

## Alexion Charitable Foundation Rare Belonging® Grant Program

# Guidelines and Criteria

Alexion, AstraZeneca Rare Disease is dedicated to transforming the lives of people affected by rare diseases through the development and delivery of innovative medicines, supportive technologies, and healthcare services. Alexion recognizes that patients and caregivers are people first and seeks to understand their unique experiences to better serve their unique needs. Alexion extends this ambition through the charitable giving efforts of the Alexion Charitable Foundation.

*Please Note: The Alexion Charitable Foundation reserves the right to change any aspects of the Rare Belonging® grant program at any time in its sole discretion, including grantee eligibility and grant criteria (without advance notice). All decisions to issue a Rare Belonging® grant are the sole discretion of the Alexion Charitable Foundation. The Alexion Charitable Foundation does not guarantee any initial grants and an initial grant is not a guarantee that an eligible entity will receive a subsequent grant.*

### Mission

The Alexion Charitable Foundation’s mission is to bring promise, hope and belonging to people living with a rare condition and those who care for them. The Alexion Charitable Foundation seeks to address health disparities among the Rare Disease Community and ensure that all underserved communities, including BIPOC families and those of lower socioeconomic status, have equitable pathways to the care, services, and resources they need to live full lives. The Alexion Charitable Foundation fulfills its mission and positively impacts communities around the world through two grantmaking programs: its signature Rare Belonging® initiative and its local community program, Local Needs.

### Rare Belonging® Grant Program

The Alexion Charitable Foundation’s Rare Belonging® grant program supports programs and services that benefit individuals, caregivers and families impacted by rare diseases listed in Global Genes’ RARE List<sup>1</sup>. **Nonprofit 501(c)(3) organizations, or the international equivalent, may apply for grants associated with the Rare Belonging® funding priorities if they meet the criteria set forth in this document.**

### Focus Areas and Funding Objectives

Rare Belonging® seeks organizations aligned to the focus areas and funding objectives listed below.

*Please Note: Grants made directly by the Alexion Charitable Foundation will be available to disease-state agnostic organizations only, with beneficiaries such as patients, caregivers, parents, siblings, and other organizations in accordance with Rare Belonging® priorities.*

Focus Areas	Funding Objectives
<p><b>Mental Health &amp; Wellbeing</b></p> <p>Improve the mental health and wellbeing of people living with rare conditions and their caregivers by tackling systemic hurdles to supports, services, and tools.</p>	<ul style="list-style-type: none"> <li>• Developing practitioner trainings and tools</li> <li>• Advancing practitioner diversity</li> <li>• Increasing access to mental health counseling &amp; services</li> <li>• Supporting emotional wellbeing via family and peer connections</li> </ul>
<p><b>Barriers to Care</b></p>	<ul style="list-style-type: none"> <li>• Providing travel and accommodations assistance for medical care</li> </ul>

<sup>1</sup> <https://globalgenes.org/rare-list/>

Improve the diagnostic journey and access to care by minimizing mobility, language, financial and knowledge barriers for people living with rare conditions.	<ul style="list-style-type: none"> <li>• Supporting housing and home modifications</li> <li>• Expanding access to trained professionals serving in a patient navigator role</li> <li>• Broadening telehealth access</li> </ul>
<b>Health Literacy</b> Empower people living with rare conditions, their caregivers, and physicians through improved health literacy across the continuum of care.	<ul style="list-style-type: none"> <li>• Underwriting rare disease and resource awareness campaigns</li> <li>• Supporting physician education on rare disease symptoms and care needs</li> <li>• Providing patient focused tools to support healthcare navigation and medical care decisions</li> </ul>

## Emergency Response

People living with, or affected by, a rare disease are often disproportionately impacted when disasters strike, or critical needs arise. In alignment with AstraZeneca’s Global Disaster Relief Policy, the Alexion Charitable Foundation will consider emergency funding efforts on a case-by-case basis that provide financial support, transportation, and accommodations for people living with, or affected by, rare disease (i.e., patients, caregivers, family members).

## Application Process

The Alexion Charitable Foundation cannot fund every worthwhile project and is thus highly selective in its philanthropic giving so that it may address critical needs and maximize impact. Any organization interested in receiving an Alexion Charitable Foundation Rare Belonging® grant must complete a grant application, which includes several questions affirming that the applicant meets the grantee eligibility requirements and that the project for which the applicant seeks funding is aligned with the Rare Belonging® focus areas and funding objectives.

*Please Note: Organizations are limited to submitting one grant application per year. Eligibility to apply does not guarantee funding of that request.*

### Timeline

Rare Belonging® grants will be awarded on an annual basis. Applicants must apply during the open call cycle for the focus area appropriate for the proposed program/project.

Focus Area	Open Call Application Period	Grant Term
Mental Health & Wellbeing Barriers to Care	March 1 - 31	June 1 – May 31
Health Literacy	October 1 - 31	January 1 – December 31

## Grant Criteria

Successful grant applications must meet the following criteria:

- Clear programmatic alignment with the Alexion Charitable Foundation’s mission and one or more of its related focus areas and funding objectives as described above.
- Demonstrated program/project need.
- Demonstrated ability to reach people and organizations nationally in the country where the primary grantee organization is based. Organizations with multi-country or global reach may be given preference.
- Demonstrated capacity to administer and deliver quality programming and meet established goals.

- Financial support from an array of sources.
- Demonstrated excellence in governance and best practices.
- Demonstrated ability to report on measurable social results and outcomes.
- No history of violating any healthcare laws, such as the anti-kickback statute, or other applicable laws.

