

2022 Health Equity in RARE Patient Impact Grant

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Thank you for your interest in applying for the 2022 Health Equity in RARE Patient Impact Grant. If you're having trouble loading or submitting the application please clear your cookies/cache and try a new browser.

STOP! Before you begin the application, please note:

Existing Foundation Alliance members and new organizations must apply for the Global Advocacy Alliance in order to be considered for this grant. Any organization who has not applied for the Global Advocacy Alliance by 11:59 pm EST on June 15, 2022 will not be considered for this grant. Please click [HERE](#) to apply if you have not applied yet.

If you were a Foundation Alliance member and have not joined the Global Advocacy Alliance, access to grant eligibility, event discounts, Global Genes Partners, Initiatives, or Tools to assist your organization with your goals and needs ended on March 21, 2022.

If you're not sure if you're a member of the GAA, please email us at raregrants@globalgenes.org

About the Grant

Falling under the Global Genes larger Health Equity Initiative, the Health Equity in RARE Patient 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 members who are interested in expanding their outreach, education, and awareness efforts supporting cultural competency. 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, religion, socioeconomic status (income, level of education, and occupation), geographic location and/or linguistic barriers. Outcomes may include the development of research, tools, resources, and programs that provide guidance and assistance to rare disease patients and their families.

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.

Grant applications will be accepted until **11:59 pm EST on June 15, 2022**. Grant applicants will be notified of award status the **week of July 11** and awardees will be publicly announced soon thereafter.

If you have any questions, please contact us at raregrants@globalgenes.org.

2022 Health Equity in RARE Patient Impact Grant Pre-Reading:

Review of the pre-reading information is a requirement of this application. Please ensure you review the information carefully, as it is pertinent to this grant opportunity and the success of your application.

Together, we are united in supporting the needs of rare disease patients and their families.

1. Who is eligible to apply?

Eligible applicants include registered charity/nonprofit organizations (501c3) that focus on rare disease. Eligible organizations must be a member of the Global Advocacy Alliance. Both US and international organizations are eligible to apply for this grant.

Note: If you were a Foundation Alliance member, you are still required to join the Global Advocacy Alliance to receive access to grant eligibility, event discounts, Global Genes Partners, Initiatives or Tools to assist your organization with your goals and needs.

If you're not sure if you're a member of the GAA, please email us at raregrants@globalgenes.org

2. How do we register our foundation to become a Global Advocacy Alliance member?

To register your foundation, please go to: <https://globalgenes.org/global-advocacy-alliance/>

Once registration is submitted, you are considered a Global Advocacy Alliance member. Please note, there will be a slight delay between registration submission and your foundation's name appearing on our Global Advocacy Alliance webpage.

***Important:** If you were a Foundation Alliance member, you are still required to join the Global Advocacy Alliance to receive access to grant eligibility, event discounts, Global Genes Partners, Initiatives or Tools to assist your organization with your goals and needs.

3. How do I apply for this grant?

The link to the application can be found [here](#).

4. 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.

5. What is the definition of a rare disease for the 2022 RARE Health Equity Patient Impact Grant?

Global Genes uses the [National Institutes of Health](#) definition of a rare disease, which is one that affects fewer than 200,000 people in the U.S.

6. What projects will be accepted?

Accepted projects must focus on underserved and underrepresented rare disease patient communities, including but not limited to race, ethnicity, age, gender identity, religion, socioeconomic status (income, level of education, and occupation), geographic location and/or linguistic barriers. All projects must be completed by October 18, 2022.

Accepted projects include research, tools, resources and programs that provide guidance, education and assistance for underserved and underrepresented patient communities due to health inequities that may impede access to diagnosis, therapy and disease management.

- **Underserved populations** are ones that are disadvantaged in relation to other groups because of structural/societal obstacles and disparities.
- **Underrepresented** describes any subset of a population that holds a smaller percentage within a significant subgroup than it holds in the general population. For example, women and women of color are often an underrepresented group in science, technology, engineering, and mathematics.

