2023 Health Equity in RARE Impact Grant

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Thank you for your interest in applying for the 2023 Health Equity in RARE Impact Grant.

To ensure Global Genes is able to address any technical issues you may have with the grant application, please submit your materials as early as possible. If you do run into a technical issue, it is important that you contact us at rare.grants@globalgenes.org immediately.

Note: If you're having trouble loading or submitting the application, please clear your cookies/cache and try a new browser. For more on how to do this, click here.

Looking for grant writing resources before starting the application?
Below is a list of free resources you might find helpful.

- Grant Writing 101: Global Genes Lunch & Learn
- Free Grant Readiness Workbook
- Free Online Grant Writing Class
- Writing a Grant Proposal 101
- Top 20 Grant Writing Classes
- Grammarly, Free Online Writing Assistant

STOP! Before you begin the application, please note:

Global Advocacy Alliance (GAA) membership is a requirement to receive grant funding.

If you are not currently a Global Advocacy Alliance member, you have until **12:00 PM EST on Friday, April 7, 2023** to become a member.

To become a Global Advocacy Alliance member, click here.

If you have any questions, please email global.advocacy.alliance@globalgenes.org

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About the Grant

Falling under the Global Genes larger Health Equity Initiative, the Health Equity in RARE Impact Grant program provides an opportunity for patient advocacy leaders to improve outreach strategies and address challenges that affect underserved and underrepresented patient communities. This grant will be awarded to 8 - 10 Global Advocacy Alliance members who are interested in expanding their knowledge, education, and awareness efforts to build a more inclusive, equitable, and accessible rare disease community. It will give foundation leaders and patient advocates the ability to stand up data collection tools, resources, and processes to better engage or understand the needs of their underserved communities, ultimately leading to more robust data sets for their rare disease, established standards of diagnosis and care, and a more comprehensive understanding of their disease and patient journey. Projects may address health inequities including but not limited to race, ethnicity, age, gender identity, ability, religion, socioeconomic status (income, level of education, and occupation), geographic location and/or linguistic barriers.

As an exclusive funding opportunity for rare patient organizations that are a part of the Global Advocacy Alliance, this grant provides patient advocacy leaders with the opportunity to make a tangible difference in the lives of rare disease patients and caregivers across the globe.

Here is the tentative timeline:
- **March 6:** Grant opens (application live)
- **April 7:** Grant closes (application closed) at **12:00pm EST**
- **April 12 - April 28:** Review Period
- **Week of May 1:** Awardees notified
- **May 10:** Required Awardee Kickoff Call - **mark your calendar!**
- **June 7:** Last day to make changes to your proposed project. Note, all changes must be approved by Global Genes.
- **November 1:** All project materials and evaluation reports due

If you have any questions, please contact us at **rare.grants@globalgenes.org**.

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2023 Health Equity in RARE Impact Grant Pre-Application Required Reading:

Please ensure you review the information carefully, as it is required for this grant opportunity and will increase the success of your application.

To ensure fairness and transparency, Global Genes has implemented this Conflict of Interest policy for grants given by the organization. *Please review the Conflict of Interest Policy here. If you have questions or concerns, please email us at rare.grants@globalgenes.org*

1. **Who is eligible to apply?**

   Eligible applicants include registered charity or nonprofit organizations that focus on rare disease. Organizations must have a **valid tax ID number** and be a **member of the Global Advocacy Alliance**.

   Both international and US-based organizations are eligible to apply.

2. **How does my organization become a member of the Global Advocacy Alliance?**

   To register your organization, please click **HERE**.

   Once registration is submitted, you are considered a Global Advocacy Alliance member.

3. **What should I do if I can't load or submit the application?**

   If you're having trouble loading the application, please clear your cookies/cache and try a new browser. For more on how to do this, click here.

   If your issue persists, please contact us at **rare.grants@globalgenes.org**.

4. **What is the definition of a rare disease for this grant?**

   The definition of rare diseases and disorders varies from country to country. In the United States, rare diseases and disorders are those which affect fewer than 200,000 individuals living in the United States.

   For international consideration, please refer to the Global Genes RARE list.

5. **What projects will be accepted?**

   Proposed projects must meet the requirements of one of the below categories and address challenges that affect underserved and underrepresented populations in the rare disease community.

- Education - Select this category if your proposed project is focused on developing an educational tool or educational materials to address the unmet needs of your underserved community based on the social determinants of health. For example, education on the way your identified disease state uniquely affects your minoritized / underserved patient community, a toolkit/web content addressing a specific cultural barrier your patient population faces in seeking care and treatment, a resource guide or awareness campaign about rare disease, diagnostic testing and/or the importance of participating in clinical trials and research for your identified underrepresented patient community.

