



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 develops educational tools and resources to help patient advocates become well-equipped activists for their disease.

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. This program is supported by proceeds from Global Genes' annual Denim Dash, Tribute to Champions of Hope and generous individual donors. To learn more about these events, please visit: www.globalgenes.org

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

2017 RARE Patient Impact Grant Program Opens	Monday, July 18 th , 2016
2017 RARE Patient Impact Grant Program <i>Application and Q&A Webinar</i>	Wednesday, July 27 th , 2016 10 a.m. PT/1 p.m. ET*
Letter of Intent Due for RARE Innovation and RARE Support	Friday, August 12 th , 2016 11:59 p.m. PT
All Applicants Notified of Letter of Intent Status	Monday, August 22 nd , 2016
Full Applications Due for RARE Innovation and RARE Support (<i>for accepted Letters of Intent only</i>)	Monday, September 19 th , 2016 11:59 p.m. PT
Final Applications Reviewed by Grant Committee	October – November 2016
RARE Innovation Applicants Notified of Presentation Status	Monday, November 28 th , 2016 – Friday, December 1, 2016
RARE Innovation Presentations	Monday, December 5 th , 2016 – Friday, December 9 th , 2016
All Awardees Notified	Monday, December 19 th , 2016
Awardees Announced Publically	Monday, January 9 th , 2017

**Webinar will be taped and made available on grant website if you aren't able to attend.*

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 those supporting 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 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 can't be accommodated at this time. At least half of the project's funding must benefit rare patients and caregivers from the United States.

3. Applicants cannot be current 2016 awardees.

2016 awardees will be eligible in 2018 funding rounds.

4. Proposed projects must impact patients and families affected by a rare disease and be achievable within 2017.

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 don't meet this definition are not eligible. At least half of the project's funding must benefit rare patients and caregivers from the United States.

SELECTION CRITERIA

- **Innovative:** Project provides creative support and/or results in unique resources, events, or programs and tackle a specific challenge(s) within your rare disease community.
- **Impactful:** Project demonstrates reach and depth of impact to rare patients/caregivers.
- **Achievable:** Project is time sensitive and achievable within 2017 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 2017 RARE Patient Impact Grant Program will be divided into two funding categories with \$75,000 available in each category (\$150,000 total). These categories will 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 2017 RARE Patient Impact Grant Program may fluctuate as new donations are made to support the program.

1. RARE Innovation

This category will be designated for projects that push the envelope and aim to craft unique ways to raise awareness, educate, collaborate and/or support the rare community. There will be approximately 5 awardees funded in this category at a max award of \$15,000 each. 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

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 and scholarships, 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 very simplistic 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.

There will be up to 15 awardees funded in this category at a max award of \$5,000 each. These applications will be evaluated based on the same basic criteria with the addition of innovation and scalability.

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 2017 RARE Patient Impact Grant Program – Application and Q&A Webinar at www.globalgenes.org/RAREgrants and submit all grant questions to raregrants@globalgenes.org in advance of the webinar (Wednesday, July 27, 2016 at 10 am PT).

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 12th, 2016 at 11:59 p.m. PT.

Step 4:

Upon recipient of accepted Letter of Intent, please complete the 2017 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, 3) required attachments are not provided before the grant deadline of Monday, September 19th, 2016 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:

For the RARE Innovation applicants 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.

SELECTED AWARDEES

All awardees will be notified by Monday, December 12, 2016 and will be asked to schedule grant contract calls with Global Genes that week. This will allow contracts to be executed as close to the beginning of 2017 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.

If your support group or nonprofit is awarded a grant for a project involving off site excursions, events or travel, 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. This information will be provided at time of grant award. In many cases, the event location has insurance coverage that extends to participants.

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 • Provide photos and/or video of project • Acknowledge Global Genes as the source of funding for the project in any marketing or promotional material related to funded project including Global Genes’ logo and templated language • Complete an End of Grant Report within three (3) months of the project ending
\$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 • Provide photos and/or video of project • Acknowledge Global Genes as the source of funding for the project in any marketing or promotional material related to funded project including Global Genes’ logo and templated 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(I);

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. But 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 back 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 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 2017 Grant Program Guidance for Applicants and available at www.globalgenes.org/RAREgrants.

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 Recipients 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 towards 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 can be no more than two pages in length, 11 pt font, Times New Roman and submitted by Friday, August 12 at 11:59 p.m. PT or else will not be included for review and evaluation.

Below is the information that you will be required to submit:

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 same selection criteria as the full grant application: 1) Innovative 2) Impactful 3) Achievable 4) Tangible and 5) Scalable.

We hope that this Guidance ensures that the application process for the **2017 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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