Projects may fall into one of three categories:

- **Education** - Developing, updating and distributing educational resources for the underserved and underrepresented patient community about rare disease, diagnostic testing and/or the importance of participating in clinical trials and research.
 - *Examples include: Translating existing materials into other languages (including infographics, toolkits, one pagers, website etc.), updating language to be more inclusive and/or an appropriate literacy level. Developing toolkits, awareness campaigns, infographics, one pagers etc. for a targeted patient population*
- **Research** - Understanding cultural sensitivities of the underserved and underrepresented patient community regarding rare disease, diagnostic testing and/or the importance of participating in clinical trials
 - *Examples include: 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.*

- **Outreach** - Expanding patient community through awareness and outreach efforts intended to widen the demographics of the patients we serve to be more inclusive and / representative.
 - *Examples include: Virtual Workshops, social media campaigns, networking. Rebranding website, social accounts and/or print materials to be more representative and inclusive.*

If you're not sure which category your project fits into, or if your project fits within the parameters of this grant opportunity, please reach out to us at RareGrants@globalgenes.org

7. When does my project need to be completed?

Final projects need to be completed and submitted to Global Genes by October 18, 2022 at 5:00pm EST.

The outcomes report needs to be completed and submitted to Global Genes by October 25, 2022 at 5:00pm EST.

For any grantees interested in sharing their project via a poster at the 2022 Health Equity Summit in Atlanta, GA, posters must be completed and submitted to Global Genes by November 02, 2022. Additional guidelines/information to be provided. You will have the opportunity to indicate interest within the application.

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

Organizations are eligible to receive up to \$15,000 or 50% of their annual revenue in funding through this grant opportunity.

9. 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. Administrative costs cannot exceed 10% of the total project/program budget. Budgets submitted with the application will be reviewed to determine appropriateness.

10. What are the review criteria?

All applications will be reviewed by a team of reviewers.

Review Criteria:

- **Strength of the statement of need.**
 - Does your application adequately describe the type(s) of health equity and disparity challenges faced by your specific community?
 - Does your application adequately describe the extent of the health equity and disparity challenges faced by your specific community?

***Note:** If you're doing research, the strength of your statement of need will be evaluated on how well you present the lack of research/data on your topic.

- **Clearly defined underrepresented or underserved community.**
 - Do you clearly define what “underserved” or “underrepresented” means in your patient population?
 - Do you clearly define who your target population is for your proposed project?
- **Addressing the identified need/problem.**
 - How well does your proposed project address the statement of need (types and extent of the challenges)?
- **SMART Goals.**
 - Does the application include three SMART (specific, measurable attainable, realistic and time bound) goals?

*A smart goal is one that is specific, measurable, attainable, realistic and time-bound. For

help developing SMART goals, use [this resource](#).

- **Achievement of Goals.**
 - Are the proposed milestones thorough and descriptive, and do they clearly describe how the project goals will be achieved?
 - Is the timeline and plan of action reasonable within the grant time frame?
- **Budget.**
 - Does the budget clearly outline how funds from this grant will be allocated and utilized with specific line items?
 - Are administrative costs (eg., staffing) within 10% of the total project/program budget?
- **Outcomes- Final Product.**
 - Does the final educational tool/resource, research or program described relate to the project description and goals.
- **Impact.**
 - How well do you illustrate how your project will drive significant long-term health equity impact in your target community.
 - Does that impact align with the goals you outlined?

11. What is the anticipated timeline:

Your projects will kick off the week of July 18th. As part of receiving the grants, at least one member from your organization will be expected to attend three virtual capacity building workshops. Attendance at these workshops is required to receive your grant funding.

- June 15, 2022 at 11:59pm EST: Grant Applications Close
- Week of July 11- 15, 2022: Awardees Notified/ Announced; All Others Notified
- August 4, 2022: Workshop 1 - Identifying / defining your underserved or underrepresented patient population

- September 1, 2022: Workshop 2 - Understanding Cultural Competencies
- October 6, 2022: Workshop 3 - Embracing new ways of communication: how to reach those you're not reaching
- October 18, 2022 at 5:00pm EST: Final Project Due
- October 25, 2022: Final outcome reports due by 5:00pm EST
- Health Equity Summit poster and presentation will be discussed upon receipt of the grant.

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

12. How will awards be disseminated?

A portion of the grant award will be paid to awardees 14 business days after all required paperwork has been submitted. The remaining portion of the grant award will be paid to awardees following the receipt of the final outcomes report and attendance at all three of the required workshops.

