



EVENT SCHEDULE

Educating the next generation
of rare disease advocates



8:30 am - **Start Your Engines!**
9:00 am Registration, Breakfast and Networking

9:00 am - **Let's Hit the Road**
9:30 am Welcome and Overview
Global Genes and The EveryLife Foundation for Rare Diseases

9:30 am - **Let's Go on a Road Trip**
9:45 am Meet a rare advocate who will share their rare disease journey
Patient Advocate

9:45 am - **Tales from the Road**
10:45 am How to tell your story and build capacity
Global Genes

10:45 am - **Rest Stop**
11:00 am Break

11:00 am - **Drive Change**
12:00 pm Why does policy matter? How does advocacy work? Take part in an ACTION ALERT!
The EveryLife Foundation for Rare Diseases

12:00 pm - **Refuel**
1:00 pm Lunch, Group Photo and Networking

1:00 pm - **Carpooling with Congress**
1:20 pm Hear from your local representative on issues that matter to you
Member of Congress or state legislator

1:20 pm - **Shifting Forward**
2:00 pm How can you make an impact on the local level? How can young advocates make their voices heard? Plan the next steps in your advocacy journey
The EveryLife Foundation for Rare Diseases

2:00 pm - **Maintain Your Ride**
3:00 pm Support Check-Up
Global Genes

3:00 pm - **Setting Out on the Open Road**
3:30 pm Your Chance to Win a Trip to Rare Disease Week on Capitol Hill or the Global Genes Summit
Global Genes and The EveryLife Foundation for Rare Diseases

RARETOUR.ORG
#RAREonTheRoad