- Outreach - Select this category if your proposed project is focused on developing an outreach strategy to address the unmet needs of your underserved community based on the social determinants of health. For example, a workshop or support group to discuss medical gaslighting or the experience of implicit bias in health care, adding a peer-to-peer support network, developing a relationship and working with community leaders to build trust within your identified underrepresented / underserved population.

- Research - Select this category if your proposed project is focused on developing / furthering research to address the unmet needs of your underserved community based on the social determinants of health. For example, evaluation of internal organizational structure and practices as it pertains to diversity, equity, inclusion, and accessibility, hosting a roundtable discussion, interviews or small working groups with community members from underserved / underrepresented backgrounds to better understand their needs based on their intersectional identity.

  Note: There will be a limited number of translational grants awarded so we encourage you to think about other ways you can address the challenges faced by underserved / underrepresented populations in your patient community.

6. **When does my project need to be completed?**

   All projects must be completed on or before **November 1, 2023.**

   All evaluation reports are to be submitted to Global Genes by **November 1, 2023.**

7. **What is the maximum amount of funding an organization can receive through this grant?**

   Organizations are eligible to receive up to $15,000 in funding through this grant opportunity.

   Organizations with annual revenue of less than $30,000 are eligible to receive up to 50% of their annual revenue in funding. For example, if your annual revenue is $14,000, your organization is only eligible to receive up to $7,000 in grant funding.

8. **What are the review criteria?**

All applications will be reviewed by a team of internal Global Genes reviewers and external members of Global Genes' Health Equity Council.

Stage 1: Screening Stage
During stage 1 of the review process, all applications will be reviewed on the project description, budget and agenda submitted using the criteria below. Note, only a portion of applications will move on to stage 2.

Stage 1 Review Criteria:
- ***Strength of the Project Description***. How well does the project description convey the need for the project, the focus, target audience and proposed impact.
- ***Grant Category.*** How well does the proposed project fit into the identified grant category?
- ***Budget.*** Does the budget include all of the identified line items? Does the budget include where Global Genes funding will be used/allocated?

Stage 2: Full Review & Final Decision
During stage 2 of the review process, all remaining applications will be reviewed in the entirety using the criteria below.

- ***Strength of the Project Description***. How well does the project description convey the need for the project, the focus, target audience and proposed impact.
- ***Grant Category***. How well does the proposed project fit into the identified grant category?
- ***Budget.*** Does the budget include all of the identified line items? Does the budget include where Global Genes funding will be used/allocated?
- ***SMART Goals.*** Does the application include three SMART (specific, measurable, attainable, realistic, and time bound) goals? How well do the goals adhere to the SMART criteria?
- ***Achievement of SMART Goals.*** How well does the goal summary describe how the proposed goals will be achieved?
- ***Inclusion, Equity and Access.*** How clear and strong are the applicant's plans to make their project as inclusive, equitable and accessible as possible to their target community?
- ***Impact.*** How well does the described impact align with the outlined project goals? How likely is it that the described project will drive significant, long-term impact on the target community?

9. **What is the anticipated timeline?**
- **March 6:** Grant opens (application live)
- **April 7:** Grant closes (application closed) at **12:00pm EST**
- **April 12 - April 28:** Review Period
- **Week of May 1:** Awardees notified
- **May 10:** Required Awardee Kickoff Call - **mark your calendar!**
- **June 7:** Last day to make changes to your proposed project. Note, all changes must be approved by Global Genes.

- **November 1:** All project materials and evaluation reports due

  Note: this is a tentative schedule and timing is subject to change.

10. **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.

11. **How will awards be disseminated?**

    A portion of the grant award will be paid to awardees within 30 days of attendance at the awardee kick-off call. The remaining portion of the grant award will be paid to awardees following an internal review of the final evaluation report. Please note, we reserve the right to withhold the final payment if the final evaluation report does not meet the standards.

    All funds will be distributed in US dollars.

    No funds can be transferred to a personal bank account. Funds must be transferred to an established bank account in the organization's name. Please note, in the US, to establish a bank account under an organization's name, you may need to apply for a Federal Identification Number.

    Global Genes reserves the right to retract the initial payment if we learn the awardee did not fulfill the project requirements.

For questions please contact: rare.grants@globalgenes.org

I acknowledge that I have read the Conflict of Interest policy. Please enter your name below: **[open text box]***

I acknowledge that I have completed the required Pre-Application Required Reading and understand the requirements of this grant. Please enter your name below: **[open text box]***

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Please select your organization using the drop down list below.

[drop down]

If you're not currently a member of the GAA or do not see your organization listed above, please type in your organization name.