No funds can be transferred to a personal bank account. Funds must be transferred to an established bank account in the organization's name. Support groups can use their endorsing institution as the fiscal agent. Please note, to establish a bank account under an organization's name, you may need to apply for a Federal Identification Number.

For questions please contact: RareGrants@globalgenes.org

Required Field:

I acknowledge that I have completed the required Pre-Reading and understand the requirements of this grant.

(By entering applicant name in the box below)

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All required fields

Primary Applicant Contact Information

- First Name
- Last Name
- Job Title
- Email Address
- Phone

Organization Details

*Please ensure this matches the organization name you entered on your Global Advocacy Alliance application **EXACTLY**.*

- Organization Name
- Country
- Address
- City
- State/Province
- Postal Code
- EIN/Official Charity Number/Tax ID (input N/A if you do not have one)
- If you do not have an EIN or Tax ID, please upload documentation that demonstrates your organization's nonprofit status.
- What is your organization's annual revenue?
 - 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.
- Please select the categories that best fit your rare disease(s).
 - Neurological
 - Autoimmune
 - Autoimmune disorders
 - Congenital malformations - genetic and non-genetic
 - Diseases of the blood and bone marrow
 - Diseases of the circulatory system
 - Diseases of the digestive system, including liver
 - Diseases of the eye
 - Diseases of the inner ear (hearing, vertigo/dizziness)
 - Diseases of the musculoskeletal system and other connective tissue: joint diseases
 - Diseases of skin and subcutaneous tissue
 - Endocrine disorders
 - Kidney Disease
 - Reproductive diseases
 - Rare/Genetic Epilepsy
 - Genetic Susceptibility to Disease
 - Immunodeficiency

- Lysosomal Storage Disease
 - Metabolic Disorders
 - Tumor Disorders, including rare cancers
 - Neurodegenerative
 - Neurodevelopment
 - Neurologic disorders (not in another category listed here)
 - Neuromuscular disorders
 - Pain disorders
 - Respiratory diseases
 - Sleep Disorders

- Primary Disease(s) or Genetic Condition(s) supported or represented by your organization/ community: (open text box)
 - Please enter the specific name of the disease that your organization works with.

- How did you hear about this grant opportunity?
 - Global Genes Social Media
 - Global Genes Newsletter
 - Global Genes Website
 - Another Organization
 - A Peer
 - A Medical Provider
 - Other (open text box)

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All required fields.

Patient Community Demographics

Please enter demographic information for the specific population you are targeting with this grant funded project.

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%.

Population Size

Estimated number of people in your community this project will directly affect. (open text box)

Ethnicity

Percentage (must add up to 100%)

- Hispanic/Latino/Spanish Origin
- Non-hispanic/Latino/Spanish Origin

Percentage (must add up to 100%)

- Indigenous, or Alaska Native
- Asian
- Black or African American
- Middle Eastern
- Native Hawaiian or Other Pacific Islander
- White
- Other (list below)
- Prefer not to disclose

All number box fields

Please list other ethnicities. (open text box)

SumTotal % MUST = 100

Primary Language

Percentage (must add up to 100%)

- English
- Spanish
- Portuguese
- Hindi
- Mandarin
- French
- Other (list below)

All number box fields

Please enter other languages. (open text box)

SumTotal % MUST = 100

Gender

Percentages (must add up to 100%)

- Female
- Male
- Non-binary
- Other (list below)

All number box fields

Please enter other genders. (open text box)

SumTotal % MUST = 100

U.S. Geographic Area Represented

Percentages (must add up to 100%)

- Northeast
- Mid-Atlantic
- Southeast
- Upper Midwest
- Lower Midwest
- Northwest
- Southwest

All number box fields

SumTotal % MUST = 100

International Regions Represented:

If applicable, please identify the geographic regions within your country that your grant funded project will target.

