











SEPTEMBER 19, 2019 - DAY ONE				
7:00a – 7:30a	Yoga <i>Sponsored by:</i>  NOVARTIS			
7:30a – 4:00p	Registration <i>Sponsored by:</i>  Alnylam <small>CHALLENGE ACCEPTED</small>			
7:30a – 8:15a	Breakfast <i>Sponsored by:</i>  Inspired by patients. Driven by science.			
8:15a – 9:30a	Welcome and Keynote with Susannah Cahalan			
9:30a – 10:30a	Networking/Appointment Break <i>Sponsored by:</i>  Intercept			
9:30a – 10:30a	Poster Presentations <i>Sponsored by:</i>  Aldevron			
9:30a – 7:30p	Exhibit Pavilion Open <i>Sponsored by:</i>  PRAHEALTHSCIENCES			
Day One	TRACK 1 Caring for Yourself and Others While Rare	TRACK 2 Building and Activating Your Community	TRACK 3 Patients as Drivers in Drug Development	TRACK 4 What's Now: Innovations in Rare Disease
10:30a – 11:30a	Eating Well: Taking Care of Yourself Through Nutrition	We Are Here: Finding Others and Building Your Community	Early Drug Development: What Patients Bring	Technologies for Learning About Rare Disease from Patients and Caregivers
11:30a – 1:00p	Lunch <i>Sponsored by:</i>  Pfizer			
1:00p – 2:00p	Getting Financial Help: Qualifying for Disability and Other Insurance Matters	Your Diagnosis Matters: What Are ICD and ORPHA Codes and Why Are They Important	Rare Disease Research: Getting Your Disease Noticed	Genome Sequencing: Hope, Promises and Limitations
2:00p – 3:00p	Networking/Appointment Break <i>Sponsored by:</i>  Leadiant Bioscience			
2:00p – 3:00p	Poster Presentations <i>Sponsored by:</i>  Aldevron			
3:00p – 4:00p	Romance While Rare	Developing Partnerships Among Rare Communities and Individuals	General Data Protection Regulation: Implications for You and Drug Development	What is Druggable? New Therapeutic Targets in Rare Disease
4:00p – 4:15p	Break			
4:15p – 5:15p	Challenge Your Limits			
5:15p – 7:30p	Day One Reception <i>Sponsored by:</i>  HORIZON			

*The agenda is subject to change. Please visit the Global Genes RARE Patient Advocacy Summit app for the most up-to-date agenda and speaker listings.

SEPTEMBER 20, 2019 - DAY TWO				
7:00a – 7:30a	Yoga <i>Sponsored by:</i>  NOVARTIS			
7:30a – 12:00p	Registration <i>Sponsored by:</i>  Alnylam <small>CHALLENGE ACCEPTED</small>			
7:30a – 8:15a	Breakfast <i>Sponsored by:</i>  IONIS			
8:15a – 9:30a	Chasing Cures: The Power of Patients			
9:30a – 10:30a	Networking/Appointment Break <i>Sponsored by:</i>  blueprint			
9:30a – 10:30a	Poster Presentations <i>Sponsored by:</i>  aldeveron			
9:30a – 4:20p	Exhibit Pavilion Open <i>Sponsored by:</i>  PRAHEALTHSCIENCES			
Day Two	TRACK 1 Owning Your Future with a Rare Disease	TRACK 2 Becoming a Stronger Advocate	TRACK 3 The Drug Development Future: Science, Policy, Partnerships and Economics	TRACK 4 What's Next: Innovations in Rare Disease
10:30a – 11:30a	Family Planning: Decisions and Considerations	Fundraising Ideas Anyone Can Try	Patients and Caregivers: Shaping Clinical Drug Development	Breakthroughs for Rare Neurological Syndromes
11:30a – 1:00p	Lunch <i>Sponsored by:</i>  avearis			
1:00p – 2:00p	Crafting a Career: Making a Fulfilling Professional Life with a Rare Disease	Leveraging Digital Tools for Reach and Impact	Patients and Advocates as Entrepreneurs: New Models for Drug Development	The Future of Rare Metabolic Syndromes
2:00p – 2:45p	Networking/Appointment Break <i>Sponsored by:</i>  REGENERON <small>science to medicine™</small>			
2:00p – 2:45p	Poster Presentations <i>Sponsored by:</i>  aldeveron			
2:45p – 3:45p	Finding Answers: The Importance of Communicating with Clinicians	The New Normal: Patient Communities Drive Innovation	The Value of Rare Disease Therapies: Patient Perspectives Needed	Advances in Rare Immunological Diseases
3:45p – 4:00p	Break			
4:00p – 5:00p	Next: Imagining the Future of Rare Disease			
6:30p – 7:30p	RARE Champion of Hope Celebration Reception			
7:30p – 10:00p	RARE Champion of Hope Celebration <i>Sponsored by:</i>  EVERSANNA			

Want to network with people who are interested in similar topics? Join one of our many hosted networking sessions. Each session has a theme and expert facilitator(s) to help you connect with other attendees around common interest areas.

Topic: Adult Rare Disease Stakeholders

Date: Thursday, September 19

Time: 9:30 – 10:30 a.m.

Location: Nautilus Ballroom 5, Bottom Floor

Facilitator: [Andra Stratton](#), President & Co-founder, Lipodystrophy United



Topic: Moms and Dads of Rare Disease Patients

Date: Thursday, September 19

Time: 9:30 – 10:30 a.m.

Location: Nautilus Ballroom 5, Bottom Floor

Facilitator: [Jennifer Siedman](#), Courageous Parents Network



Topic: Storytelling

Date: Thursday, September 19

Time: 2:00 – 3:00 p.m.

Location: Nautilus Ballroom 5, Bottom Floor

Facilitators: [Travis Flores](#), Speaker and Author
[Madison McLaughlin](#), Actress



Topic: Genetic Testing 101

Date: Friday, September 20

Time: 9:30 – 10:30 a.m.

Location: Nautilus Ballroom 4, Bottom Floor

Facilitators: [Jessica Shiles](#), Genetic Counselor, Fulgent Genetics
[Laura Drzich](#), Curation QA Associate, Fulgent Genetics



Topic: Working with Researchers

Date: Friday, September 20

Time: 9:30 – 10:30 a.m.

Location: Nautilus Ballroom 5, Bottom Floor

Facilitator: [Sandra Bedrosian-Sermone](#), President and Executive Director, ADNP Kids Research Foundation



Topic: Travel

Date: Friday, September 20

Time: 2:00 – 2:45 p.m.

Location: Nautilus Ballroom 5, Bottom Floor

Facilitator: [Kevan Chandler](#), Founder, We Carry Kevan

