

# 2024 RARE Research Readiness Fellowship

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Thank you for your interest in applying for the 2024 RARE Research Readiness Fellowship. 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](#).

**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 [PDF of the application here](#).

**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, [click here](#).

If you have any questions, please email [global.advocacy.alliance@globalgenes.org](mailto:global.advocacy.alliance@globalgenes.org)

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## About the Fellowship

The RARE Research Readiness Fellowship will provide awardees with **high-touch support and mentorship around research readiness and strategic planning**. The program will include a gap analysis of ongoing and completed research and assistance in developing a prioritization strategy. This will help guide awardees in making impactful decisions regarding their grant awards and community engagement activities. The RARE Research Readiness Fellowship will fund this collaborative work and provide financial support of up to \$2,500 (USD) for awardees to apply to continued work in one of the following areas:

- Development of an RFP (request for proposal) for a specific grant opportunity
- Narrowing their short-term research focus to a project most aligned with the gaps identified in their research readiness
- Expanding their scientific advisory board to include expertise needed to undertake new research paths
- Engaging their patient community to begin or expand standardized data collection or to participate in a natural history study

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

**NOTE:** This is not a traditional funding opportunity through Global Genes. Organizations selected for this fellowship will receive up to \$2,500 (USD) in funding to apply to one of the above mentioned outcomes. Organizations will also receive six months of high touch support and mentorship from Global Genes around research readiness and strategic planning.

Fellowship applications will be accepted until **12:00 PM (noon) EST on Wednesday, April 3, 2024**. Fellowship 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 [rare.grants@globalgenes.org](mailto:rare.grants@globalgenes.org).

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## 2024 RARE Research Readiness 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 fellowship opportunity and the success of your application.

- **Who is eligible to apply?**

There are two eligibility requirements for this fellowship. Please read the information provided **in full**.

Eligibility Criteria #1: Eligible applicants include registered charity, nonprofit, or non government organizations that focus on one or more rare diseases. 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.

Eligibility Criteria #2: This is a program intended to help PAGs toward developing a strategic research plan. Patient Advocacy Groups must be:

- A minimum of one year old (founded in 2022 or before)
- Involved in or intending to become involved in rare disease research
- Able to designate at least two members of the patient advocacy community to work with Global Genes on this work for a minimum of 10 hours in the first month and 5 hours per month thereafter over the 6 month fellowship period. The 10 hours in the first month can be split between the two representatives. **Note**, we acknowledge that many organizations may not have anyone who is truly research-focused. Given this, the two designated individuals do not need to be research-focused or have a research background.
- Able to identify a minimum of five (5) doctors or researchers working on their condition. **Note**, this can include physicians who care for patients as well as laboratory researchers doing any relevant work.

**NOTE:** This is not a program intended for organizations that have a current strategic research plan. This program is not ideal for large, well-established organizations.

- **How do we register our organization to become a Global Advocacy Alliance?**

To register your organization, please click [HERE](#).

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

- **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](mailto:rare.grants@globalgenes.org).

- **What is the definition of a rare disease for this fellowship?**

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 [Global Genes RARE list](#). **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.**

- **When will the work under this fellowship be completed?**

All projects are expected to be completed by November 30, 2024.

Evaluation surveys must be completed by December 10, 2024.

- **What is the maximum amount of funding an organization can receive through this fellowship?**

Organizations are eligible to receive up to \$2,500 (USD) in funding for awardees to apply to continued work in one of the following areas:

- Development of an RFP (request for proposal) for a specific grant opportunity
- Narrowing their short-term research focus to a project most aligned with the gaps identified in their research readiness
- Expanding their scientific advisory board to include expertise needed to undertake new research paths
- Engaging their patient community to begin or expand standardized data collection or to participate in a natural history study

**Note:** *In addition to the \$2,500 (USD) in funding to apply to work following the completion of the Fellowship, organizations will also receive six months of high touch support and mentorship from Global Genes around research readiness and strategic planning—including a gap analysis of ongoing and completed research and assistance in developing a prioritization strategy.*

- **What are the review criteria?**

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

**Stage 1 Review Criteria: Screening:**

During stage 1 of the review process, all applications will be screened using the below eligibility criteria. Note, only a portion of applications will move on to stage 2.

1. ***Established as a registered charity, non-government or nonprofit organization.***
2. ***A member of Global Genes Global Advocacy Alliance***
3. ***Age of organization.***
4. ***Involvement or intention to be involved in rare disease research.***
5. ***Ability to designate at least two members to work with Global Genes on this work***
6. ***Ability to identify a minimum of five (5) doctors or researchers working on their condition.***

### **Stage 2 Review Criteria: Full Review & Final Decision**

During stage 2 of the review process, all remaining applications will be reviewed in the entirety using the criteria below.

- ***Need for a strategic research plan.*** How well does the applicant convey the need for a strategic research plan in their community?
  - ***Research Progress.*** How significantly has progress in this rare disease been slowed by the lack of a clearly prioritized research plan?
  - ***Involvement in Research.*** Has this rare disease group made progress supporting research? Does the group have existing ideas for which research groups to potentially support and/or fund?
  - ***Research By Other Organizations.*** To what extent does the applicant collaborate with other related patient advocacy groups and researchers?
  - ***Focus of the Organization.*** Does the organization have a stated focus on research as part of their mission?
- **What is the anticipated timeline?**
    - **March 4:** Fellowship opens (application live)
    - **April 3:** Fellowship 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!**
    - **November 30, 2024:** All work with Global Genes is expected to be completed
    - **December 10, 2024:** All Statements of Intent must be submitted to Global Genes
    - **December 10, 2024:** All evaluation reports must be completed.

