



Saturday, May 18, 2019
History of Colorado Center - MDC Terrace Room
1200 N Broadway, Denver, CO 80203
#RAREontheRoad

Time	Session	Speaker
8:30am – 9:00am	Start Your Engines! <i>Registration, Breakfast and Networking</i>	
9:00am – 9:30am	Let's Hit the Road: <i>Welcome and Overview</i>	Ashley Yee, Global Genes and Britta Vander Linden, The EveryLife Foundation for Rare Diseases
9:30am – 9:45am	Let's Go on a Road Trip: <i>My Rare Disease Journey</i>	Rachael Jones XLH Network
9:45am – 10:45am	Tales from the Road: <i>How to Tell Your Story and Build Capacity</i>	Ashley Yee Global Genes
10:45am – 11:00am	Rest Stop	
11:00am – 12:00pm	Being Seen and Heard: Social Media <i>Strategies to Click and Connect</i>	Lee Aase Mayo Clinic Social Media Network
12:00pm – 12:15pm	Group Photo	
12:15pm – 12:30pm	The Path to Partnering with Congress: <i>Remarks from Your Representatives</i>	Annie Larson Office of Senator Cory Gardner
12:30pm – 1:30pm	Refueling Lunch	
1:30pm – 1:45 pm	Gain Momentum and Drive Change: <i>A Historical Primer</i>	Mark Dant and Lisa Schill The EveryLife Foundation for Rare Diseases
1:45pm – 2:45pm	What is on the Legislative Road Ahead? <i>Accelerating Change in the Rare Disease Community</i>	Shannon von Felden, The EveryLife Foundation for Rare Diseases And Stephanos Koutsoukos, YARR Member
2:45pm – 3:00pm	Rest Stop	
3:00pm – 4:00pm	Maintain Your Ride: <i>Self-Care Check-Up</i>	Nissa Jackman LMFT, ATR-BC Board Certified Art Therapist
4:00pm – 4:30pm	Accelerate Your Mission: <i>Your Chance to Win a Trip to Rare Disease Week on Capitol Hill or the Global Genes Summit*</i>	Erin Garcia, The EveryLife Foundation for Rare Diseases and Ashley Yee, Global Genes

**Must be present to win. Raffle winners will receive a voucher to attend the 2019 Global Genes Patient Advocacy Summit (value of \$750) or a voucher to attend the 2020 EveryLife Foundation's Rare Disease Week on Capitol Hill (value of \$800).*

Agenda Presented by Biogen and Takeda