



## 2022 Financial Advocacy in RARE Patient Impact Grant Pre-Reading Document

Our [2021 Financial Advocacy in Rare Disease Landscape Assessment](#) and [Financial Advocacy Toolkits](#) revealed significant gaps in providing robust and accessible health and financial literacy education and support for patients and caregivers. Falling under Global Genes' larger Health Equity Initiative, the **2022 Financial Advocacy In RARE Patient Impact Grant program** empowers patient advocacy leaders to educate their communities on tackling issues that impact financial well-being and financial literacy for patients. Through this grant program, it is expected that one component of the proposed project will address the cultural, socioeconomic (income, age, level of education, religion and occupation), geographic location and/or linguistic barriers and factors that contribute to the community's limited access to and understanding of financial literacy and financial well-being. This can be done through the development of research, tools, resources and programs that provide guidance and assistance to rare disease patients and their families as they encounter financially stressful situations that may impede access to diagnosis, therapy and disease management.

Together, we are united in supporting the needs of rare disease.

### 1. Who is eligible to apply?

Eligible applicants include support groups and nonprofit organizations that focus on rare disease. Eligible organizations must also be a member of the Global Advocacy Alliance.

**Please Note:** Both US and international organizations are eligible to apply for this grant.

### 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:** Existing Foundation Alliance members and new organizations must apply for the Global Advocacy Alliance in order to be considered for this grant.



## 2022 Financial Advocacy in RARE Patient Impact Grant Pre-Reading Document

### 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 Financial Advocacy In RARE 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 rare disease patients and/or caregivers, and be completed by September 12, 2022.

Accepted projects include research, tools, resources and programs that provide guidance, education and assistance to rare disease patients and their families as they encounter financially stressful situations that may impede access to diagnosis, therapy and disease management.

It is expected that one component of the proposed project will address the cultural, socioeconomic (income, age, level of education, religion and occupation), geographic location and/or linguistic barriers and factors that contribute to the community's limited access to and understanding of financial literacy and financial well-being.

#### ***Looking for inspiration?***

[Here](#) are projects funded by the Financial Advocacy in RARE Grant in 2021.



## 2022 Financial Advocacy in RARE Patient Impact Grant Pre-Reading Document

### 7. When does my project need to be completed?

Final projects need to be completed and submitted to Global Genes by September 12, 2022 at 5:00pm EST.

The outcomes report needs to be completed and submitted to Global Genes by October 4, 2022 at 5:00pm EST.

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

Organizations are eligible to receive up to \$7,500 or 50% of their annual revenue in funding through this grant opportunity.

### 9. What are the review criteria?

All applications will be reviewed by a team of reviewers.

#### Review Criteria:

- **Strength of the statement of need.**
  - Does the application adequately describe the type(s) of financial literacy and/or financial well-being challenges faced by your specific community?
  - Does the application adequately describe the extent of the financial literacy and/or financial well-being 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.
- **Addressing the identified need/problem.**
  - How well does the 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?
- **Achievement of Goals.**
  - Are the proposed activities and timeline thorough and descriptive, and do they



## 2022 Financial Advocacy in RARE Patient Impact Grant Pre-Reading Document

clearly describe how the project goals will be achieved?

- **Budget.**
  - Does the budget clearly outline how funds from this grant will be allocated and utilized with specific line items?
- **Diversity, Equity and Inclusion.**
  - How well does the project address the cultural, socioeconomic (income, age, level of education, religion and occupation), geographic location and/or linguistic barriers and factors that contribute to the community's limited access to and understanding of financial literacy and financial well-being?
- **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 the final educational tool/resource, research or program will drive significant long-term impact? Does that impact align with the goals you outlined?

### 10. What is a SMART Goal?

A smart goal is one that is specific, measurable, attainable, realistic and time-bound. For help developing SMART goals, use [this resource](#).

### 11. What is the anticipated timeline:

- May 11, 2022 at 11:59pm EST: Grant Applications Close
- Week of June 13-17: Awardees Notified/ Announced; All Others Notified
- September 12, 2022 at 5:00pm EST: Final Project Due
- October 4: Final outcome reports due by 5:00pm EST

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

### 12. Can staff salaries be included in the project budget?



## **2022 Financial Advocacy in RARE Patient Impact Grant Pre-Reading Document**

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.

### **13. 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.

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](mailto:RareGrants@globalgenes.org)