



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 | Kendall Davis Global Genes |
| 9:30am - 10:30am | What's Under the Hood? <i>Understanding Rare Disease Resources</i> | Kendall Davis 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 | Lindsey Cundiff EveryLife Foundation for Rare Diseases |
| 12:00pm - 12:15pm | Group Picture | |
| 12:15pm - 1:00pm | Refueling Lunch | |
| 1:00pm - 1:15pm | Messages from Members | 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> | Kendall Davis Global Genes |
| 4:15pm - 4:30pm | Let's Hit the Road: <i>Your Journey Begins with a Single Step</i> | Anne Bruns Parent Advocate |