









SCHEDULE OF EVENTS *(subject to change)*

WEEK 1 - CONNECT AND INSPIRE

Date	Time (EST)	
Tuesday, September 15, 2020	9:00pm–10:15pm	The Next Generation of RARE Changemakers Sponsored by  HORIZON
Wednesday, September 16, 2020	8:30pm–10:00pm	RARE Together Watch Together Film Selections from The Disorder Channel: Just Diagnosed RARE Film selections from The Disorder Channel: <i>Hope for Haley</i> ; <i>Menkes Disease: Finding Help & Hope</i> ; <i>Foundations of Rare Syngap</i> ; <i>Tess Is Not Alone: A USP7 Story</i> Sponsored by  The Assistance Fund
Thursday, September 17, 2020	8:30pm–10:00pm	RARE Together Watch Together Film Selections from The Disorder Channel: Siblings Experience Film selections from The Disorder Channel: <i>Me, My Sister and Blau</i> ; <i>Unconditional: Raising a Glass Child with a PACS1 Sibling</i> ; <i>Rare Disease in Children: Voices of the Siblings</i> ; <i>Perfect Brothers</i> Sponsored by  The Assistance Fund
Friday, September 18, 2020	8:30pm–10:30pm	RARE Together Watch Together Film Selections from The Disorder Channel: More Than a Quest – Success Film selections from The Disorder Channel: <i>Life & Atrophy</i> ; <i>Brick in the Wall</i> ; <i>Counting Every Second</i> Sponsored by  The Assistance Fund
Sunday, September 20, 2020	8:00pm–10:00pm	A Celebration of Hope with the RARE Disease Community Fundraiser

WEEK 2 - CONNECT AND EMPOWER

Date	Time (EST)	
Monday, September 21, 2020	12:00pm–1:00pm	Harnessing the Power of New Genomic Frontiers
	1:10pm–2:00pm	Engaging Diverse Voices at the Research Table
	1:10pm–2:00pm	Ensuring Inclusivity through Organizational Leadership
	2:10pm–3:00pm	Global Rare Disease Advocacy & Cross-Border Collaborations
	3:00pm–4:30pm	Networking and 1:1 Meetings Sponsored by  EVERSANA™
	7:00pm–8:00pm	Rare Disease Awareness Activities: Yoga Sponsored by  Mallinckrodt Pharmaceuticals

WEEK 2 Continued...

Date	Time (EST)	
Tuesday, September 22, 2020	12:00pm-1:00pm	From Data to Decisions – Leveraging Genetic Data Beyond a Diagnosis
	12:00pm-1:00pm	Accelerating Rare Disease Diagnosis with AI and ML
	1:10pm–2:00pm	Elevate Natural History Study Planning and Reach
	1:10pm–2:00pm	Communication Tools for Accessible Science
	2:10pm–3:00pm	Proactive Planning for Continuity of Research During a Crisis
	3:00pm-4:30pm	Networking and 1:1 Meetings Sponsored by  EVERSANA™
	7:00pm-8:00pm	Rare Disease Awareness Activities: Storytelling Meets Science Sponsored by  genehome <small>built by bluebird bio</small> <small>your voice is heard. your genes matter.</small>
Wednesday, September 23, 2020	12:00pm–1:00pm	Gene to Therapy: How Individualized Therapies are Becoming Reality Sponsored by  TAYSHA <small>GENE THERAPIES</small>
	1:10pm–2:00pm	Mapping Patient Inclusion in Drug Development
	1:10pm–2:00pm	Is a Gene Therapy Right for Your Disease? Sponsored by  TAYSHA <small>GENE THERAPIES</small>
	2:10pm–3:00pm	The Patient-Centered Future of Clinical Trials
	2:10pm–3:00pm	Are Oligonucleotide Therapeutics Right for Your Disease?
	3:00pm-4:30pm	Networking and 1:1 Meetings Sponsored by  EVERSANA™
	7:00PM - 8:00PM	Reflections on Building Successful Collaborations Between Advocates and Researchers, Hosted by Debra Melikian and Jason Sicklick

Date	Time (EST)	
Thursday, September 24, 2020	12:00pm–1:00pm	Be Heard: Patient Perspectives in Novel Therapeutics Value-based Discussions
	1:10pm–2:00pm	Navigating the Transition of Care for Young Adult Patients
	1:10pm–2:00pm	Mitigating Familial Financial Toxicity Through Planning
	2:10pm–3:00pm	Patient Stories: How to Become a Proactive Financial Advocate for Young Adults
	3:00pm–4:30pm	Networking and 1:1 Meetings Sponsored by  EVERSANA™
	7:00pm–8:00pm	Angel Aid Presents – StressRx: Stress Resilience & Sensory Self-Care [in Micro-Moments A Day]
Friday, September 25, 2020	12:00pm–1:00pm	The Power of Human Connections and Resilient Communities
	1:10pm–2:00pm	Operationalizing Patient Inclusivity and Maintaining Compliance
	2:10pm–3:00pm	Lives Can be Changed with Answers Sponsored by  EVERSANA™
	3:00pm–4:30pm	Networking and 1:1 Meetings

Proudly Sponsored by



#2020GGSummit