



Saturday, June 30, 2018
Intermountain Primary Children's Hospital
(Eccles Outpatient Building)
81 N. Mario Capecchi Dr.
Salt Lake City, UT 84113

Time	Session	Speaker
8:30am - 9:00am	Start Your Engines! <i>Registration and Breakfast</i>	
9:00am - 9:15am	Tales from the Road: <i>My Rare Disease Journey</i>	Anne Bruns Parent Advocate
9:15am - 9:30am	Let's Go on a Road Trip: Ice Breaker	Ashley Yee Global Genes
9:30am - 10:30am	What's Under the Hood? <i>Understanding Rare Disease Resources</i>	Ashley Yee Global Genes
10:30am - 11:30am	Being Seen and Heard: <i>Social Media Strategies to Click and Connect</i>	Dan Hinmon Mayo Clinic
11:30am - 12:00pm	Drive Change: How the EveryLife Foundation Can Help You in Your Journey	Grant Kerber EveryLife Foundation for Rare Diseases
12:00pm - 12:15pm	Group Picture	
12:15pm - 1:00pm	Refueling Lunch	
1:00pm - 1:15pm	The Path to Partnering with Congress	Representatives TBD
1:15pm - 2:00pm	What's on the Legislative Road Ahead? <i>Accelerating Change in the Rare Disease Community</i>	Lisa Schill EveryLife Foundation for Rare Diseases
2:00pm - 2:45pm	Gain Momentum: <i>Public Policy is Easy as a Phone Call</i>	Lisa Schill and Erin Garcia EveryLife Foundation for Rare Diseases
2:45pm - 3:00pm	Rest Stop	
3:00pm - 4:15pm	Detours to Destinations: <i>Navigating Your Rare Disease Landscape</i>	Ashley Yee Global Genes
4:15pm - 4:30pm	Let's Hit the Road: <i>Your Journey Begins with a Single Step</i>	Anne Bruns Parent Advocate