



**Saturday, July 13, 2019**  
**Sanford Research Center – Coyote Room**  
**2301 E 60<sup>th</sup> Street North**  
**Sioux Falls, SD 57104**  
**#RAREontheRoad**

Time	Session	Speaker
8:30am – 9:00am	<b>Start Your Engines!</b> <i>Registration, Breakfast and Networking</i>	
9:00am – 9:30am	<b>Let's Hit the Road:</b> <i>Welcome and Overview</i>	Lindsey Cundiff The EveryLife Foundation for Rare Diseases and Laura Borruso Global Genes
9:30am – 9:45am	<b>Let's Go on a Road Trip:</b> <i>My Rare Disease Journey</i>	Kendra Gottsleben Patient Advocate
9:45am – 10:45am	<b>Tales from the Road:</b> <i>How to Tell Your Story and Build Capacity</i>	Danielle Thompson Global Genes
10:45am – 11:15am	<b>Rest Stop</b> <i>Tour of Sanford Lab and Group Photo</i>	
11:15am – 11:45am	<b>Gain Momentum and Drive Change:</b> <i>A Historical Primer</i>	Lisa Schill The EveryLife Foundation for Rare Diseases
12:00pm – 12:15pm	<b>The Path to Partnering with Congress:</b> <i>Remarks from Your Representatives</i>	Tyler Tordsen Office of Senator Mike Rounds
12:15pm – 12:45pm	<b>Refueling Lunch</b>	
12:45pm – 1:45pm	<b>What is on the Legislative Road Ahead?</b> <i>Accelerating Change in the Rare Disease Community</i>	Sarah Gelbard The EveryLife Foundation for Rare Diseases and Rasheera Dopson YARR Member
1:45pm – 2:45pm	<b>Being Seen and Heard: Social Media</b> <i>Strategies to Click and Connect</i>	Lee Aase Mayo Clinic Social Media Network
2:45pm – 3:45pm	<b>Maintain Your Ride:</b> <i>Self-Care Check-Up</i>	Lora Barthelman Music Therapy Services of South Dakota, LLC
3:45pm – 4:00pm	<b>Accelerate Your Mission:</b>	Lisa Schill The EveryLife Foundation for Rare Diseases and

	<i>Your Chance to Win a Trip to Rare Disease Week on Capitol Hill or the Global Genes Summit*</i>	Laura Borruso Global Genes
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*\*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 and Takeda**