

2022 RARE Meet-Ups Impact Grant

Page 1

Thank you for your interest in applying for the **2022 RARE Meet-Ups Impact Grant**.

RARE meet-ups for 2022 will consist of Five (5), 3-4 hour regional/local **in-person** meetings that will be held between April and November 2022 in partnership with regional/local RARE Foundation Alliance member(s). Please note that each grant awardee will be required to host **one** meet-up. Through our RARE Patient Impact Grant Program, Global Genes will determine and partner with grant awardees to provide marketing support and materials, resources and co-development content.

Grant applications will be accepted until **Friday, February 2, 2022**. Grant recipients will be notified of acceptance by **Monday, February 21, 2022**, and publicly announced later that week.

For more information on this grant opportunity, click [HERE](#).

If you have any questions, please contact us at raregrants@globalgenes.org.

Grant Category

Please select the primary category for your grant application. *

- 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 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 (i.e., 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 make 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.

Please select the secondary category for your grant application.

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 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 (i.e., 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 make 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.

Primary Applicant Contact Information

First Name *

Last Name *

Job Title *

Email Address *

Phone *

Project Manager First Name *

Project Manager Last Name *

This is the person Global Genes will be working with to organize and manage these meet-ups. If the project manager is also your primary applicant, then please enter the same name as above.

Organization Details

Organization Name *

Address *

City *

State *

Postal Code *

Official Charity Number/Tax ID *

Specialties involved in diagnosing and treating the disease: Disease area. Please select the categories that best fit your rare disease(s)? *

- Neurological
- Autoimmune
- Autoimmune disorders
- Congenital malformations - genetic and non-genetic
- Diseases of the blood and bone marrow
- Diseases of the circulatory system
- Diseases of the digestive system, including liver
- Diseases of the eye
- Diseases of the inner ear (hearing, vertigo/dizziness)
- Diseases of the musculoskeletal system and other connective tissue: joint diseases
- Diseases of skin and subcutaneous tissue
- Endocrine disorders
- Kidney Disease
- Reproductive diseases
- Rare/Genetic Epilepsy
- Genetic Susceptibility to Disease
- Immunodeficiency
- Lysosomal Storage Disease
- Metabolic Disorders
- Tumor Disorders, including rare cancers
- Neurodegenerative
- Neurodevelopment
- Neurologic disorders (not in another category listed here)
- Neuromuscular disorders
- Pain disorders
- Respiratory diseases
- Sleep Disorders

Primary Disease(s) or Genetic Condition(s) supported or represented by your organization/ community: *

Please enter the specific name of the disease that your organization works with.

[Next Page](#)

2022 RARE Meet-Ups Impact Grant

Page 2

Patient Community Demographics

Estimated number of people directly affected (patients) in your community *

Please enter demographic information for your patient population below.

Tips:

- Please do not enter the percent sign when inputting values.
- Please input values as whole numbers. For example, if the percent of your patient population that identifies as Native American is 3.8%, you can enter that as 4.
- Percentages in each demographic category must add up to be 100%.

Ethnicity

Percentage (must add up to 100%)

Caucasian

*

Asian

*

Native American

*

Black/African American

*

Hispanic

*

Latino

*

Other (list below)

Percentage (must add up to 100%)

Other

Sum 0

Total % MUST = 100

Primary Language

Percentage (must add up to 100%)

English

*

Spanish

*

Portuguese

*

Hindi

*

Chinese

*

French

*

Other

*

Other

Sum 0

Total % MUST = 100

Gender

Percentages (must add up to 100%)

Female

*

Male

*

Other

*

Percentages (must add up to 100%)

Other

Sum

Total % MUST = 100

U.S. Geographic Region Represented

Percentages (must add up to 100%)

Northeast

*

Mid-Atlantic

*

Southeast

*

Upper Midwest

*

Lower Midwest

*

Northwest

*

Southwest

*

Sum

Total % MUST = 100

Age Range

Percentages (must add up to 100%)

Newborn - 5

*

6 - 17

*

18 - 34

*

35 - 50

*

51+

51+

P () (%)
*

Sum

Total % MUST = 100

[Previous Page](#)

[Next Page](#)

2022 RARE Meet-Ups Impact Grant

Page 3

Organizational Capacity

Organization Annual Income/Revenue *

Please input only the digits for your annual revenue without dollar signs or commas. For example, if your annual revenue is \$5,000, you would input that value as 5000.

How many of your volunteers would be dedicated to this meet-up? *

How many full-time employees would be dedicated to this meet-up? *

How many planning and logistical support team members would be dedicated to this meet-up? *

Please describe your marketing capabilities and assets (e.g., social media, newsletters, etc.). *

Is your organization the only patient advocacy group in your specific disease area? *

Yes No

Proposed Meet-Up Details

Do you have a proposed venue or location for the meet-up? *

Yes No, we need assistance

How many participants do you expect at this meet-up? *

Please select your top two primary target audiences for this meet-up. *

- Patients
- Caregivers
- Patient Advocates
- Researchers
- Healthcare Professionals

Do you have proposed speakers for the meet-up? *

- Yes
- No, we need assistance

What language access services would be helpful for this meet-up?

- Translations
- American Sign Language (ASL)
- Captioning

What are your proposed meet-up dates? *

Please attach a detailed budget to include the following line items:

Administration Fees

Marketing and Communication Fees (Social Media, Prints, Invitations, Email Distribution)

Direct Costs (Audio/Visual, Food/Beverage, Venue Space)

*

Choose File No file chosen

Please provide us with a brief description of the meet-up (500 characters). *

Please attach a proposed agenda for your meet-up.

*

Choose File No file chosen

Meet-Up Goals

Please list your top three goals for the meet-up below.

Goal 1 *

Goal 2 *

Goal 3 *

Please describe any additional support you intend to request from Global Genes for this meet-up (e.g., speaker recruitment, marketing, venue or audio/visual contracting, etc.).

Are you interested in presenting or publishing the outcomes of this meet-up? *

Yes Not sure No

Is there anything else you would like us to know about your community or this proposed event?

I declare that the information included in the above application and declaration is true, and that this application shall form part of the terms and conditions of any grant awarded. (By entering applicant name in the box below) *

[Previous Page](#)

Submit