



Global Genes®
Allies in Rare Disease

Global Genes is a leading rare disease advocacy organization with the mission to eliminate the challenges of rare disease.



Established in September 2008, Global Genes is a leading rare disease patient advocacy organization whose mission is to connect, empower and inspire the rare disease community. With international scope, Global Genes develops educational resources, programs, and events that unite patients, advocates and industry experts.

The **RARE Patient Impact Grant Program** is an exclusive funding opportunity for rare patient support groups and RARE Foundation Alliance partner organizations. Global Genes seeks to fund projects that will make a tangible difference in the lives of rare patients and caregivers in the United States.

For more information, please visit the **RARE Patient Impact Grant Program** landing page: www.globalgenes.org/raregrant.

KEY DATES

2019 RARE Patient Impact Grant Program Opens	Wednesday, May 1, 2019
2019 RARE Patient Impact Grant Program Application and Q&A Webinar*	Thursday, May 30, 2019 10 a.m. PT/1 p.m. ET
Letter of Intent Deadline	Wednesday, July 3, 2019 11:59 p.m. PT
All Applicants Notified of Letter of Intent Status	Wednesday, July 24, 2019
Full Applications Due <i>(for accepted Letters of Intent only)</i>	Friday, August 23, 2019 11:59 p.m. PT
Final Applications Reviewed by Grant Committee	August – October 2019
Applicants Notified of Presentation Status	Monday, October 21, 2019
RARE Patient Impact Grant Presentations	Monday, November 4, 2019 – Friday, November 8, 2019
All Awardees Notified <i>(Awardee phone calls to be scheduled from November 18 to November 22, 2019)</i>	Friday, November 15, 2019
Awardees Announced Publicly	December 2019

**Webinar will be taped and made available on grant website for individuals unable to participate.*

ELIGIBILITY CRITERIA

To be considered for a grant, applicants and proposed projects must meet the following criteria:

1. Applicant must be a registered 501c(3) or a not-for-profit support group.

We recognize that it is not always possible for groups that support patients and families affected by a rare disease to have an established nonprofit organization. This may be because there are too few people in the U.S. affected by the disease or because a support group is in the earlier stages of development. Global Genes will accept applications from support groups working on behalf of patients and families affected by a rare disease, if they are endorsed by a medical professional with recognized expertise in the disorder. A letter from the medical professional with their signature on institutional letterhead must be submitted with the Letter of Intent and the full application (this can be the same letter).

All 501c(3) organizations and support groups must be members of the RARE Foundation Alliance prior to the application deadline to be considered. Information on how to join can be found here: <https://globalgenes.org/foundation-alliance/>

2. Applicants must be based in the United States.

This current funding round is for U.S. based organizations ONLY with at least half of the project's funding benefiting rare patients and caregivers in the United States. Global Genes is working on a funding round to support international based organizations and intends to offer an international based funding round at the end of 2019 or in early 2020.

3. Applicants cannot be current 2019 awardees.

2018 awardees are eligible to apply.

4. Proposed projects must impact patients and families affected by a rare disease and be achievable within 2020.

Global Genes can only accept one application per organization per year. If you are not selected this year, you are encouraged to apply in the future. Rare disease is defined in the United States as a prevalence of less than 200,000 people. Diseases or disorders that do not meet this definition are not eligible. At least half of the project's funding must benefit rare patients and caregivers in the United States.

SELECTION CRITERIA

- **Impactful:** Project demonstrates reach and depth of impact to rare patients/caregivers.
- **Achievable:** Project is time sensitive and achievable within 2020 calendar year.
- **Tangible:** Project and results demonstrate real, identifiable change that can be/are repeatable in the community.
- **Scalable:** Project can be scaled in the future or repeated by other rare communities.

PROJECT CATEGORIES AND FUNDING

Global Genes aims to foster innovation within the rare community but also recognizes that there is still a dire need for simple and consistent support and educational resources. To achieve both these goals, the 2020 RARE Patient Impact Grant Program will be divided into three funding categories: RARE Innovation, RARE Support and RARE Capacity Building. These categories have separate funding allocations and applications will be reviewed separately. It should be noted that the grant review committee may decide to award either partial or complete funding of the requested amount. The final dollar amount available for the 2020 RARE Patient Impact Grant Program may fluctuate as new donations are made to support the program.

