



RARETOUR.ORG
#RAREONThEROAD

A VIRTUAL EVENT

Part 1: Interactive Webinar

TUESDAY, JUNE 23RD
11:00 a.m. ET – 1:30 p.m. ET

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- 11:00-11:05 **Welcome to Rare on the Road Part I:**
A Rare Disease Leadership Interactive Webinar
A few housekeeping notes about the webinar software, how to ask questions, and anything else you need to know to get the most out of your virtual experience.
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- 11:05-11:15 **Let's Hit the Road**
Welcome and Overview.
– Britta Dornan, Susan Brisendine
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- 11:15-11:45 **Tales from the Road**
How to tell your story and build capacity.
– Hira Chowdhary
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- 11:45-12:00 **Let's Go on a Road Trip**
Storytelling in action - meet a rare disease advocate who will share their rare disease journey.
– Parvathy Krishnan
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- 12:00-12:10 **Rest Stop**
Break.
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- 12:10-12:20 **Roadside Assistance**
A brief Q&A to get your questions answered about this morning's sessions.
– Hira Chowdhary, Parvathy Krishnan
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- 12:20-12:50 **Drive Change**
How to make your voice heard and make a difference.
– Annie Kennedy, Shannon von Felden
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- 12:50-1:00 **Roadside Assistance**
A second Q&A to answer any final questions.
– Annie Kennedy, Shannon von Felden, Representative Gus M. Bilirakis
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- 1:00-1:20 **Pitstop with a Policy Maker**
Learn about policy issues that impact you.
– Representative Gus M. Bilirakis
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- 1:20-1:30 **Setting Out on the Open Road**
Map out the next steps in your rare disease journey.
– Grant Bonebrake, Kanoe Flores



Part II: RARE Chats

WEDNESDAY, JUNE 24th

11:00 a.m. ET - 12: 00 p.m. ET

This virtual event will focus on issues and resources specific to California, Louisiana, Minnesota, and North Carolina, but residency is not required to register. Industry members are not permitted..

11:00-11:05
EST

Welcome to Rare on the Road Part II: A Local RARE Chat

Welcome and Overview - a few housekeeping notes and an introduction to RARE Chats.

11:05-11:20

Introductions and Ice-breaker

Split into your RARE Chat groups according to state and meet other locals. Give your name, location, connection to rare disease, and your favorite self-care activity to break the ice.

11:20-11:55

Group Chats

With the help from your RARE Chat moderator, you'll discuss your experiences and community involvement with others from your state.

11:55-12:00

Thank you for joining

Closing remarks from your RARE Chat moderator, including how you can stay in contact after the event.

Chat Moderators

Northern California

Nicole Boice
Christine Von Raesfeld
Pat Egan
Angela Ramirez

Southern California

Emily Bridges
Michelle Padilla
Marc Yale
Heather Brown

Minnesota

Jana Healy
Erica Barnes
Vicki Strong
Cristol O'Loughlin

North Carolina

Tara Britt
Parvathy Krishnan
Sandra Talbird
Sharon King

Louisiana

Eric Hartman
Rodney Reese

