

Alexion Charitable Foundation Rare Belonging™ Grants

Guidelines and Criteria

Mission

Alexion Pharmaceuticals is a global biopharmaceutical company focused on serving patients and families affected by rare diseases through the discovery, development and commercialization of life-changing therapies, and it is Alexion Pharmaceuticals' responsibility to listen to, understand, and change the lives of patients and those who work tirelessly to help them. And now, Alexion Pharmaceuticals extends this ambition through the establishment of the **Alexion Charitable Foundation, whose mission is to offer promise and cultivate a sense of belonging — particularly for people affected by a rare disease — through initiatives that advance emotional well-being, educational opportunities and economic relief.**

In furtherance of its mission, the Alexion Charitable Foundation seeks a limited number of nonprofit organizations to help serve the community of individuals living with or affected by any of the rare diseases listed in Global Genes' RARE List¹ (each, a "Rare Disease") as part of the Foundation's Rare Belonging™ suite of funding priorities designed to benefit people living with or affected by a Rare Disease. Leading 501(c)(3) nonprofit organizations, or the international equivalent, may apply for grants associated with the Rare Belonging™ suite of funding priorities if they meet the criteria set forth in this document.

Potential primary grantee organizations (see definition below) must be disease-state agnostic, have funding from a variety of sources and be willing and able to appropriately review, examine, approve and administer financial grants directly to qualifying people living with or affected by a Rare Disease and to appropriately review, examine, approve and administer financial grants directly to other nonprofit organizations that work to positively impact and support the Rare Disease community. Disease-state agnostic means that 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). 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. Potential primary grantee organizations must have national reach within the country where the primary grantee organization is based. Organizations with multi-country or global reach may be given preference. Please see additional detail on these requirements in the Grantee Eligibility section below. More than one organization may apply for the same or similar grants associated with the Rare Belonging™ suite of funding priorities.

Funding Priorities and Objectives

Grants from the Alexion Charitable Foundation Rare Belonging™ suite of funding priorities seek to achieve one or more of the objectives identified below for people living with or affected by a Rare Disease. Grants made directly by the Alexion Charitable Foundation will be available to disease-state agnostic organizations only (and not to organizations focusing only on specific Rare Diseases), which will then, without the involvement of the Alexion Charitable Foundation, determine how to make further grants of such funds in accordance with these guidelines. Ultimate beneficiaries can include patients, caregivers, parents and/or siblings, as well as other organizations, as

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

determined by the primary grantee organization in accordance with the objectives of the Rare Belonging™ priorities.

- **Connecting people living with or affected by a Rare Disease with mental health professionals:** Psychologists, social workers and other licensed mental health professionals can provide critical support to help people living with or affected by a Rare Disease cope with feelings of isolation, loneliness and neglect, and the accompanying depression and anxiety. Yet, a portion of this population who want access to mental health services don't have it. As such, the Alexion Charitable Foundation will consider funding for efforts that:
 - Provide financial support for patients, caregivers, parents and/or siblings who seek mental health counseling services, excluding medications, from licensed professionals, but have challenges accessing mental health counseling services due to lack of insurance coverage and/or financial hardship.
 - Provide financial support through a primary grantee organization for organizations that seek funding to create mental health tracks at Rare Disease conferences that address any of the disease states listed in the Global Genes RARE List and are open to patients, caregivers, parents and/or siblings.
 - Provide financial support for patients, caregivers, parents and/or siblings who cannot afford the tuition for Rare Disease conferences with mental health tracks or other events geared towards mental health.
- **Supporting the educational needs of people living with a Rare Disease:** Many people living with a Rare Disease (i.e., patients) can benefit from educational assistance. Children in this community often miss significant amounts of school, are home-schooled, or are isolated from peers in separate classes where a broad array of instruction may be left to a single special education teacher. This isolation from traditional educational journeys may result in lifelong cognitive and developmental challenges. Similarly, older students living with a Rare Disease seeking secondary education may find themselves in need of college readiness courses or simply supplemental funding for their college education. Additionally, adults who have been newly diagnosed with a Rare Disease may find themselves challenged to continue in their present careers and in need of new job-readiness skills. As such, the Alexion Charitable Foundation will consider funding efforts that:
 - Cover or offset the cost of providing licensed teachers for home tutoring, professional tutoring services and/or educational support services for school-age children (grades K-12) living with a Rare Disease.
 - Cover or offset the cost of accredited college readiness courses or tuition for accredited colleges for young adults living with a Rare Disease.
 - Cover or offset the cost of job-readiness or reskilling courses for adults who have been newly diagnosed with a Rare Disease.
- **Providing transportation and accommodation funding for pressing needs:** The financial burden of living with or being affected by a Rare Disease can make important activities out of reach due to the cost of transportation and accommodations. Such isolation may deprive people living with or affected by a Rare Disease of important social, educational and advocacy opportunities. Additionally, the costs of travelling to doctor appointments, hospitals, infusion centers, clinical trials and medical centers of excellence can be financially burdensome or even cost-prohibitive. As such, the Alexion Charitable Foundation will consider funding efforts that:
 - Provide financial support for patients, caregivers, parents and/or siblings for rides and/or parking fees to events designed to bring members of the rare community together for socializing, support and/or educational purposes.
 - Provide financial support for patients, caregivers, parents and/or siblings for transportation and accommodations for attending Rare Disease conferences.