1. RARE Innovation (max. request is \$15,000)

The RARE innovation category is designated for projects that craft **unique** ways to support the rare community by establishing projects that meet the general rare disease population, can be applied to other disease communities or advance science and technology applicable to the community. These applications will be evaluated based on the same basic criteria with an emphasis on **scalability**. The results and learnings from these projects can be applied to other disease communities and can be scaled so that impact is potentially far reaching. *Example projects: phone apps, 3-D printing, conference CEU establishment.*

2. RARE Support (max. request is \$15,000. If requesting travel support, max. request is \$5,000)

The RARE Support category is designed for projects that help organizations directly serve existing communities through service and support, by providing funding to expand a foundation's capacity to help the basic needs of their patient communities that would not be possible without the support of these funds. ****Foundations may apply for grant funding to support travel stipends/scholarships but may only request a maximum of \$5,000.** *Example projects: Webinar series, equipment lending program, adding music therapy to a conference.*

3. RARE Capacity Building (max. request is \$10,000)

The RARE Capacity Building category is designed for organizational capacity support. The funding will support building and/or sustaining organizations or patient communities. This category will support disease specific community groups looking to establish as a 501(c)(3) or support newly established 501(c)(3) organizations by funding organizational infrastructure needs. ****Funded programs will receive additional technical and training support from Global Genes to support their efforts.** *Example projects: organizational planning meeting, creation of website, strategies to find and build community, establishment of non-profit.*

THE GRANT PROCESS

Step 1:

Read through this Guidance, paying careful attention to the type of organization and activities we fund. Please note that we cannot consider applications that fail to meet **all** of our eligibility criteria.

Step 2:

Register for 2020 RARE Patient Impact Grant Program FAQ Webinar at www.globalgenes.org/raregrant and submit all grant questions to raregrants@globalgenes.org in advance of the webinar (Thursday, May 30, 2019 at 10 am PT).

Step 3:

Review and complete the Letter of Intent guidance included as Appendix B. Letters of Intent must be submitted electronically through the portal on www.globalgenes.org/raregrant by Wednesday, July 3, 2019 at 11:59 p.m. PT.

Step 4:

If your Letter of Intent does not result in an invitation to submit a full application, please consider applying again next year.

If your Letter of Intent is accepted, you will receive an email with a link to submit your full 2020 RARE Patient Impact Grant application. A template of the application can be found online at www.globalgenes.org/raregrant. Please note that your application will **NOT** be considered if 1) you do not receive approval of your Letter of Intent from Global Genes and/or 2) the application is incomplete by the grant deadline of Friday, August 23, 2019 by 11:59 p.m. PT. It is recommended that you first answer grant application questions in a word document so that you will not lose any answers in case of technology malfunctions.

Step 5:

Selected applicants from all three categories will be invited to present their project to their respective committee. Foundations may select up to two representatives to present. Presentations (**no more than 10 slides total**) will be requested upon acceptance into presentation round.

SELECTED AWARDEES

All awardees will be notified by Friday, November 15, 2019 and will be asked to schedule grant contract calls with Global Genes for the next week. This will allow contracts to be executed as close to the beginning of 2020 as possible. Grants of \$5,000 or less will be paid in full. Grants of \$5,000 or more will be paid in two installments: an initial payment of \$5,000 and the balance three (3) months following the first payment. Please note that we are unable to transfer monies to an individual's bank account. Newly established support groups must ensure that a bank account is set up in the group's name before funds can be transferred.

Support and Innovation grant awardees, will have to provide proof of liability insurance coverage and put in place policies to ensure that patient advocates, children, and organizations involved are protected.

In an effort to highlight the work our grant awardees are doing in the community, awardees will receive one (1) free registration and travel scholarship per organization for the Global Genes 2020 Patient Advocacy Summit. We encourage all of our grantees to join us at our annual summit. Awardees will also have the opportunity to present a poster about their funded project or program at our Summit. If unable to attend, a poster may still be submitted for display.

GRANT REPORTING REQUIREMENTS

Below is a general outline of reporting requirements for applicants that are selected for funding. These reporting requirements and additional guidance will be shared with awardees upon receipt of grant. This section is intended to provide potential applicants an understanding of obligations associated with the funding announcement.

