



2019 Draft Agenda

March 30th Cambridge, MA - May 4th Birmingham, AL
 May 18th Denver, CO - July 13th Sioux Falls, SD

Time	Session	Speaker
8:30 – 9:00	Start Your Engines! <i>Registration, Breakfast, and Networking</i>	
9:00 – 9:30	Let's Hit the Road: <i>Welcome and Overview</i>	The EveryLife Foundation for Rare Diseases and Global Genes
9:30 – 9:45	Let's Go on a Road Trip: <i>My Rare Disease Journey</i>	Patient/Parent Advocate Moderator
9:45 – 10:45	Tales from the Road: <i>How to Tell Your Story and Build Capacity</i>	Global Genes
10:45 – 11:00	Rest Stop	
11:00 – 11:45	Gain Momentum and Drive Change: <i>A Historical Primer</i>	The EveryLife Foundation for Rare Diseases
11:45 – 12:00	The Path to Partnering with Congress: <i>Remarks from Your Member of Congress</i>	Member of Congress
12:00 – 12:45	Refueling Lunch and Group Photo	
12:45 – 1:45	What is on the Legislative Road Ahead? <i>Accelerating Change in the Rare Disease Community</i>	The EveryLife Foundation for Rare Diseases
1:45 – 2:45	Being Seen and Heard: <i>Social Media Strategies to Click and Connect</i>	Mayo Clinic Social Media Network
2:45 – 3:00	Rest Stop	
3:00 – 4:00	Maintain Your Ride: <i>Self-care Check-up</i>	Global Genes
4:00 – 4:30	Accelerate Your Mission: <i>Your Chance to Win a Trip to Rare Disease Week on Capitol Hill or the Global Genes Summit*</i>	The EveryLife Foundation and Global Genes

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