

Rare Across America FAQ

Where can I find more information and/or one pagers on the Legislative Asks or other materials?

The recording and slides from the training webinars, one pagers on the three Legislative Asks, and other materials are posted on the website at www.RareAcrossAmerica.org. The three suggested legislative asks for the meetings are to join the Rare Disease Caucus, ***update others***

I am sick/going on vacation/my plans changed. How do I cancel or reschedule my virtual Hill meeting/s?

Meetings will take place on March 3rd and 4th. If you are unable to attend a meeting, please contact Katelyn at klaws@everylifefoundation.org. Please do not contact the Congressional office directly. Most meetings will have more than one person attending so in most cases we will just be telling the office to expect one less attendee.

If you are unable to attend a meeting or multiple meetings, please let us know as soon as possible. No shows for meetings negatively reflect on the rare disease community and RDLA.

Who do I go to with a specific question about policy and/or the legislative asks?

You can email Jamie, our Director of Public Policy, at jsullivan@everylifefoundation.org.

How do I check on the date/time/location of my meeting?

All meetings will be scheduled **the month before the virtual Hill meetings take place**. Once meetings have been scheduled they will be posted on a portal through Advocacy Associates linked to our [website](#). The portal contains all information needed for your virtual meetings including who you will be meeting with, the date and time of the meeting, and the call-in details.

Can additional people (spouse, board members) attend my meeting with me?

Yes, but they must [register](#). If it's past the registration deadline on January 22nd, 2021, please email Katelyn at klaws@everylifefoundation.org with your registration request.

Who else will be in my meetings with me?

Other advocates from your state and district may also attend the same meetings as you. You can find the names of these individuals on the schedule portal and message them through the

portal. In addition, for larger groups a Team Coordinator may be assigned. The Team Coordinator will reach out to the advocates in their group ahead of time and help coordinate the group before their meeting to determine the speaking order and flow of the meeting.

What is a “Team Coordinator”?

A Team Coordinator has been assigned by RDLA to help coordinate all the advocates in a meeting beforehand. Team Coordinators are specifically assigned for meetings with more than five people in the meeting. The coordinator may email everyone before the meeting so everyone can introduce themselves and let the group know which “ask” they plan to make in the meeting. The coordinator may assign everyone an order to introduce themselves and help decide who tells their stories during the meeting especially if there are a lot of attendees for the meeting.

Where can I find a link to the Meeting Feedback Form?

You can access the Meeting Feedback Form on the [Rare Across America website](#).

Will every registrant meet with all their Members of Congress? If they are not is it because what they entered when they registered?

If someone is not registered for a Senate or House meeting, it’s most likely because they chose to only do House or Senate meetings. If you would like to request to be added to your state’s Senate or House meeting, please email Noah at Noah@advocacyassociates.com.

I would like to meet with a Representative or Senator who is NOT from my state. Is this possible?

Rare Across America is an opportunity for individuals to meet with their own Representative or Senators. If you chose to have more than three meetings when you registered, you may meet with other House Representatives from your state.

Will meetings ever not get scheduled? Or can meetings get cancelled?

Advocacy Associates works diligently to schedule all meetings, but confirmation of each meeting depends on the individual offices. Meetings are usually not cancelled, but if they are, we work to reschedule the meetings for the advocates. Please check the Advocacy Associates Platform to see if any scheduling updates have been made.

Will there be any in-person meetings scheduled or will they only be virtual?

All meetings for Rare Across America 2021 will be held virtually. However, we are holding Rare Disease week July 19th- 22nd and all meetings will be held in person on Capitol Hill. To learn more about Rare Disease Week 2021, click [here](#).

How do we get staffer emails if we would like to email them before the meeting?

If you would like the staffer's email address before the meeting, you can request it by emailing Noah.

Will groups be able to log on a few minutes early to get situated like they would in person?

Advocacy Associates provides the conference lines for all the meetings unless the Congressional office insists on using their own. The conference line Advocacy Associates provides will be accessible to attendees before the meetings. However, if any offices provide their own conference lines, then attendees will have to wait until the host (staffer) starts the call. If this is the case, it will be noted clearly on your online schedules. Otherwise, all conference lines are provided by Advocacy Associates.

I am new to advocacy and have never met with my Senators or Representative before? What should I do to prepare?

Rare Disease Legislative Advocates provides training webinars for those who are new to advocacy or who would like to brush up on their advocacy skills before their meetings. You do not need to prepare for these trainings. Simply register for them with the links on the Rare Across America website and be sure to save each date! If you have any questions, please email Katelyn at klaws@everylifefoundation.org.

Will there be a translator during House and Senate meetings for Spanish speakers?

If you are a Spanish speaker, please let us know before your meetings that you will require a translator and we will work to provide a translator for your meeting. All training webinars/briefings associated with Rare Across America will be equipped with Spanish closed captioning, as well as other languages.