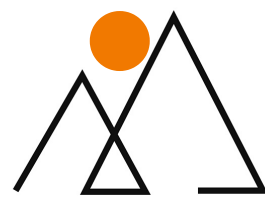


2021 Family Conference: Moving Mountains

Schedule is subject to change



July 6th, 2021

Time	Topic
4:30	New Family Orientation
5:30	Dinner
7:30	Poker Night

July 7th, 2021: Clinical Care, Research & Genetics

Time	Topic	Speaker	Dup15q Breakout	Project 8P Breakout	Ring14 Breakout
6:30	Breakfast				
7:30	Welcome and Family Parade				
8:00	What Brings Us Together	Commission for Neurodevelopmental CNV's			
8:10	TikTok Genetics				
8:20	Neurology Panel	Dr. Jeste/ Dr. Walleigh Dr. Demarest			
9:20	Break				
9:35	Electronic Diaries can Improve the Lives of those Living with Seizures	Rob Moss			
10:05	Technology & Devices in Epilepsy	Tom Stanton/ Mary Duffy			
10:25	Surgical Treatments for Epilepsy	Monica Jones			
10:55	Autism Brain Net	Alycia Halladay			
11:10	Sleep	Dr. Tourjee			
11:40	Lunch				
12:40	EEGs as Biomarkers	Dr. Eisermann/ Dr. Dangles/ Dr. Sravanapandian			
1:10	Adult Neuromuscular and Noninvasive Expert	Dr. Mirza			
1:40	Developmental Pediatrics	Dr. Reynolds			
2:10	Medication Based Treatments for Behavioral Concerns	Dr. Kearny			
2:40	Gastrointestinal Dysfunction in 15q Duplication Syndrome	Dr. Balasuriya			
2:55	Gastrointestinal Care	Dr. Bass			
3:25	Understanding the Genetics of your Diagnosis	Dr. Duis			
3:55	Implications of Understanding your Genetic Diagnosis	Emily Soludcyck			
4:25	Break				
4:40	BREAK OUTS	BREAK OUTS	Genetics of Dup15q. (Dr. Schanen) Dr. Duis	Characteristics of Individuals with chromosome 8p rearrangement - Dr. Chung	Genetics of Ring14 Dr. DeWoody.
5:10	BREAK OUTS	BREAK OUTS	Characterization of Ube3a Overexpression Mice - Dr. Judson	Continuation of 8p Genetics and Multi-Disciplinary Care Dr. Saenz	Complex Contribution to Epilepsy in 14q. Rearrangements Dr. Vaisfeld
5:30	BREAK OUTS	BREAK OUTS	15q iPSC Research Dr. Chamberlain	(Jason Colquitt)/ Clinical Data collection with Jason Colquitt and Scott Demarest	
6:00	BREAK OUTS	BREAK OUTS	Decompress: Facilitated Discussion of Learnings	Decompress: Facilitated Discussion of Learnings	Decompress: Facilitated Discussion of Learnings
6:30	Dinner: Birthday Party!				

July 8th, 2021: Treatments, Therapeutics & Supports

Topic	Speaker	Breakout Room	Breakout Room	Breakout Room
6:30	Breakfast			
7:30	Family Strategies for Living with a Genetic Condition	Dr. Doyle/ Dr. Bell		
8:15	Collaborating with your Medical Team	Dr. Segal		
8:45	Neuropsychological Evaluation and Utilities	Dr. Berger		
9:15	Physiotherapy	Dr. Páez		
9:45	Education and Interventions for school aged children	Dr. Distefano		
10:15	Addressing Challenging Behavior	Dr. Call		
10:45	Break			
11:00	BREAK OUTS	BREAK OUTS	Parenting Vulnerable Populations	IEPs: Best Practices and Real World Solutions Catherine Whitcher
12:00	Lunch			
1:00	Siblings: Concerns, Opportunities, and Effective Support Strategies for Parents and Providers	Emily Holl	Sibling Support SibShops (adolescent) Elina Marchenko	Sibling Support SibShop (under 12) Naka King
2:00	BREAK OUTS	BREAK OUTS	Identifying Genes That Contribute to Dup15q. Syndrome Using a Human Stem Cell Model - Dr. Levine	Deeper Dive into Family Strategies with Dr. Doyle/Dr. Bell
2:30	BREAK OUTS	BREAK OUTS	Q-State Approach to Therapeutics in Dup15q Syndrome	Ring14 USA Board (Silvia Weitzman)
3:00	Break			
3:15	Be Part of the Solution	Janine Cody		
3:45	Relationship communication counselor	Dr. Doyle		
4:15	BREAK OUT: Mom/Dad/ Extended Support Groups	BREAK OUTS	Extended Supporters Breakout	Mom's Group Breakout by Age Group
6:15	Dinner: Movie Night			

