



## 2020 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. Global Genes is working on a funding round to support international based organizations intends to offer an international based funding round at the end of 2019 or in early 2020.

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 in 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.

### 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 as one document.

### 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.

### 6. WHAT PROJECTS ARE ACCEPTABLE?

Accepted projects must focus on rare disease patients and/or caregivers, must be completed within 2020, 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.



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

### 9. WHAT FINANCIALS ARE REQUIRED FOR A 501 C (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.

For those applying in the Capacity Building category, this submission may be waived.

### 10. 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.

### 11. WHAT IS THE PRESENTATION ROUND AND HOW SHOULD THE PRESENTATION SLIDES BE SUBMITTED?

Highest scoring applications will be invited to present their proposal to the respective committee. Applicants will be provided further instruction on signing up for a presentation slot, how to submit their presentation and content that should be considered. The submitted presentation will be a maximum of 10 slides. Review the grant guidance to determine when presentations will occur.



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### 12. 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.

### 13. CAN YOU APPLY TO MORE THAN ONE CATEGORY?

Foundations and groups may submit more than one letter of intent to a specific category or submit letters of intent into multiple categories. All submissions will be reviewed. Foundations and groups will be notified if any submissions were accepted to submit a full application, BUT at this time, if more than one letter was approved, the foundation may only move onto the next round with ONE application proposal.

### 14. DO YOU PROVIDE ANY CONSULTATION OR FEEDBACK?

In an effort to better support our community, Global Genes is able to provide feedback and consultation on proposals prior to the Letter of Intent submission deadline.

Feedback may be requested for denied applications ONLY after the 2020 grant round has been completed.

To schedule feedback or consultation, email [raregrants@globalgenes.org](mailto:raregrants@globalgenes.org)