



Global Genes is a leading rare disease patient advocacy organization whose mission is to connect, empower and inspire the rare disease community



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 information on past grant recipients and additional information about the open funding opportunities, please visit the **RARE Patient Impact Grant Program** landing page: www.globalgenes.org/RAREgrants.

KEY DATES

| | |
|--|---|
| 2019 RARE Patient Impact Grant Program Opens | Friday, June 1, 2018 |
| 2019 RARE Patient Impact Grant Program Application and Q&A Webinar* | Tuesday, June 26, 2018 10 a.m. PT/1 p.m. ET |
| Letter of Intent Due for RARE Innovation; RARE Support; and RARE Travel Support | Friday, August 10, 2018 11:59 p.m. PT |
| All Applicants Notified of Letter of Intent Status | Monday, August 20, 2018 |
| Full Applications Due for RARE Innovation; RARE Support; and RARE Travel Support <i>(for accepted Letters of Intent only)</i> | Friday, September 14, 2018 11:59 p.m. PT |
| Final Applications Reviewed by Grant Committee | September – November 2018 |
| RARE Support and Innovation Applicants Notified of Presentation Status | Monday, November 12, 2018 |
| RARE Support and Innovation Presentations | Monday, December 3, 2018 – Wednesday, December 5, 2018 |
| All Awardees Notified <i>(Awardee phone calls to be scheduled from December 17 to December 20, 2018)</i> | Monday, December 10, 2018 |
| Awardees Announced | Wednesday, January 16, 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). Additionally, support groups will be required to have a fiscal sponsor with nonprofit status. Information regarding a support group's fiscal sponsor will be submitted in the full application when regarding finances.

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/>

2. Applicants must be based in the United States.

The goal is for this grant program to be opened up to international organizations in future funding rounds but unfortunately this cannot be accommodated at this time. At least half of the project's funding must benefit rare patients and caregivers in the United States.

3. Applicants cannot be current 2018 awardees.

2017 awardees are eligible for 2019 funding.

4. Proposed projects must impact patients and families affected by a rare disease and be achievable within 2019.

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 2018 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 2019 RARE Patient Impact Grant Program will be divided into three funding categories: RARE Innovation, RARE Support and RARE Travel Support. These categories have separate funding allocations and applications will be reviewed separately. Applicants may request up to \$15,000 in RARE Innovation and RARE Support; and up to \$5,000 in RARE Travel Support. 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 2019 RARE Patient Impact Grant Program may fluctuate as new donations are made to support the program.

1. RARE Innovation (Max. \$15,000)

This category is designated for projects that push the envelope and aim to craft **unique** ways to raise awareness, educate, collaborate, and/or support the rare community. These applications will be evaluated based on the same basic criteria with an emphasis on innovation and **scalability**. Ideally, 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.

2. RARE Support (Max. \$15,000)

The RARE Support category is designed for projects that help organizations serve the basic needs of their patient communities including, but not limited to, conference activities, educational materials (newly diagnosed packets, webinars, etc.), and connection and support. Even though this category is carved out for projects that serve the rare community in basic ways, these funds are not intended to supplement conference, event, and/or project budgets. The funds are intended to help expand the capacity of an organization to fill a specific need that would not be possible without the support of these funds. For example, an organization could apply so that daycare could be provided at their conference for the first time or expanded to fill the unmet requests from previous years. They would not be able to apply simply for the conference itself.

3. RARE Travel Support (Max. \$5,000)

The RARE Travel Support category is designed to support the growing need in our community to help patients attend their disease specific conferences. Foundations may apply for this funding to allocate to their community as travel conference scholarships.

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 the 2019 RARE Patient Impact Grant Program FAQ Webinar on Tuesday, June 26, 2018 at 10:00am PT at www.globalgenes.org/RAREgrants and you can submit all grant questions in advance to raregrants@globalgenes.org.

Step 3:

Review and complete the Letter of Intent guidance that is found at the end of this document in Appendix B. Letters of Intent must be submitted electronically through the portal on www.globalgenes.org/raregrants by Friday, August 10, 2018 at 11:59 p.m. PT. Applicants may submit more than one letter of intent, but only one application may continue in the grant process. If you submit more than one letter of intent, and all are approved, a staff member will reach out to determine which project/program the foundation would like to apply for.

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 you are a recipient of an accepted Letter of Intent, please complete the 2019 RARE Patient Impact Grant Application Form online at www.globalgenes.org/raregrants. Please note that your application will **NOT** be considered if 1) you do not receive approval of your Letter of Intent from Global Genes, 2) the application is incomplete, or 3) required attachments are not provided before the grant deadline of Friday, September 14, 2018 by 11:59 p.m. PT. It is recommended that you first answer grant applications in a word document so that you will not lose any answers in case of technology malfunctions.

Step 5:

If you are a RARE Innovation or RARE Support applicant requesting over \$10,000 and are invited to present to the grant review committee, select one or two representatives to present. Please note, presentation slides (**no more than 10 slides total**) are due at time of the application. **(Only applications over \$10,000 need to submit a presentation)**

Slides should include but not limited to: introduction to project or program, timeline, budget, potential challenges and solutions, metrics and evaluation, impact on community (specific disease and/or rare disease).

SELECTED AWARDEES

All awardees will be notified by Monday, December 10, 2018 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 2019 as possible. Grants of \$5,000 or less will be paid in full. Grants of more than \$5,000 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, as a result, support groups will need to have a fiscal sponsor with nonprofit status along with their medical endorsement.

If your support group or nonprofit is awarded a grant, you 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 2019 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 showing purposes.

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 |
| \$5,001 - \$10,000 | <ul style="list-style-type: none"> • Display the “RARE Foundation Alliance Member” badge on nonprofit website and communications • Provide three (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 |
| \$10,001 - \$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 |

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 administrative costs incurred 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 to 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 2019 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, be completed in an 11 pt, Times New Roman font, and submitted by Friday, August 10, 2018 at 11:59 p.m. PT or it will not be included for review and evaluation.

You will be required to submit the following information:

| | |
|---------------------------|--|
| Organization Name | |
| Rare Disease(s) Supported | |
| Tax ID # | |
| Contact Name | |
| Contact Title | |
| Contact Email | |
| Contact Phone Number | |

In the narrative of your letter, please describe the need and scope of your organization's proposed project and the anticipated impact. Be sure to include numbers and specific details whenever possible. Your Letter of Intent 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 **2019 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.

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

*Global Genes is a national 501c3 nonprofit charity.
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