



## 2021 KAND FAMILY & SCIENTIFIC ENGAGEMENT CONFERENCE

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

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

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SATURDAY, JULY 10	
1:00 – 1:05 p.m.	<p>Welcome to Day Two</p> <ul style="list-style-type: none"> <li>• <i>Kathryn Atchley, President, KIF1A.ORG</i></li> </ul>
1:05 – 1:35 p.m.	<p>Care Guidelines: What We Have &amp; What We Need</p> <ul style="list-style-type: none"> <li>• <i>Wendy Chung, MD, PhD, Chief of Clinical Genetics Division in Pediatrics &amp; Principal Investigator – Columbia University Irving Medical Center</i></li> <li>• <i>Dr. Shannon Dennis, Chief Patient Officer – KIF1A.ORG</i></li> </ul>
1:35 – 1:45 p.m.	<p>Break &amp; Networking</p>
1:45 – 2:45 p.m.	<p>KAND Symptoms Q&amp;A</p> <ul style="list-style-type: none"> <li>• <i>Wendy Chung, MD, PhD, Chief of Clinical Genetics Division in Pediatrics &amp; Principal Investigator – Columbia University Irving Medical Center</i></li> <li>• <i>Dr. Lia Boyle, Researcher, Chung Lab – Columbia University Irving Medical Center</i></li> <li>• <i>Jennifer Bain, MD, PhD, Assistant Professor of Neurology – Columbia University Irving Medical Center</i></li> <li>• <i>Moderated by: Dr. Shannon Dennis, Chief Patient Officer – KIF1A.ORG</i></li> </ul>
2:45 – 2:50 p.m.	<p>Treatment Accelerator Program (TAP) Update</p> <ul style="list-style-type: none"> <li>• <i>Dominique Lessard, PhD, Chief Science Officer – KIF1A.ORG</i></li> </ul>
2:50 – 3:00 p.m.	<p>Introducing Good Dogg Beverage</p> <ul style="list-style-type: none"> <li>• <i>Luke Rosen, Co-Founder &amp; Board Chair – KIF1A.ORG</i></li> <li>• <i>Andrew Parry, Director, Marketing and Communications – Good Dogg Beverage</i></li> </ul>
3:00 – 3:45 p.m.	<p>Break &amp; 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&amp;A</p> <ul style="list-style-type: none"> <li>• <i>Omid Karkouti, MS, Co-Founder &amp; COO – Rarebase</i></li> </ul>
4:00 – 4:15 p.m.	<p>Ovid Therapeutics Update Q&amp;A</p> <ul style="list-style-type: none"> <li>• <i>Patrick Sarmiere, PhD, Senior Director, Molecular Pharmacology – Ovid Therapeutics</i></li> </ul>
4:15 – 4:30 p.m.	<p>BioLoomics Update Q&amp;A</p> <ul style="list-style-type: none"> <li>• <i>Douglas Chapnick, PhD, CEO &amp; Founder – BioLoomics</i></li> </ul>
4:30 – 4:45 p.m.	<p>Murdoch Children's Research Institute Update Q&amp;A</p> <ul style="list-style-type: none"> <li>• <i>Simran Kaur, PhD, Research Officer &amp; Research Fellow – Murdoch Children's Research Institute</i></li> </ul>
4:45 – 5:00 p.m.	<p>Closing Remarks</p> <ul style="list-style-type: none"> <li>• <i>Kathryn Atchley, President – KIF1A.ORG</i></li> </ul>
5:00 – 5:30 p.m.	<p>Networking</p>