Grant Funding Level	Selected Grantees will:
\$100 - \$5,000	<ul style="list-style-type: none"> • Display the “RARE Foundation Alliance Member” badge on nonprofit website and communications • Provide two (2) case studies that capture project stories and/or successes, include photos and/or video of project • Acknowledge Global Genes as the source of funding for the project in any marketing or promotional materials related to funded project including the Global Genes logo and boilerplate language • Complete an End of Grant Report within three (3) months of the project ending • Capacity Building grantees will provide monthly summary reports
\$5,000 - \$10,000	<ul style="list-style-type: none"> • Display the “RARE Foundation Alliance Member” badge on nonprofit website and communications • Provide two (3) case studies that capture project stories and/or successes, include photos and/or video of project • Acknowledge Global Genes as the source of funding for the project in any marketing or promotional materials related to funded project including the Global Genes logo and boilerplate language • Complete an End of Grant Report within three (3) months of the project ending • Capacity Building grantees will provide monthly summary reports
\$10,000 - \$15,000	<ul style="list-style-type: none"> • Display the “RARE Foundation Alliance Member” badge on nonprofit website and communications • Provide four (4) case studies that capture project stories and/or successes, include photos and/or video of project • Acknowledge Global Genes as the source of funding for the project in any marketing or promotional materials related to funded project including the Global Genes logo and boilerplate language • Complete an End of Grant Report within three (3) months of the project ending • Capacity Building grantees will provide monthly summary reports

APPENDIX A STANDARD TERMS AND CONDITIONS

1. GENERAL

Definitions:

Grant means all monies given by Global Genes to the recipient in accordance with these Standard Terms and Conditions and no other monies whatsoever;

The “Primary Contact Person” shall have the meaning given in clause 2(l);

The “Project” refers to the project or activities as detailed in the grant application form attached to these Terms and Conditions;

The “Recipient” means the organization specified in the letter from Global Genes confirming the award of the Patient Impact Grant and shall, where appropriate, include reference to authorized employees and agents of the Recipient.

2. OBLIGATIONS OF THE RECIPIENT

(a) The Grant must be used exclusively for the Project. The Recipient may use up to ten percent of the Grant for administration costs incurred by it including, but not limited to selecting, monitoring, auditing, and reporting on the Project.

(b) No material change to the Project or its implementation may be made without the prior written consent of Global Genes, such consent not to be unreasonably withheld or delayed.

(c) The Grant will not be increased if there is an overspend on the Project.

(d) The Grant must be shown in the Recipient’s annual accounts as a restricted fund and not included under general funds. This means that the unspent funds and/or assets with respect to this Grant must be shown separately in the Recipient’s account.

(e) The use of any underspend accumulated within a twelve-month period of the Grant must be agreed upon by Global Genes and for the reason of the stated purpose within the grant application. If at the end of the Project the Recipient has spent less than the full grant, then the unspent amount must be returned to Global Genes promptly.

(f) The Recipient must not, without prior written agreement of Global Genes, change its constitution as regards to its purposes, payments to members of its governing body, distribution of its assets (whether on a dissolution or not) or admission of members (where it has a membership).

However, such dates are estimates only and time shall not be of the essence for payment of the Grant. Global Genes will not accept liability, of any nature, for any losses or costs (whether foreseeable or not) arising from any failure to make any Grant payments on any agreed date or otherwise. If the Recipient is in breach of any of these Standard Terms and Conditions, or goes into insolvent liquidation, or has a receiver appointed over its assets or any part thereof, or makes any composition with its creditors, Global Genes may refuse to pay any further Grant payments due.

(g) Global Genes expects to make Grant payments in accordance with the timeframe set out in the Grant Program Guidance for Applicants document.

(h) The Recipient shall comply with all applicable laws and regulations whether or not related to the Project. In particular, the Recipient shall comply with applicable legal requirements relating to the collection, use, safe-keeping and distribution of personal data and to disclose the charitable status of Global Genes and the Recipient in fundraising or publicity material.

(i) For the duration of the agreement reflected in these Standard Terms and Conditions, the Recipient will do nothing that would or may bring Global Genes into disrepute or which may damage the goodwill attached to the Global Genes brand or its distinctiveness.

(j) In all publicity relating the Project, the Recipient will ensure that it states as a minimum “Our thanks to Global Genes for funding of this project”.

(k) The Recipient agrees that Global Genes may use its name and logo in any publicity material for any similar future appeals.

(l) The Recipient will ensure that the Primary Contact Person named in the grant application is easily contactable and responds adequately and in reasonable time to all reasonable requests made by Global Genes. The Recipient will promptly notify Global Genes of any change in the identity of and/or contact details for the Primary Contact Person.

APPENDIX A

STANDARD TERMS AND CONDITIONS (CONTINUED)

(m) The Recipient agrees to share Global Genes' educational tools and resources to its members and supporters.

n) The Recipient agrees to keep confidential all information that it receives about Global Genes, other than information that is in the public domain or intended for use in marketing that the Recipient possesses before applying for the Grant.

