



Saturday, May 4th, 2019

Children's of Alabama - Children's Harbor Building

Bradley Conference Center, 4th Floor

1600 6th Avenue South, Birmingham, AL 35233

#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 Erin Garcia, The EveryLife Foundation for Rare Diseases
9:30am – 9:45am	Let's Go on a Road Trip: <i>My Rare Disease Journey</i>	Kristin Anthony PTEN Hamartoma Tumor Syndrome Foundation
9:45am – 10:45am	Being Seen and Heard: Social Media <i>Strategies to Click and Connect</i>	Dan Hinmon Mayo Clinic Social Media Network
10:45am – 11:00am	Rest Stop	
11:00am – 11:45am	Gain Momentum and Drive Change: <i>A Historical Primer</i>	Lisa Schill The EveryLife Foundation for Rare Diseases
11:45am – 12:00pm	The Path to Partnering with Congress: <i>Remarks from Your Representatives</i>	TBD
12:00pm – 12:45pm	Refueling Lunch and Group Photo	
12:45pm – 1:45pm	Tales from the Road: How to Tell Your Story and Build Capacity	Ashley Yee Global Genes
1:45pm – 2:45pm	What is on the Legislative Road Ahead? <i>Accelerating Change in the Rare Disease Community</i>	Lindsey Cundiff, The EveryLife Foundation for Rare Diseases And Swapna Kakani, Alabama Rare
2:45pm – 3:00pm	Rest Stop	
3:00pm – 4:00pm	Maintain Your Ride: <i>Self-Care Check-Up</i>	Christianne E. Strang, PhD, ATR-BC, CEDCAT-S President, American Art Therapy Association Assistant Professor, Behavioral Neuroscience
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>	The EveryLife Foundation for Rare Diseases and 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