REMINDER.

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To become a Global Advocacy Alliance member, click here.

If you have any questions, please email global.advocacy.alliance@globalgenes.org

Grant Category:

Please select the primary category for your grant application. **[single select]***
- <u>Education</u> - Select this category if your proposed project is focused on developing an educational tool or educational materials to address the unmet needs of your underserved community based on the <u>social determinants of health</u>. For example, education on the way your identified disease state uniquely affects your minoritized / underserved patient community, a toolkit/web content addressing a specific cultural barrier your patient population faces in seeking care and treatment, a resource guide or awareness campaign about rare disease, diagnostic testing and/or the importance of participating in clinical trials and research for your identified underrepresented patient community.

- <u>Outreach</u> - Select this category if your proposed project is focused on developing an outreach strategy to address the unmet needs of your underserved community based on the <u>social determinants of health</u>. For example, a workshop or support group to discuss medical gaslighting or the experience of implicit bias in health care, adding a peer-to-peer support network, developing a relationship and working with community leaders to build trust within your identified underrepresented / underserved population.

- <u>Research</u> - Select this category if your proposed project is focused on developing / furthering research to address the unmet needs of your underserved community based on the <u>social determinants of health</u>. For example, evaluation of internal organizational structure and practices as it pertains to diversity, equity, inclusion, and accessibility, hosting a roundtable discussion, interviews or small working groups with community members from underserved / underrepresented backgrounds to better understand their needs based on their intersectional identity.

  Note: There will be a limited number of translational grants awarded so we encourage you to think about other ways you can address the challenges faced by underserved / underrepresented populations in your patient community.

Contact Information:
If any pre-populated data below is incorrect, please update it accordingly.
Note, applicant and project manager contact information may be the same.

<u>Applicant Contact</u>
- First Name **[open text box]***
- Last Name **[open text box]***
- Job Title **[open text box]***
- Email Address **[open text box]***
- Phone **[open text box]***

<u>Project Manager Contact</u>

This is the person Global Genes will be working with to organize and manage the proposed project. If the project manager is also your primary applicant, then please enter the same information as above.

- First Name **[open text box]***
- Last Name **[open text box]***
- Job Title **[open text box]***
- Email Address **[open text box]***
- Phone **[open text box]***

Organization Details:
Organization Name **[open text box]***
Country **[open text box]***
Address **[open text box]***
City **[open text box]***
State/Province **[open text box]***
Postal Code **[open text box]***

EIN/Official Charity Number/Tax ID (input N/A if you do not have one) **[open text box]***

If you do not have an EIN or Tax ID, please upload documentation that demonstrates your organization's nonprofit status. **[upload button]**

What is your organization's annual revenue? **[open text box]***
Please enter the value without a dollar sign, commas or decimals. For example, an annual revenue of $50,123.50 should be entered as 50124.

Diseases:

What diseases/disease areas does your organization support or represent? Please select as many as apply. **[multi-select]***

Does your organization serve diseases not captured above (e.g., CACNA1A-related disorders)? If so, please enter them here. **[open text box]**

Does your organization primarily support or represent an ultra-rare disease? **[single-select]***
- Yes
- No
- Not sure
  - Please explain **[open text box]***

Referral Source:
How did you hear about this grant opportunity? Select all that apply. **[multi-select]***
- Global Genes Social Media
- Global Genes Newsletter
- Global Genes Website
- Another Organization
- A Peer

- A Medical Provider
- Other
  - Please explain **[open text box]***

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Please enter demographic information for the specific population you are targeting with this grant funded project. If you don't have this information, please use demographic data from peer-reviewed or scientific literature to complete this section. Note, this information will not be used to assess your application and is for internal use only.

Tips:
- Please do not enter the percent sign when inputting values.
- Please input values as whole numbers. For example, if the percent of your patient population that identifies as Native American is 3.8%, you can enter that as 4.
- Percentages in each demographic category must add up to be 100%.

Ethnicity and Race
Percentage (must add up to 100%)
- **Hispanic / Latino/a/x / Spanish Origin [open text box]***
- **Non-Hispanic / Latino/a/x / Spanish Origin [open text box]***

Percentage (must add up to 100%)
- **American Indian or Alaska Native [open text box]***
- **Asian [open text box]***
- **Black or African American [open text box]***
- **Middle Eastern or North African [open text box]***
- **Native Hawaiian or Pacific Islander [open text box]***
- **White [open text box]***
- **Other (list below) [open text box]***
- **Please list any other ethnicities not fully described by the above categories [open text box]**