(o) The Recipient will immediately upon receipt pass any and all donations that were intended for the benefit of Global Genes directly to Global Genes. This includes any details in its possession relating to the donor together with any Gift Aid declaration made by them.

(p) The recipient shall comply with the relevant requirements of the grant reporting requirements and contract terms that is part of the 2020 Grant Program Guidance for Applicants and available at www.globalgenes.org/RAREgrants.

(q) Failure to meet reporting requirements and/or failure to complete project/program within the contracted time agreement may jeopardize future funding opportunities.

3. GLOBAL GENES NAME AND LOGO

(a) Subject to clause 3(c) below, the Recipient may use the Global Genes name and logo, but only in connection with the Grant.

(b) The Recipient will not acquire any other rights to use the Global Genes name and logo, and it must not allow any third parties to use them.

(c) Global Genes may revoke the Recipient's permission to use the Global Genes name and logo immediately by notifying the Recipient in writing if the Recipient is in material breach of any of these Terms and Conditions. If Global Genes does so, the Recipient must immediately stop all use of the Global Genes name and logo.

4. MONITORING AND EVALUATION

(a) The Recipient must keep proper and up-to-date accounts and records, including invoices, which show how the Grant has been used. These financial records must be copied to Global Genes on request and be available to Global Genes or its representative for inspection and copying.

(b) The Recipient must inform Global Genes of any adverse changes in its finances or reputation, which could affect its obligations toward Global Genes.

(c) The Recipient must take steps to monitor the success of the Project and complete an End of Grant Report that will be available on the Global Genes website.

(d) The Recipient will provide a copy of its annual accounts within 10 months after the end of the financial year in which Grant payments are made. The Recipient must meet any relevant statutory requirements regarding accounts, audit or examination of accounts, annual reports and annual returns.

5. DURATION OF THE GRANT AGREEMENT

(a) These Terms and Conditions will (unless the context or express provisions otherwise indicate) prevail and remain in force as follows:

- (i) For the period of one year following payments of the last installment of Grant Funds;
- (ii) For the period that any Grant funds remain unspent; and
- (iii) For the period that any of the Terms and Conditions of these Standard Terms and Conditions remains unperformed or any breach of the same continues.

(b) Global Genes may continue to use the personal data relating to the Primary Contact Person and any volunteers who assist with Global Genes in accordance with the Grant Collaboration Framework set out in the application pack, to contact and inform such individuals about future appeals. The Recipient will ensure that it has any authorization required to allow Global Genes to use the data this way.

6. INTERPRETATION

These Standard Terms and Conditions and any dispute or claim arising out of or in connection with them or their subject matter or formation (including non-contractual disputes or claims), shall be governed by, and construed in accordance with the law and the parties irrevocably submit to the exclusive jurisdiction of the courts.

APPENDIX B LETTER OF INTENT GUIDELINES

All Letters of Intent must be submitted through the online portal found at www.globalgenes.org/raregrants. The letter may be no more than two pages in length and must be submitted by Wednesday, July 3, 2019 at 11:59 p.m. PT or it will not be included for review and evaluation.

The following information must be stated clearly at the top of your submission; failure to do so will result in an incomplete submission:

Organization Name	
Rare Disease(s) Supported	
Tax ID #	
Contact Name	
Contact Title	
Contact Email	
Contact Phone Number	
Grant Category	
Amount Requested	

In the narrative of your letter, please include an organization introduction, the need of your community, scope of your organization's proposed project, and the anticipated community impact. Be sure to include specific details and numbers whenever possible, this may include but is not limited to: credentials of the team best equipped to implement activity, general description of funding needs, statistics as to why this proposal will resolve the need, potential outcomes you hope to achieve, details of evaluation, existing collaborations and partnership, etc.

All submissions will be evaluated based on the same selection criteria as the full grant application: 1) Impactful, 2) Achievable, 3) Tangible, and 4) Scalable.

We hope that this Guidance ensures that the application process for the **2020 RARE Patient Impact Grant Program** is straightforward and transparent. If you have questions about the **RARE Patient Impact Grant Program** or the application process, please email raregrants@globalgenes.org. We welcome any suggestions that you may have regarding the current grant program and application process.

Global Genes – Allies in Rare Disease
World Headquarters
28 Argonaut - Suite 150
Aliso Viejo, CA 92656

RAREgrants@globalgenes.org
www.globalgenes.org/raregrants

*Global Genes is a national 501c3 nonprofit charity.
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