



2020 RARE on the Road FAQs

General

What are the new dates for 2020 RARE on the Road?

This year, due to the COVID-19 crisis, we are hosting RARE on the Road as a two-day, virtual series taking place on Tuesday, June 23rd, 2020 (11:00 a.m. - 1:30 p.m. ET) and Wednesday, June 24th, 2020 (11:00 a.m. - 12:00 p.m. ET).

What knowledge can I expect to gain from this two-day, virtual event?

With feedback from the community, we designed a unique virtual experience that will empower attendees to build their skill set, enhance their knowledge, engage in advocacy, and network with their local rare disease community.

Part I: Interactive Webinar - Tuesday, June 23rd, 11:00 a.m. - 1:30 p.m. ET

Participants will engage in interactive tutorials on how to tell their rare story and how to get involved in advocacy. This portion of the event will feature special guest speakers, including a rare disease patient and policy expert.

Part II: RARE Chats - Wednesday, June 24th, 11:00 a.m. - 12:00 p.m. ET

Participants will have the chance to meet local rare disease community members during a unique video chat experience. This event offers participants the opportunity to learn from local rare disease leaders, share ideas, and form lasting relationships with their local peers.

For more details about each day's event, [click here](#) for a detailed agenda.

Do I need to live in a specific city and/or state to participate in the 2020 RARE on the Road virtual events?

These events are geared toward rare disease community members who want to tell their rare disease story, make an impact in the lives of others, and connect locally with fellow rare disease community members. All are welcome to register for Part I, Part II, or both!

However, please note: *Part II: RARE Chats (Wednesday, June 24th)* will focus on issues and resources specific to California, Louisiana, Minnesota, and North Carolina, but residency in one of these states is not required to register (industry members are not permitted to participate in the RARE Chat sessions).



Registrants will be divided into Chat groups based on their proximity to the four states listed above so participants can interact and network with others in their geographical region.

How will the 2020 RARE on the Road events run virtually?

This unique two-part, online event will take place on two user-friendly platforms.

When you register for *Part I: Interactive Webinar - Tuesday, June 23rd, 11:00 a.m. - 1:30 p.m. ET*, you will receive a link via email prior to the event for easy access. Note: when clicking the link you may be prompted to enter the email address associated with your registration before entering the webinar.

Part II: RARE Chats - Wednesday, June 24th, 11:00 a.m. - 12:00 p.m ET will use a digital conference platform. Similar to Part I, participants will receive a link via email prior to the event for easy access to their RARE Chat group with instructions for access.

What equipment will I need to participate virtually?

You will need an internet connection and a computer, tablet or smartphone. If you choose to participate in a RARE Chat, your computer, tablet, or smartphone must also have a microphone and a camera to fully participate.

Will *Part I: Interactive Webinar* be live or recorded?

The webinar on Tuesday, June 23rd will be live and provide opportunities for brief Q&A sessions throughout.

How can I ask the speaker or presenter questions during the webinar?

During *Part I: Interactive Webinar*, there will be a digital Q&A box available throughout the event where you can type any questions you have as they come up. If your question is not answered live, the speaker or presenter will follow up with answers to your questions via email after the event.

In case I can't attend the entire *Part I: Interactive Webinar* session for any reason, will the presentations be recorded for later viewing?

Yes, *Part 1: The Interactive Webinar* will be recorded and available for viewing post-event. A link to the webinar recording will be emailed to all participants after the event and will also be made available on the Global Genes resources page, [here](#), and on the EveryLife Foundation website [here](#).



How can I network with other 2020 RARE on the Road attendees?

Part II: RARE Chats is all about networking! During this unique video chat experience, you will have the opportunity to interact with up to 15 other local attendees living near your geographical region. This portion of the event is all about networking and forming relationships with others in your area.

Registration

How do I register for 2020 RARE on the Road?

You can register for Part I, Part II, or both at this link [here](#).

Can I register for *Part I: Interactive Webinar ONLY*?

Absolutely! When registering, [here](#), you can select whether you'd like to attend Part I, Part II or both. As a reminder, Part II 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 allowed to participate in the RARE Chat sessions).

Is there a registration fee for 2020 RARE on the Road?

Since 2017, Global Genes and the EveryLife Foundation have partnered to host RARE on the Road events around the country, developing the next generation of advocacy leaders. To help us continue to provide opportunities for the rare disease community to connect, we request a nominal registration fee of **\$25.00**. However, if you are unable to financially cover the cost of the registration fee, you can select to have your registration fee waived on the registration form [here](#).

Is there a deadline to register?

For Part I: Interactive Webinar, there is no deadline to register. You may register all the way up until the day of the event. For Part II: RARE Chats, space is limited and is first come, first served. The deadline to register for the chats is **June 15th, or until all available spots are filled**. If at that time you'd like to be added to our RARE Chats waitlist, you can send us an email at events@globalgenes.org.



Also, due to the generous support of our sponsors, participants of either event will receive a RARE Care Package, including a RARE on the Road t-shirt and other merchandise. In order to receive a physical RARE Care Package, you must register by **June 1st**. Anyone registering after June 1st, will receive a digital, downloadable RARE Care Package instead. RARE Care packages can only be shipped within the U.S. International participants will receive a digital, downloadable RARE Care Package. T-shirt not included.

How can I update or make a correction to my registration?

To modify your registration:

1. Go to the registration page [here](#) and click the “Already Registered?” button in the top right corner.
2. Enter your email address and confirmation number.
3. Scroll to the bottom of the page and click on the “Modify Registration” button.
4. Make corrections and changes as needed.

Can I transfer my registration to another participant if I can no longer attend?

Yes. If you’d like to transfer your registration to another participant, please send us an email at events@globalgenes.org with your substitution request. In the email, we ask that you provide the following information:

1. The event name
2. Your full name and email address used to register for the event
3. The full name and email address of the person you would like to transfer the registration to

I lost my registration confirmation. How can I have my registration confirmation resent to me?

Please send us an email at events@globalgenes.org to request your registration confirmation details. Be sure to include the following information in your email:

1. The event name
2. The full name and email address used to register for the event



What is the registration cancellation policy for the 2020 RARE on the Road virtual event?

If you would like to cancel your registration, please send us an email events@globalgenes.org. Registration fees are non-refundable.

I registered for a 2020 RARE on the Road in-person event and am unable to attend the new event dates. Can I receive a refund?

If you previously registered for one of our four in-person RARE on the Road events and can no longer attend due to the date change, please send us an email at events@globalgenes.org and we can work to process a refund for you.

Sponsorship Information

Who can I contact for information about sponsorship opportunities for this event?

For information about sponsorship opportunities, please contact our sponsorship team:

- Carol Kennedy – CKennedy@everylifefoundation.org
- Ted Brasfield – tbrasfield@everylifefoundation.org
- Kathy O'Connor – kathyo@globalgenes.org

If you are already a sponsor and have any questions about this newly virtual event, please feel free to reach out to the sponsorship team as well for more details.

Other

My question is not listed here. Whom do I contact?

Please reach out to events@globalgenes.org for additional questions.