## Grantee Eligibility

To be considered for an Alexion Charitable Foundation Rare Belonging® grant, the organization and the program/project for which funds are being requested must meet the following eligibility requirements:

- **Disease Agnostic:** Be a disease-state agnostic organization, meaning the organization serves individuals living with or affected by any rare disease (as opposed to serving only individuals living with or affected by specific rare diseases). *Please Note: The Alexion Charitable Foundation recognizes that the individual beneficiaries of activities or initiatives may be living with or be affected by one rare disease, but individuals living with or affected by any rare disease should have the opportunity to access the benefit. Availability of support should be widely disseminated, and support should be provided to equally eligible individuals or organizations on a first-come, first-serve basis.*
- **Capacity:** A primary grantee organization is defined as an organization that accepts one or more grant(s) directly from the Alexion Charitable Foundation and subsequently administers grants from said funds in lesser amounts to multiple individuals and/or other organizations in accordance with these Guidelines and Criteria and the resulting Grant Agreement. All primary grantee organizations must have the ability to appropriately review, examine, approve, and administer financial grants directly to qualifying people living with or affected by a rare disease and organizations that work to positively impact and support the Rare Disease Community.
- **Nonprofit Status:** All grant recipients must be nonprofit organizations tax-exempt **under section 501(c)(3) of the Internal Revenue Code and qualify as public charities**, or the international equivalent. Grant recipients must further meet generally recognized benchmarks demonstrating excellence for public charities (such as the percentage of funding used for charitable activities rather than administration and fundraising).
  - **Emergency service providers** such as fire and police departments must apply under their own public charity with 501(c)(3) designation, or the international equivalent.
  - **Religious organizations** such as churches, mosques and synagogues may qualify only if they are established as 501(c)(3) organizations and qualify as public charities, or the international equivalent of such organizations, to operate the funded program AND the program is offered to the general population of individuals living with or affected by a rare disease regardless of religious affiliation.
  - **Elementary and secondary schools** cannot be funded directly; programs administered within a school environment by a separate 501(c)(3) organization, or the international equivalent, may be considered.
- **Expertise:** All primary grantee organizations must have demonstrated expertise with, or capacity to, scale reach to the Rare Disease Community. This includes but is not limited to:
  - Relationships with Patient Advocacy Organizations (PAOs) and with patients who have conditions for which PAOs do not exist.
  - Ability to direct patients to other organizations, if needed.
- **Other Restrictions:** Additionally, the following organization types and activities are **INELIGIBLE** for grants awarded directly from the Alexion Charitable Foundation and, except for Individuals, **INELIGIBLE** for grants awarded by the primary grantee organization:
  - Individuals
  - Programs and projects that do not align with the Alexion Charitable Foundation's stated objectives

- Requests for general operating support.
- Social, labor, alumni, and fraternal organizations (e.g., higher education alumni groups, sororities, fraternities, workers' unions, exclusive membership clubs limited to a specific constituency, etc.).
- Professional and amateur sports events, organizations, and teams (e.g., Little Leagues).
- Political organizations and organizations whose primary purpose is to influence legislation or participate/intervene in political campaigns on behalf of or against any candidate for public office.
- Organizations requiring a fiscal sponsor because they do not have their own 501(c)(3) status or the international equivalent.
- Private foundations.
- Organizations that discriminate based on race, religion, national origin, gender, age, disability, sexual orientation or identification, political affiliation or any other characteristic protected by law or local policy.
- Terrorist organizations or those not compliant with the USA Patriot Act.
- Event sponsorships, fundraising events, and campaigns (e.g., galas, golf tournaments, annual awards ceremonies, raffles, telethons, walk-a-thons, auctions, endowments, memorial campaigns, parades, etc.).
- Loans, debt reduction and operating deficits.
- Costs of clinical care to treat Rare Diseases, including the cost of drug therapy. In particular, funding may not be used to pay for co-pays, deductibles or co-insurance for any prescription drug costs or other clinical care. Funding may be provided for behavioral health services to address the impact of rare disease on individuals with a rare disease so long as: (1) Health Care Providers (HCPs) providing the services are not the HCPs treating the Rare Disease, and (2) consistent with other restrictions, financial assistance provided to individuals is not limited to individuals with one or more specific diseases. Financial assistance will be provided to patients (not to HCPs).
- Any activity, initiative or organization for which Alexion Pharmaceuticals could not provide funding – to avoid any appearance of impropriety given the association of the Alexion Charitable Foundation with Alexion Pharmaceuticals.

## Measurement and Reporting

The Alexion Charitable Foundation expects primary grantee organizations that have been awarded Rare Belonging® grants to provide a grant Impact Report on activities completed and project outcomes at the conclusion of the grant period. Grant recipients will be asked to report on the following, if applicable, to the proposed program or project, among other parameters outlined in the grant Impact Report:

- Progress against intended objectives, outputs, and outcomes (as proposed in the organization's grant application).
- Explanation if objectives were not met.
- Status update on funds expended.
- Qualitative data (such as stories about specific individuals helped).

***Please Note:*** Alexion Charitable Foundation grant recipients that fail to submit a grant Impact Report for their grant will not be eligible for future funding.

### Timeline

Focus Area	Impact Report Deadline
Mental Health & Wellbeing Barriers to Care	July 31
Health Literacy	Feb 28

## Technical Difficulties and Other Assistance

If you are experiencing difficulties — technical or otherwise — in the application process, please send an email inquiry to [ACF@Alexion.com](mailto:ACF@Alexion.com). Foundation staff will make every effort to respond to your email within 48 hours.