Founded in 2008, Global Genes® is a 501(c)(3) nonprofit organization that connects, empowers, and inspires the rare disease community, with the ultimate goal of eliminating the burdens of rare disease for patients and families everywhere. We provide hope for the more than 400 million people affected by rare disease around the globe. We fulfill our mission by helping patients find and build communities, gain access to information and resources, connect to researchers, clinicians, industry, government and other stakeholders, share data and experiences, and stand up, stand out and become effective advocates on their own behalf.

The 2020 Continuity of Care RARE Patient Impact Grant is an exclusive funding opportunity for rare patient support groups, RARE Foundation Alliance partner organizations and patients and caregivers. Global Genes seeks to fund projects that will make a tangible difference in the lives of rare disease patients and caregivers in the United States.
## KEY DATES

<table>
<thead>
<tr>
<th>Event</th>
<th>Date/Details</th>
</tr>
</thead>
<tbody>
<tr>
<td>Program Opens</td>
<td>Thursday, April 23, 2020</td>
</tr>
<tr>
<td>Completed Applications Due</td>
<td>Ongoing during remainder of 2020</td>
</tr>
<tr>
<td>Applications Reviewed by Grant Committee</td>
<td>Ongoing during remainder of 2020</td>
</tr>
<tr>
<td>Applicants Notified of Awards</td>
<td>Ongoing during remainder of 2020</td>
</tr>
<tr>
<td>Applicants will be notified by phone/email within two (2) weeks of submission of grant application</td>
<td></td>
</tr>
<tr>
<td>Outcomes Reporting Due</td>
<td>Within 30 days of project completion or Dec 15, 2020 (whichever sooner)</td>
</tr>
<tr>
<td>2020 Awardee Outcomes Announced Publicly</td>
<td>Early 2021</td>
</tr>
</tbody>
</table>
ELIGIBILITY CRITERIA

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

1. **Applicant must be a registered 501(c)(3) or a nonprofit 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 designation. 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.

   All 501(c)(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/](https://globalgenes.org/foundation-alliance/)

2. **Applicants must be based in the United States.**
   This current funding round is for United States-based organizations only with project funding benefiting rare patients and caregivers in the United States and its territories. Global Genes is working on a future funding round to support international based organizations.

3. **Proposed projects must impact patients and families affected by a rare disease and be delivered in 2020.**
   Global Genes recognizes the unprecedented situation with COVID-19 and has modified the RARE Patient Impact Grant to directly provide resources supporting the urgent needs of patient families. **We will accept multiple applications per organization during the COVID-19 pandemic.** If you are not selected, 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.
SELECTION CRITERIA

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

PROJECT CATEGORIES AND FUNDING

Global Genes aims to foster innovation within the rare disease community but also recognizes that there is a dire need for basic assistance that has been amplified due to the COVID-19 pandemic. The 2020 Continuity of Care RARE Patient Impact Grant program will be focused on rare disease aid. It should be noted that the grant review committee may decide to award either partial or complete funding of the requested amount. The funds available for the 2020 Continuity of Care RARE Patient Impact Grant program may fluctuate as new donations are made to support the program and so repeat applications will be accepted.

**Continuity of Care** (up to a maximum request of $20,000)

The Continuity of Care category is designed to assist patient households during the COVID-19 crisis. This category will support disease-specific community groups with an existing 501(c)(3) or established disease-specific support groups by providing direct financial aid relief to these organizations for distribution. Support may be distributed in maximum increments of up to $2,500 per household. Examples include telehealth psychosocial counseling services, special education and distance learning teachers, homeschooling tools and resources, and career counseling services.
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:
Review and complete the online application and submit electronically via the Global Genes website www.globalgenes.org/raregrant. 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 3:
Regardless as to if your grant is accepted or declined, you will receive a response by phone or email from Global Genes within two (2) weeks of submission. If you are notified as an awardee, your funds will be released approximately one (1) week after approval.

Step 4:
Commence award project.

You will be required to keep records during the grant process and provide outcomes reporting to Global Genes on or before the end of the 2020 calendar year.

SELECTED Awardees

All awardees will be notified on a rolling basis and will be asked to complete grant contracts with Global Genes following award notification.

Please note that we are unable to transfer monies to an individual's bank account for foundations and support groups. Support groups must ensure that a bank account is set up in the group's name before funds can be transferred.

In an effort to highlight the work our grant awardees are doing in the community, awardees will be asked to complete outcomes reporting for each award given. Failure to provide reporting will result in funds needing to be refunded to Global Genes.

Awardees will have the opportunity to present a poster about their funded project or program at our next annual RARE Patient Advocacy Summit.
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 the grant. This section is intended to provide potential applicants with an understanding of obligations associated with the funding announcement.

<table>
<thead>
<tr>
<th>Grant Funding Level</th>
<th>Selected Grantees will:</th>
</tr>
</thead>
</table>
| Up to $20,000       | ● Display the “RARE Foundation Alliance Member” badge on nonprofit website and communications  
                     ● Provide two to four (2-4) case studies that capture project stories and/or successes, include photos and/or video of the project if possible  
                     ● Acknowledge Global Genes as the source of funding for the project in any marketing or promotional materials  
                     ● Complete an End of Grant Outcomes Report within 30 days of the project completion or December 15, 2020, whichever comes first |
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 six (6%) 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. If outcomes reporting is not provided to Global Genes by December 15th of given year of grant, the recipient will be expected to repay the grant in full.

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.

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

(g) 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.

(h) 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”.

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

(j) 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.
(k) The Recipient agrees to share Global Genes’ educational tools and resources to its members and supporters.

(l) 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.

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

(n) 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 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.

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.

(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 on or before deadline due.

(d) Upon request, 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.

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 California law and the parties irrevocably submit to the exclusive jurisdiction of the courts.