2024 RARE Mental Health Impact Grant

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Thank you for your interest in applying for the 2024 RARE Mental Health Impact Grant. 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, <u>click here</u>.

NOTE: This application is not saveable. In order to avoid losing any of your work, we recommend drafting responses to all questions in a word or google document, and inputting them into the application only when you are ready to submit everything. You can view a <u>PDF of the application here</u>.

Looking for grant writing resources before starting the application?

Below is a list of free resources we believe might be helpful.

- Grant Writing 101: Global Genes Lunch & Learn
- Free Grant Readiness Workbook
- Free Online Grant Writing Class
- Writing a Grant Proposal 101
- <u>Top 20 Grant Writing Classes</u>
- 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. You will not be able to submit this application if your organization is not a GAA member. To become a Global Advocacy Alliance member, <u>click here</u>.

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

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About the Grant

The RARE Mental Health Impact grant provides an opportunity for patient advocacy group leaders to improve the health and mental well-being of the rare disease community-including children, siblings, adults, caregivers/care partners and those who are grieving. This grant will be awarded to up to 10 Global Advocacy Alliance members who are interested in creating programs, educational tools/materials and support networks to address unmet mental health and social support needs of their community.

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 **12:00 PM (noon) EST on Wednesday, April 3, 2024**. Grant applicants will be notified of award status the **week of April 29** and awardees publicly announced soon thereafter.

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

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2024 RARE Mental Health Grant Pre-Application Required Reading:

Review of the following 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.

1. Who is eligible to apply?

Eligible applicants include non-governmental organizations, registered charities and 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.

If you have questions regarding your organization's eligibility, please contact us at rare.grants@globalgenes.org.

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

To register your organization, please click **<u>HERE</u>**.

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, <u>click here</u>.

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 small patient populations with fewer than 200,000 individuals.

For international consideration, please refer to the <u>Global Genes RARE list</u>. **Note**, *if your disease is not listed on the Global Genes RARE list, it may be because it was discovered or described too recently to be found using this resource. Inability to find your rare disease on this list does NOT disqualify your organization from applying.*

5. What projects will be accepted?

Proposed projects must meet the requirements of one of the below categories and address unmet mental health and social support needs of the rare disease community,

including but not limited to patients, families, siblings, spouses, caregivers, care partners, etc.

Categories:

- <u>Program:</u> Select this category if your proposed project is focused on developing a program to address the unmet mental health and social support needs of the rare disease community. For example, a meditation program to reduce anxiety, a workshop on navigating life after loss or a series of in person and/or virtual support groups.
- Educational Tools/Materials: Select this category if your proposed project is focused on developing an educational tool or educational materials to address the unmet mental health and social support needs of the rare disease community. For example, how to identify someone/a family in crisis, steps to support someone in crisis, a grief packet/web content, an end-of-life transition packet/web content, etc.
- <u>Support Network:</u> Select this category if your proposed project is focused on enhancing an existing support network to address the unmet mental health and social support needs of the rare disease community. For example, adding a peer-to-peer support component to the network, training a care coordinator, improving the functionality of a resource hotline or developing a list of mental health therapists with experience in rare disease (potentially separated by locale, payment type, etc.) with a guide or resource on how to use the list, collaborating with a short-term consultant/subject matter expert to improve existing work, etc.

Note: This grant will not fund projects that are solely for the salary of a care coordinator or a staff person/contractor to staff a resource hotline.

6. When does my project need to be completed?

All projects must be completed before **October 31, 2024.**

All evaluation reports are to be submitted to Global Genes by October 31, 2024.

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

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

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

8. What are the review criteria?

All applications will be reviewed by a team of internal Global Genes reviewers.

Stage 1: Screening Stage

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.** Is the budget in the provided Global Genes format? Does the budget include all of the identified line items? Does the budget include where Global Genes funding will be used/allocated? Does the budget include line item justifications? How reasonable are the justifications and the associated line item costs?

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? Does the budget include line item justifications?
- **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 4: Grant opens (application live)
- April 3: Grant closes (application closed) at 12:00pm EST (noon)
- April 10-April 26: Review Period
- Week of April 29: Awardees notified
- May 8: Required Awardee Kickoff Call mark your calendar!
- June 3: Last day to make changes to your proposed project. Note, all changes must be approved by Global Genes.
- October 31: 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 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.

Global Advocacy Alliance (GAA) membership is a requirement to receive grant funding. If you do not see your organization's name in the dropdown above, then your organization is not a GAA member. To become a Global Advocacy Alliance member, <u>click here</u>. If you believe your organization is already a GAA member, please email <u>global.advocacy.alliance@globalgenes.org</u>.

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REMINDER: This application is not saveable. In order to avoid losing any of your work, we recommend drafting responses to all questions in a word or google document, and inputting them into the application only when you are ready to submit everything. You can view a PDF of the application here.

Grant Category:

Please select the primary category for your grant application. [single select]*

- <u>Program:</u> Select this category if your proposed project is focused on developing a program to address the unmet mental health and social support needs of the rare disease community. For example, a meditation program to reduce anxiety, a workshop on navigating life after loss or a series of in person and/or virtual support groups.
- <u>Educational Tools/Materials</u>: Select this category if your proposed project is focused on developing an educational tool or educational materials to address the unmet mental health and social support needs of the rare disease community. For example, how to identify someone/a family unit in crisis, steps to support someone in crisis, an end-of-life transition packet, a grief packet, etc.
- <u>Support Network:</u> Select this category if your proposed project is focused on enhancing an existing support network to address the unmet mental health and social support needs of the rare disease community. For example, adding a peer-to-peer support component to the network, training a care coordinator, improving the functionality of a resource hotline or developing a list of mental health therapists with experience in rare disease (potentially separated by locale, payment type, etc.) with a guide or resource on how to use the list, collaborating with a short-term consultant/subject matter expert to improve existing work, etc.

Note: This grant will not fund projects that include hiring a care coordinator or a staff person/contractor to staff a resource hotline.

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.

Applicant Contact

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

Project Manager Contact

This is the person Global Genes will be working with to organize and manage these meet-ups. 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/NGO/charity 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. All values should be entered in US Dollars.*

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.

<u>Tips:</u>

- 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]***

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Grant Specific Questions:

Stage 1 Screening Questions:

<u>Project Description</u>: 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]*

<u>Proposed Budget:</u> Please attach a proposed budget in US dollars for your proposed project. *Note, all budgets must include a budget justification as noted in <u>this example</u>.*

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

The template used in this example can be <u>found here</u>. Use of the template is not required, but is recommended. To use the template, you must make a copy of it. DO NOT request access to edit, as we are unable to grant it.

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

Stage 2 Review Questions:

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<u>this resource</u>.*

- <u>Goal 1:</u> [open text box]*
- Goal 2: [open text box]*
- <u>Goal 3:</u> [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]*

Mental health challenges 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: <u>https://diversity.uiowa.edu/resources/dei-definitions</u>.

• 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]*

Do you have plans to disseminate this work to the larger rare disease community? If so, how? (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 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]