Gender
Percentage (must add up to 100%)
- **Female/woman/girl [open text box]***
- **Male/man/boy [open text box]***
- **Nonbinary, genderqueer, or not exclusively female or male [open text box]***
- **Transgender female/woman/girl [open text box]***
- **Transgender male/man/boy [open text box]***
- **Other (list below) [open text box]***
- **Please list any other genders not fully described by the above categories [open text box]**

Age Range
Percentages (must add up to 100%)
- **Newborn - 5 years [open text box]***
- **6-17 years [open text box]***
- **18-34 years [open text box]***
- **35-50 years [open text box]***

- **51+ years [open text box]***

How did you decide on the target audience for your proposed project? For example, the target audience represents the overall makeup of your community, the target audience is a sub-group within the overall community, etc. (100 words max) **[short answer text box]***

Grant Specific Questions:

Stage 1 Screening Questions:

Project Description: Please provide a description of your proposed project, including the need for the project, the focus, target audience and proposed impact. (300 words max) **[short answer text box]***

Proposed Budget: Please attach a proposed budget in US dollars for your proposed project.
Note, all budgets must include the following line items: Administrative Fees, Marketing and Communication Fees (ex. social media, prints, invitations, email distribution, scholarships/stipends), Direct Costs. If you don't plan to incur costs in one of the above line items, please explain.

All budgets must also indicate where Global Genes funds will be used/allocated.

Need assistance crafting a budget? A sample can be found here.

Stage 2 Review Questions:

What is the total amount (USD) you are requesting for this grant? Please enter a whole number. [open text box]*

How many individuals do you expect to be impacted by this proposed project? [number text box]*

Please explain the goals of this proposed project. *Note, goals should be SMART (specific, measurable, attainable, realistic and time bound). For more information on how to develop SMART goals, reference* **this resource**.

- *Goal 1:* **[open text box]***
- *Goal 2:* **[open text box]***
- *Goal 3:* **[open text box]***

Please provide a detailed summary of the activities you will complete to accomplish the goals identified above. This includes the tasks you will need to accomplish in order to develop and implement a successful grant funded project. (250 words max) **[short answer box]***

The challenges faced by underserved and underrepresented populations may differ greatly across patient communities. We invite you to discuss the ways you plan to ensure your project is inclusive, equitable and accessible to all members within your target audience(s).
For definitions of the terms inclusive, equitable and accessible, please refer to this document:
https://diversity.uiowa.edu/resources/dei-definitions.

- **How do you plan to ensure your project is inclusive of as many people within your target audience(s) as possible?** *For example, how do you plan to ensure members of your target audience feel respected, have a sense of belonging, and are able to participate and achieve their full potential.* (75 words max) **[short answer box]***

- **How do you plan to ensure your project is equitable?** *For example, if you're providing a travel stipend for participants to attend a support group, is the amount of money a participant receives based on how far away from the support group the participant lives (equity) and not just a set amount for all participants (equality)?* (75 words max) **[short answer box]***

- **How do you plan to ensure your project is accessible to as many people within our target audience(s) as possible?** *For example, what considerations are you making around language, literacy level (reading level), audio/visual impairment, internet access, etc. For a definition of equity, <u>click here</u>.* (75 words max) **[short answer box]***

Please describe how you anticipate your educational, research or outreach program to impact your community in the short-term and in the long-term. For example, improved understanding of the underserved/underrepresented population's needs. (250 words max) **[short answer box]***

How do you plan on measuring the short and long-term outcomes of this project? (100 words max) **[short answer box]***

Is there anything else you would like us to know about your community or this proposed project? [open text box]

Global Genes seeks to make its grant application review process inclusive and equitable. Therefore, we invite you to describe any challenges you faced in compiling this application. These may include but not be limited to language barriers, time challenges, limited staff, lack of grant writing experience, etc. Please know that disclosing any challenges will NOT negatively impact your chance of acquiring the grant award, but rather provide us additional context with which to review your application. [open text box]

Would you be willing to present your findings at a Global Genes event or with the Global Genes community? [Yes/No]*
- Yes
- No

Would you be comfortable with Global Genes sharing the outputs of this project with the larger Global Advocacy Alliance community for their benefit/use? *Note, any use of outputs from this project would be credited to your organization.* **[Yes/No]***
- Yes
- No

I certify that my organization is a member of the Global Advocacy Alliance. [Yes/No]

- Yes
- No

==*If no…==
I understand that I have until 12:00pm EST on April 7, 2023 to submit an application for the Global Advocacy Alliance. Please enter your name below: **[By entering applicant name in the box below]***

I declare that the information included in the above application and declaration is true, and that this application shall form part of the terms and conditions of any grant awarded.

Please enter your name below: **[By entering applicant name in the box below]***

[submit button]