Age Range

Percentages (must add up to 100%)

- Newborn - 5
- 6-17
- 18-34
- 35-50
- 51+

SumTotal % MUST = 100

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Grant Category

- Please select the primary category for your grant application.
 - Education - Developing, updating and distributing educational resources to our underserved and underrepresented patient community about rare disease. diagnostic testing and/or the importance of participating in clinical trials and research.
 - Examples include:* Translating existing materials into other languages (including infographics, toolkits, one pagers, website etc.), updating language to be more inclusive and/or an appropriate literacy level. Developing toolkits, infographics, one pagers etc. for a targeted patient population.
 - Research - Understanding cultural sensitivities of our underserved and underrepresented patient community regarding rare disease, diagnostic testing and/or the importance of participating in clinical trials.
 - Examples include:* 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.
 - Outreach - Expanding patient community through awareness and outreach efforts intended to widen the demographics of the patients we serve to be more inclusive and / representative.
 - Examples include:* Virtual Workshops, social media campaigns, networking. Rebranding website, social accounts and/or print materials to be more representative and inclusive.

Project Specific Questions - Target Population

1. **How do you define the primary underserved/underrepresented patient community you are targeting with this grant funded project? (multiselect)**
 - By Age
 - By Disability
 - By Ethnicity
 - By Gender
 - By Geography
 - By Linguistic Barriers
 - By Race
 - By Religion
 - By Sexual Orientation
 - By Socioeconomic status (income, level of education, and occupation)
 - Other (list below)

Please enter other defined underserved/underrepresented patient community (open text box)

2. **Is there a secondary underserved/underrepresented patient community you are targeting with your project?**

- Yes
- No

3. **How do you define the secondary underserved/underrepresented patient community you are targeting with this grant funded project?** (conditional if selected yes to above question)

- By Age
- By Disability
- By Ethnicity
- By Gender
- By Geography
- By Linguistic Barriers
- By Race
- By Religion
- By Sexual Orientation
- By Socioeconomic status (income, level of education, and occupation)
- Other (list below)

Please enter other defined underserved/underrepresented patient community

4. **Who is the intended audience for your proposed health equity rare disease project** (please provide percentages, must add up to 100%). *All number box fields*

- Patient ____
- Caregiver__
- Healthcare Professionals ____
- Other (list below)

Please list other intended audience for your proposed health equity project. (open text box)

Statement of Need:

5. **Describe the type(s) of health equity and disparity challenges faced by your target audience.**
(250-500 words open text)

6. Describe the extent of the health equity and disparity challenges faced by your target audience. *(250-500 words open text)*

Project Overview

7. Please provide a brief description of your proposed health equity in rare disease project. Be sure to include your target audience. *(250-500 words open text)*
8. List up to 3 brief goals and/or objectives for the proposed health equity rare disease 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](#).*
 1. *(open text box) (required)*
 2. *(open text box) (optional)*
 3. *(open text box) (optional)*
9. Please provide a set of milestones outlining how you will achieve the goals identified above. This includes the tasks you will need to accomplish to complete the project as well as a timeline for accomplishing these tasks.
 1. *(open text box)*
 2. *(open text box)*
 3. *(open text box)*
10. Please attach a detailed budget to include the following line items (Funding of up to \$15,000 available). *[Attachment]*
 - Administration Fees
 - Marketing and Communication Fees
 - Direct Costs
 - Total amount of funding requested

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Outcomes:

11. Please describe the final educational, research or outreach project you plan to create through this grant funding. *(250-500 words open text)*

12. Please describe how you anticipate your educational, research or outreach program to impact your community in the short-term. For example, improved understanding of the underserved/underrepresented population's needs. *(250-500 words open text)*

13. Please describe the intended long-term impact of this project. For example, the creation of a more diverse, equitable, inclusive and accessible organizational structure. *(250-500 words open text)*

14. How do you plan on measuring the short and long-term impacts of this project? *(250-500 words open text)*

15. Would you be willing to present your findings at a Global Genes event or with the Global Genes community?

- Yes
- No

I certify that I have submitted an application for the Global Advocacy Alliance.

**Note, If you were a Foundation alliance member and have not joined the Global Advocacy Alliance, access to grant eligibility, event discounts, Global Genes Partners, Initiatives or Tools to assist your organization with your goals and needs ended on March 21, 2022.*

- Yes
- No

***If no...**

I understand that I have until 5:00pm EST on June 15, 2022 to submit an application for the Global Advocacy Alliance. (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