



2019 SUMMIT OVERVIEW

WEDNESDAY, SEPTEMBER 18 - FRIDAY, SEPTEMBER 20

WEDNESDAY, SEPTEMBER 18, 2019 - PRE SUMMIT

8:00a - 5:00p	RARE Entrepreneur Bootcamp (Application Required)
1:00p - 5:00p	Corporate Alliance Meeting (Invitation Only)
12:00p - 6:00p	Registration <i>Sponsored by:</i>  <small>CHALLENGE ACCEPTED</small>
3:00p - 6:00p	Exhibit Pavilion Open <i>Sponsored by:</i>  PRAHEALTHSCIENCES
4:00p	Freshman Orientation
6:00p - 8:00p	Welcome Reception <i>Sponsored by:</i>  PRAHEALTHSCIENCES



THURSDAY, SEPTEMBER 19, 2019 - DAY ONE



7:00a	Yoga			
7:30a – 4:00p	Registration <i>Sponsored by:</i> CHALLENGE ACCEPTED			
7:30a – 8:30a	Breakfast <i>Sponsored by:</i> Inspired by patients. Driven by science.			
8:30a – 9:30a	Welcome and Keynote			
9:30a – 10:30a	Networking/Appointment Break/Poster Presentations			
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 <i>FL</i>	We Are Here: Finding Others and Building Your Community	Drug Development Basics: What Patients Bring <i>FL</i>	Technologies for Learning about Rare Disease from Patients and Caregivers <i>EL</i>
11:30a – 1:00p	Lunch <i>Sponsored by:</i>			
1:00p – 2:00p	Getting Financial Help: Qualifying for Disability and Other Insurance Matters <i>FL</i>	Your Diagnosis Matters: What are ICD and ORPHA Codes and Why are They Important <i>FL</i>	Rare Disease Research: Getting Your Disease Noticed	Genome Sequencing: Hope, Promises and Limitations
2:00p – 3:00p	Networking/Appointment Break/Poster Presentations			
3:00p – 4:00p	Romance While Rare <i>FL</i>	Developing Partnerships Among Rare Communities and Individuals <i>EL</i>	General Data Protection Regulation: Implications for You and Drug Development	What is Druggable? New Therapeutic Targets in Rare Disease
4:15p – 5:15p	Closing Session			
5:15p – 7:30p	Day One Reception <i>Sponsored by:</i> HORIZON			

EL - Expansion level course
FL - Foundational level course

FRIDAY, SEPTEMBER 20, 2019 - DAY TWO

7:00a	Yoga
7:30a - 12:00p	Registration <i>Sponsored by:</i>  Alnylam CHALLENGE ACCEPTED
7:30a - 8:30a	Breakfast
8:30a - 9:30a	The Future of Rare Disease: 10 Years Hence
9:30a - 10:30a	Networking/Appointment Break/Poster Presentations
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: Science and Treatment for Rare Disease
10:30a - 11:30a	Family Planning: Decisions and Considerations	Fundraising Ideas Anyone Can Try <i>FL</i>	Patients and Caregivers: Shaping Clinical Drug Development <i>EL</i>	Breakthroughs for Rare Neurological Syndromes
11:30a - 1:00p	Lunch <i>Sponsored by:</i> 			
1:00p - 2:00p	Crafting a Career: Making a Fulfilling Professional Life as a Patient or a Caregiver	Leveraging Digital Tools for Reach and Impact	Patients and Advocates as Entrepreneurs: New Models for Drug Development <i>EL</i>	The Future of Rare Metabolic Syndromes
2:00p - 3:00p	Networking/Appointment Break/Poster Presentations			
3:00p - 4:00p	Finding Answers: The Importance of Communicating with Clinicians <i>FL</i>	The New Normal: Patient Communities Drive Innovation <i>EL</i>	The Value of Rare Disease Therapies: Patient Perspectives Needed <i>FL</i>	Advances in Rare Immunological Diseases

EL - Expansion level course
FL - Foundational level course

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4:20p – 5:00p	Closing Session
6:30p – 7:30p	RARE Champion of Hope Celebration Reception
7:30p – 10:00p	RARE Champion of Hope Celebration

SATURDAY, SEPTEMBER 21, 2019 - POST-SUMMIT

8:30a – 11:00a	Foundation Alliance In Person Meeting (Invitation Only)
12:00p – 5:00p	RARE Global Advocacy Leadership Symposium (Invitation Only)



Global Genes[®]

Allies in Rare Disease