

## RARE Meet-Ups FAQ



The RARE Patient Impact Grant Program was created with the goal of making a tangible difference in the lives of rare disease patients and caregivers in the United States. As an exclusive funding opportunity for members of Global Genes RARE Foundation Alliance, these grants provide the opportunity for organizations to make a positive impact on patient communities in need. Five awards will be granted. Each awardee is expected to host one, three to four hour meet-up.

**Together, we are united in supporting the needs of rare disease.**

### **1. Who is eligible to apply?**

Eligible applicants include support groups and nonprofit organizations that focus on rare disease and are based and accredited in the United States. Eligible organizations must also be a member of the Global Genes RARE Foundation Alliance.

Unfortunately, Global Genes will not be accepting internationally based foundation applications at this time. The goal is for this grant program to be opened up to international organizations in future funding rounds.

### **2. How do I apply?**

The link to the application can be found [here](#).

### **3. What is the definition of a rare disease for the 2022 RARE Meet-Up RARE Impact Grant?**

Global Genes uses the [National Institutes of Health](#) definition of a rare disease, which is one that affects fewer than 200,000 people in the U.S.

### **4. How do we register our foundation to be a RARE Foundation Alliance member?**

To register your foundation, please go to: <https://globalgenes.org/foundation-alliance/>.

Once registration is submitted, you are considered a RARE Foundation Alliance member. Please note, there may be a slight delay between registration submission and your foundation's name appearing on our Foundation Alliance webpage.

## 5. What projects are acceptable?

Accepted projects must focus on rare disease patients and/or caregivers, and be completed by November 2022.

### Projects must fall under one of the following categories:

- Caregiver/Patient Support: Select this category if you are focused on broader patient/caregiver support across the Rare Disease Community, including addressing the local and long-term impacts of COVID.
  - Examples: Program on family support, sibling support, mental health issues, navigating the health care system in your region.
- Scientific Updates and/or Clinical Research: Select this category if you are focused on patient registry, scientific data or clinical trials.
  - Examples:
    - Convening researchers/clinicians/advocates to discuss advances in research in specific diseases or larger disease classifications (ie. neurological conditions);
    - Educating your community about your registry or natural history data.
- Capacity building: Select this category if you are focused on capacity building to expand your organization's work on fundraising, volunteer expansion, community outreach and addressing the local and long-term impacts of COVID.
  - Examples:
    - Creating a program to meet the needs Healthcare services more accessible to your community
- Ultra rare diseases: Select this category if you are focused on ultra rare diseases to increase awareness and/or improve the diagnostic odyssey by early testing.
  - Examples:
    - Clinical guidelines from experts on early detection;
    - Understanding the significance of diagnosis.

## 6. What is the anticipated timeline:

- February 4, 2022 Grant applications due
  
- February 21, 2022 Awardees notified. Later that week, recipients will be publicly announced
  
- March 1, 2022 Begin planning meetings

## **7. What level of liability insurance is required? And is it required for all projects?**

Commercial general liability insurance indemnifying Global Genes is required for all proposed projects. The required liability insurance level, type and additional insured language will be discussed and verified upon award announcement. You must provide appropriate verification to receive funding.

## **8. Can staff salaries be included in the project budget?**

Staff salaries for those that will be supporting a proposed project/program can be included in the project budget, but should not be the majority of the budgetary line items. Administrative costs cannot exceed 50% of the total project/program budget. Budgets submitted with the application will be reviewed to determine appropriateness.

## **9. How will event registration be managed?**

Global Genes is happy to provide some level of support for registration support/management. If you require event registration support/management, please indicate so in your grant application. If you are using your own event registration vendor, please indicate that in your application as well.

As part of the registration process, Global Genes will require all participants to sign a COVID waiver and oblige by our code of conduct.

## **10. How will awards be disseminated?**

Grant awards will be paid 14 business days post award announcement.

No funds can be transferred to a personal bank account. Funds must be transferred to an established bank account in the organization's name. Support groups can use their endorsing institution as the fiscal agent. Please note, to establish a bank account under an organization's name, you may need to apply for a Federal Identification Number.

For questions please contact: [RareGrants@globalgenes.org](mailto:RareGrants@globalgenes.org)