

2022 Financial Advocacy in RARE Patient Impact Grant

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Thank you for your interest in applying for the 2022 Financial Advocacy 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 11:59pm EST on May 11, 2022 will not be considered for this grant. Please click [HERE](#) to apply if you have not applied yet.

About the Grant

Financial literacy in the **context of health** involves the ability to assess, understand, and use financial information in ways that support good health and financial outcomes.

Financial literacy in the **context of health and healthcare** involves being equipped to:

- Identify your needs and understand your treatment options
- Make sound healthcare decisions with available resources
- Manage healthcare expenses
- Pay medical bills

Financial well-being means having financial security and financial freedom of choice, in the present and in the future.

Most individuals have limited exposure to financial and health insurance literacy education in school, college or through work. As a result, many rare disease patients and families find themselves ill-equipped to navigate the health insurance landscape, have conversations with providers about the costs associated with care, afford and transition to independent living, access or obtain financial assistance, stay up to date on tests and treatments, etc. This in turn causes financial hardship and prevents individuals from achieving financial well-being, which can greatly impact one's care satisfaction, clinical outcomes and quality of life.

Our 2021 Financial Advocacy in Rare Disease Landscape Assessment and Financial Advocacy Toolkits reveal 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 organizations 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 research or development of tools, resources and programs that provide guidance and assistance to underserved and underrepresented rare disease patients and families as they encounter financially stressful situations that may impede access to diagnosis, therapy and disease management.

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 **11:59pm EST on May 11, 2022**. Grant applicants will be notified of award status the **week of June 13** and awardees publicly announced soon thereafter.

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

2022 Financial Advocacy in RARE 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.

- **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-based and international organizations are eligible to apply for this grant.**
- **How do we register our foundation to become a Global Advocacy Alliance member?**
 - To register your foundation, please click [HERE](#).
 - Once registration is submitted, you are considered a Global Advocacy Alliance member.
 - ***Important:** Existing Foundation Alliance members and new organizations must apply for the Global Advocacy Alliance in order to be considered for this grant.
- **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.
- **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.
- **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.
- **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 evaluation report needs to be completed and submitted to Global Genes by **October 4, 2022 at 5:00pm EST.**
- **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.
- **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 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?
- **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](#).
- **What is the anticipated timeline:**
 - **May 11, 2022 at 11:59pm EST:** Grant Applications Close
 - **Week of June 13-17, 2022:** Awardees Notified/Announced; All Others Notified
 - **September 12, 2022 at 5pm EST:** Final Project Due
 - **October 4, 2022 at 5pm EST:** Final Evaluation Report Due
 - ***Note:** this is a tentative schedule and timing is subject to change.

- **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.
- **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

I acknowledge that I have completed the required Pre-Reading and understand the requirements of this grant. Please enter your name below:

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Grant Category

- Please select the primary category for your grant application.
 - Educational Tools/Resources:** Select this category if you intend to create and implement educational tools and resources 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.
 - Research:** Select this category if you intend to conduct research to assess and identify the financial hardships or factors influencing financial hardship in your rare disease community.
 - Program:** Select this category if you intend to host a virtual workshop(s) 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.

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:
 - 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

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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%.

Estimated number of people in your community this project will directly affect

Ethnicity

Percentage (must add up to 100%)

- Caucasian
- Asian
- Native American
- Black/African American
- Hispanic
- Latino
- Other (list below)

Please list other ethnicities.

SumTotal % MUST = 100

Primary Language

Percentage (must add up to 100%)

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

Please enter other languages.

SumTotal % MUST = 100

Gender

Percentages (must add up to 100%)

- Female
- Male
- Other (list below)

Please enter other genders.

SumTotal % MUST = 100

U.S. Geographic Area Represented

Percentages (must add up to 100%)

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

SumTotal % MUST = 100

Age Range

Percentages (must add up to 100%)

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

SumTotal % MUST = 100

Project-specific Information

Statement of Need

- Describe the **types of financial literacy and/or financial well-being challenges** faced by your target audience. Please include statistical facts and figures to support your claims when possible. [For example, lack of understanding of how to navigate health insurance, etc.] **(250-500 words)**
- Describe the **extent of the financial literacy and/or financial well-being challenges** faced by your target audience. Please include statistical facts and figures to support your claims when possible. [For example, 50% of our target population does not have health insurance or only has short-term health insurance, etc.] **(250-500 words)**

Project Overview

- Please provide a description of your proposed project. **(250-500 words)**
- Who is your target audience for this project? Please select up to two audiences.
 - Patient
 - Caregiver
 - Patient Advocate
 - Researcher
 - Healthcare Professional
 - Young Adults
 - Payers (insurance agents/companies/health plan providers)
- Please describe the target audience (aside from the role identified above) in a few sentences. [For example, Spanish-speaking individuals with low socioeconomic status and literacy rates living in a rural area]
- Explain the goals of this 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
 - Goal 2
 - Goal 3
- Please provide a detailed summary of 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 detailed timeline for accomplishing these tasks. [For example, if you are conducting research you will need to outline where/how you will collect your data, how you will recruit participants if you are conducting a survey, how you plan to

compile your findings, etc. and attach a timeline to each of these tasks.] **(250-500 words)**

- How will funds from this grant be utilized and allocated? For example, print materials, zoom, administrative costs, etc. Please attach a detailed budget.
- Based on the expected component described above, how do you feel your project addresses 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? **(250-500 words)**

Evaluation

- Please describe the final educational tool/resource, research or program you plan to create through this grant funding. **(250-500 words)**
- Please describe how you anticipate your educational tool/resource, research or program to impact your community in the short-term. For example, improve knowledge of health insurance terms, improve confidence in using health insurance, etc. **(250-500 words)**
- Please describe the intended long-term impact of this project. For example, x% of our target population will have health insurance. **(250-500 words)**
- How do you plan on measuring the short and long-term impacts of this project? **(250-500 words)**
- 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.
 - Yes
 - No
- Please provide any additional comments you have that would help us evaluate your application.
- 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: