



Saturday, July 15th, 2017
Shriners Hospital for Children
3101 SW Sam Jackson Park Road
Portland, Oregon 97239

Time	Session
8:30 am	Registration
9:00 am	My Journey Driving Change Along the Rare Disease Road <i>Presented by Sandra Sermone, Founder/President, ADNP Kids Research Foundation</i>
9:15 am	Ice Breaker – RARE Introductions <i>Presented by Sandra Sermone, Founder/President, ADNP Kids Research Foundation</i>
9:30 am	EveryLife Foundation for Rare Diseases Introduction and Upcoming In-District Lobby Days <i>Presented by Lindsey Cundiff, Events and Logistics Manager, EveryLife Foundation for Rare Diseases</i>
9:45 am	The RARE Patient Journey: Plotting Your Path to Drive Change <i>Presented by Kendall Davis, Senior Manager of Strategic Alliances, Global Genes</i>
10:45 am	Break
11:00 am	Discover the Keys to Your Story to Make the Most Impact <i>Presented by Chris Smith, President/CEO, SmithSolve</i>
12:00 pm	Group Photo
12:15 pm	Lunch
1:00 pm	Patient Activism: How Cupcakes Helped Make a New Law <i>Presented by Jennifer Knapp, Executive Director, AIUnited</i>
1:15 pm	Oregon State Legislator: A Letter From Senator Wyden Advocating for Rare Disease <i>Presented by Richard Cundiff, Secretary, Health Care Caucus of the Democratic Party of Oregon</i>

1:30 pm	The Crucial Need to Support Fundamental Research – A Key to Rare Disease <i>Presented by Andrea DeBarber, Ph.D., Research Associate Professor, Department of Physiology and Pharmacology, Oregon Health and Science University (OHSU)</i>
1:45 pm	The Impact of Public Policy, How to Navigate Congress and Your Right to Lobby <i>Presented by Julia Jenkins, Executive Director, EveryLife Foundation for Rare Diseases</i>
2:30 pm	Break
2:40pm	Patient Activism: Putting Your Words Into Action <i>Presented by Elisabeth Parker, Member at Large, RASopathies Network</i>
2:50 pm	Public Policy is as Easy as a Phone Call <i>Presented by Lindsey Cundiff, Events and Logistics Manager, EveryLife Foundation for Rare Diseases</i>
3:00 pm	Your Personal Advocacy Forecast: Where Do You Fit In? <i>Presented by Kendall Davis, Senior Manager of Strategic Alliances, Global Genes, and Katie Stevens, President, Dyskeratosis Congenita Outreach, Inc.</i>
4:00 pm	Program Conclusion/Postcard Project <i>Presented by Sandra Sermone, Founder/President, ADNP Kids Research Foundation</i>

RARE on the Road is a collaboration between the EveryLife Foundation for Rare Diseases and Global Genes – Allies in Rare Disease.

Thank you to our sponsors.