July 9th, 2021: Enablement and Empowerment

Topic	Speaker	Breakout Room	Breakout Room	Breakout Room
6:30	Breakfast			
7:50	Becoming a Behavioral Detective	Kim Barthel		
8:50	My Personal Experience with Autism	Dr. Temple Grandin		
9:50	Break			
10:05	Special Recreation Associations and the Benefits of Therapeutic Recreation Cooperatives	Keith Wallace	Frédéric Guez CEO Essentis® (VIRTUAL ONLY)	
10:50	Family Bootcamp in Oral Health	Dr. David Fray		
11:35	Group Photo (Wear T-Shirts)			
11:45	Lunch			
12:45	Starting A Life-Plan	Eric Goll		
1:45	Break			
2:00	BREAK OUTS	VIRTUAL ONLY: What's Happening Around the World in Dup15q International Members - All International Attendees Welcome	Fostering Friendships: Creating Connections for People with Dup15q. Nicole Cleary	Exchanging Hacks on Potty Training and Constipation
3:00	Closing Remarks			
3:15	Goodbyes		Dup15q Alliance Farewell Room	Project 8p Farewell Room
				Ring14 Farewell Room

Research Participation opportunities available both in-person and virtually. For more information contact Zoe at coordinator@15qclinicalresearchnetwork.org

Our Mission

To establish a patient-led Commission to rapidly tackle scientific and financial resources collectively to prioritize treatment for those living with neurodevelopmental chromosome disorders.

Our Vision

Advance the field of technological discovery for treatment of neurodevelopmental disorders with a focus on copy number variants

Our Goals

Short-term goals:

1. Foster team science on proposals and accessing funding through collaboration and synergy, under the premise that collectively we can make more progress than what can be achieved individually.
2. Create a Neurogenetics Data Platform and Biorepository that is interoperable and has value for patients, families, clinicians, and researchers to participate and contribute to
3. Bridge gaps in knowledge and resources by summarizing latest developments and approaches, and identifying needs, through oral and written presentations (e.g., conferences, research roadmap, and review articles)

Long-term goals:

1. Accelerate research by identifying and developing novel methods, tools and technologies
2. Provide strategic direction and support in order to grow and increase the impact of the CNV scientific community
3. Enhance the active relationship between researchers and the patient/family community on a global basis
4. Serve as an umbrella for multiple chromosomal disorders and destination for large CNV research
5. Maximize political awareness and financial capital through targeted promotion of key stakeholders



Meeting Objectives

- Facilitate enthusiastic commitment towards the Commission's mission and goals
- Raise awareness among participants about the value, importance, and benefits of aligning their work with the Research Roadmap
- Mobilize energy around the strategies described in the Research Roadmap
- Get commitments from participants to align their work with the Research Roadmap

Those that have registered and are not Commission Members will be able to attend virtually only. Information on how to access this will be provided.

Monday - July 5th, 2021

Time	Topic
4:00 pm	Registration open
4:30 pm	Welcome and Ice-Breaker *Commission Only*
5:00 pm	Hors d'oeuvres and open bar
7:00 pm	Adjourn

Tuesday - July 6th, 2021

Time	Topic
8:00 am	Welcome
8:30 am	The Value of the Commission
8:45 am	Breakout Groups
9:00 am	Dan Lowenstein <ul style="list-style-type: none"> • Impact of Team Science • Opportunities for younger scientists • The importance of our Charter
9:10 am	Our Shared Journey
9:30 am	Break
9:45 am	How the Research Roadmap Will Move Us Ahead
10:15 am	The Research Roadmap in Focus
11:15 am	Lunch
12:00 pm	Refining the Roadmap
12:15 pm	Refining the Roadmap: Breakout Groups
1:15 pm	Refining the Roadmap: Plenary Review
2:00 pm	Break
2:15 pm	Bringing the Roadmap to Life, Part 1
2:45 pm	Bringing the Roadmap to Life, Part 2
3:30 pm	Winding Down
4:00 pm	Adjourn
5:00 pm	Dinner
7:00 pm	Poker