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

- **How will awards be disseminated?**

The grant award will be paid to awardees following the receipt and internal review of a one page statement of intent and final evaluation report no later than 31 January 2025. Please note, we reserve the right to withhold the final payment if the statement of intent is not completed or final 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](mailto:rare.grants@globalgenes.org)

I acknowledge that I have completed the required Pre-Application Required Reading and understand the requirements of this fellowship. 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, [click here](#). If you believe your organization is already a GAA member, please email [global.advocacy.alliance@globalgenes.org](mailto:global.advocacy.alliance@globalgenes.org).

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**REMINDER:**

Before you begin, please remember: This is **not** a traditional funding opportunity through Global Genes. Organizations selected for this fellowship will receive up to \$2,500 (USD) in funding for travel support to attend Week in RARE. Organizations will also receive six months of high touch support and valuable mentorship from Global Genes around research readiness and strategic planning.

**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 [PDF of the application here](#).

**Contact Information:**

*Note, applicant and one primary contact 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]\***

Primary Contacts:

*Please identify the two individuals your organization will dedicate to working on this fellowship. If one of the contacts is also the applicant contact, please enter the same information as above.*

*Primary Contact 1:*

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

*Primary Contact 2:*

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

***If any pre-populated data below is incorrect, please update it accordingly.***

**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? *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.* **[open text box]\***

### **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? If so, please enter them here. **[open text box]**

Does your organization primarily support or represent an ultra-rare disease? Note, an ultra rare disease is defined as a rare disease with a prevalence (or total number of people in a population who have a disease) of less than 1 in 50,000 people. **[single-select]\***

- Yes
- No
- Not sure
  - Please explain **[open text box]\***

### **Referral Source:**

How did you hear about this fellowship opportunity? Please select all that apply. **[multi-select]\***

- Another Patient Advocacy Group
- Family, Friend or Colleague
- Global Genes Email/Newsletter
- Global Genes Event or Conference
- Other Event or Conference
- Global Genes Social Media
- Other Social Media
- Global Genes Website
- RARE Concierge - Patient Services
- RARE Compassion Program (RCP)
- RARE-X Program
- Search Engine (e.g., Google)
- Other
  - Please expand. **[open text box]\***

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**Fellowship Specific Questions:**

**Stage 1: Screening Questions**

**What year was your organization founded?** *Note, organizations must be a minimum of one year old to be eligible for this opportunity.* [year text box]\*

**Is your organization currently involved in or intend to become involved in rare disease research?** [Yes/No]\*

**Are you able to designate at least two members of the patient advocacy community to work with Global Genes on this work?** *Reminder, representatives must be able to commit a minimum of 10 hours in the first month and 5 hours per month thereafter over the 6 month fellowship period. The 10 hours in the first month can be split between the two representatives.* [Yes/No]\*

**Please identify a minimum of five (5) doctors or researchers working on their condition.** *Note, this can include physicians who care for patients as well as laboratory researchers doing any relevant work.* [multi-entry text box]\*

- 1.
- 2.
- 3.
- 4.
- 5.

Additional doctors or researchers [open text box]

**Stage 2: Complete Application Review**

**Please describe the need for a strategic research plan.** (300 words max) [short answer text box]\*

**Has progress in this rare disease been slowed by the lack of a clearly prioritized research plan?** [yes/no]\*

[If Yes] **Please describe.** (250 words max) [short answer text box]\*

[If No] Skip to next question

**Does your organization currently support data collection through a registry or a natural history study?** [yes/no]\*

[If Yes] **Please describe.** (150 words max) [short answer text box]\*

[If No] Skip to next question

**Please describe the ways in which your advocacy organization has been involved in research to date.** Please include any research studies/ activities that have been funded or spearheaded by your organization. How have you as an organization prioritized requests for research funding? How do you engage researchers working on your disease currently?

**Are there other advocacy groups focused on the same disorder as your group? [yes/no]\***

**[If Yes] Does that organization actively fund research? Do you collaborate, why or why not?** (150 words max) **[short answer text box]\***

**[If No] Skip to next question**

**What are the greatest areas of focus for your group in the next 1-2 years? (Choose up to 3)**

- Develop cellular models of disease
- Develop mechanisms for predicting effects of specific genetic variants (Genotype/ phenotype-related studies)
- Develop or validate a meaningful animal model
- Find others with this condition
- Fund a drug repurposing program
- Identify additional researchers to focus on this condition
- Identify or validate better outcome measures for clinical trials
- Plan or initiate a natural history study
- Start a registry or improve engagement/ data in an existing registry
- Support basic science lab research
- Work towards gene-based therapy (gene therapy, ASO, CRISPR, etc)
- Uncertain - we need a strategy for determining our focus
- Other **[open text box]**

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

**Global Genes seeks to make its fellowship 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 fellowship award, but rather provide us additional context with which to review your application. [open text box]**

**Would you be willing to present your learnings 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 fellowship awarded.**

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

**[submit button]**