



2019 RARE Patient Impact Grant Program Frequently Asked Questions

1. WHO IS ELIGIBLE TO APPLY?

Support groups and nonprofit organizations that focus on rare disease and are based in the United States are eligible to apply. Foundations must be a member of the Global Genes RARE Foundation Alliance to be eligible. Support groups ONLY must provide an accompanying endorsement letter signed by a medical professional that is on the organization's letterhead (i.e. the hospital or clinic letterhead) with their application.

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.

If the project or program that is submitted for funding affects local and international individuals, at least half of the funding must benefit rare patients and caregivers from the United States.

2. WHAT IS THE DEFINITION OF A RARE DISEASE FOR THE RARE PATIENT 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.

3. HOW DO WE REGISTER OUR FOUNDATION TO BE A RARE FOUNDATION ALLIANCE PARTNER?

To register your foundation, please go to:

<https://globalgenes.org/foundation-alliance/>.

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

4. HOW DO SUPPORT GROUPS SUBMIT THE REQUIRED MEDICAL PROFESSIONAL ENDORSEMENT LETTER?

Support groups applying for the RARE Patient Impact Grant must provide an endorsement letter signed by a medical professional on the institutional letterhead of the endorsing professional. These letters should be submitted with the Letter of Intent by August 10, 2018 at 11:59 pm PST to qualify. Please use the subject line: Medical Professional Endorsement Letter

5. WHAT TYPE OF MEDICAL PROFESSIONAL?

The medical professional must be connected to the specific disease community and currently in practice. Examples of acceptable medical professionals: Neurologist, Dietician, Nurse, Endocrinologist, Cardiologist, Physical Therapist, etc.



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6. WHAT PROJECTS ARE ACCEPTABLE?

Accepted projects must focus on rare disease patients and/or caregivers, must be completed within 2019, and at least 50 percent of the beneficiaries of the project must be in the United States. The RARE Patient Impact Grant will not fund: 1) research or 2) personal requests.

7. CAN I SUBMIT AN APPLICATION TO MORE THAN ONE CATEGORY?

At this time we are only allowing one application be submitted per foundation. But we invite foundations to submit more than one Letter of Intent for different projects in different categories and if each LOI is approved, a Global Genes staff member will reach out to determine which application the foundation would like to continue on with.

8. 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.

9. 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 **10%** of total project/program budget.

10. WHAT FINANCIALS ARE REQUIRED FOR A 501C (3)? FOR A SUPPORT GROUP?

Please include enough financial history to provide the review committee with a good assessment of your ability to manage funding and a solid understanding of the financial security of the organization or support group. Support groups can use the financial history of their endorsing agency. If your organization does not currently manage funds, you will be not be immediately disqualified. Grant applications will be evaluated on a number of criteria.

11. WHAT IS A CASE STUDY AND CLOSING REPORT?

The case study and closing report is a qualitative and quantitative report and is a reporting requirement for any proposals that are awarded. The case study will help capture the impact of the grant funding in a qualitative way through stories, quotes, patient experience as well as videos and photos. A template will be provided by Global Genes for the closing report which will review the outcomes and lessons learned of the program/project as well as assess and review the program/project budget. These reporting requirements can be used by both Global Genes and the awardee to share successes of the RARE Patient Impact Grant program.

12. FOR APPLICANTS REQUESTING MORE THAN \$10,000, HOW SHOULD THE REQUIRED PRESENTATION SLIDES BE SUBMITTED?



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Applicants applying for more than \$10,000 of grant funding are required to submit a presentation slide deck **with** the application. The presentation slide deck can be a maximum of 10 slides.

Those invited to present will be contacted by a Global Genes staff member to coordinate the date and time. The presentations will take place in December and will last about 20 minutes (10 minutes of applicant presentation and 10 minutes of questions from review committee).

13. HOW WILL AWARDS BE DISSEMINATED?

Grant awards less than \$5,000 will be paid 30 days post award announcement. Grant awards more than \$5,000 will be paid in two installments: 1) \$5,000 will be paid 30 days post award announcement; and 2) remaining balance will be paid three months following the first payment.

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.