <i>Simran Kaur, PhD, Research Officer & Research Fellow – Murdoch Children's Research Institute</i> |
| 4:45 – 5:00 p.m. | <p>Closing Remarks</p> <ul style="list-style-type: none"> <i>Kathryn Atchley, President – KIF1A.ORG</i> |
| 5:00 – 5:30 p.m. | <p>Networking</p> |