- Provide financial support for patients, caregivers, parents and/or siblings for transportation to mental health professionals.
- Provide financial support for patients, caregivers, parents and/or siblings for transportation (and accommodations if applicable due to travel distances) to doctor appointments, hospitals, infusion centers, centers of excellence and clinical trials.
- **Providing people living with or affected by a Rare Disease with direct financial assistance in times of critical need:** People living with or affected by a Rare Disease can be disproportionately impacted when natural or manmade disasters strike or critical needs arise. As such, Alexion Charitable Foundation will consider funding efforts that:
 - Provide financial support to people living with or affected by a Rare Disease (i.e., patients, caregivers, parents and/or siblings) who need transportation to alternative locations for medical care when natural or manmade disasters make access to their typical healthcare professionals difficult or impossible.
 - Provide financial support to people living with or affected by a Rare Disease (i.e., patients, caregivers, parents and/or siblings) for transportation and accommodations in the event they are temporarily displaced in the aftermath of natural or manmade disasters.
 - Provide financial support to people living with or affected by a Rare Disease (i.e., patients, caregivers, parents and/or siblings) for home repairs, property damage and similar needs in the aftermath of natural or manmade disasters.
 - Provide financial support to people living with or affected by a Rare Disease (i.e., patients, caregivers, parents and/or siblings) for unexpected major expenses like home repairs, automotive repairs and similar needs (excluding medical care or medication) regardless of whether they were the result of natural or manmade disasters.

Rare Belonging™ Grant Criteria

In order for an application to be considered for a Rare Belonging™ grant it must meet the following criteria:

- Clear programmatic alignment with the Alexion Charitable Foundation mission and one or more of its related objective(s) as described above.
- Demonstrate excellence on key benchmarks for good governance and best practices as a charitable organization.
- Demonstrate need for the program or project.
- Demonstrate capacity of the organization to administer and deliver quality programming and meet established goals.
- Demonstrate ability to reach people and organizations nationally in the country where the primary grantee organization is based.
- Use grant funds on a disease-agnostic basis by offering assistance to or otherwise benefitting patients, caregivers or family living with, or affected by, any and all Rare Diseases, rather than focusing on specific Rare Diseases.
- Demonstrate ability to report on grant impacts.
- Demonstrate potential for positive, measurable social benefit across the Rare Disease community.
- No history of violating any healthcare laws, such as the anti-kickback statute, or other applicable laws.

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 key needs and maximize impact within the Rare Disease community.

Nonprofit organizations that meet the criteria set forth in this document are invited to apply for Rare Belonging™ grants, and only those meeting said criteria that demonstrate the strongest programmatic alignment with the Foundation's Rare Belonging™ suite of funding priorities and objectives will be awarded funding.

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™ suite of funding priorities and objectives. **Please note: eligibility to apply does not guarantee funding of that request.**

Grantee Eligibility

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

- **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 of such organizations. 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).
 - **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.
- **Capacity:** 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. Capabilities must include:
 - Defining clear requirements and eligibility for grants provided to people living with or affected by a Rare Disease, on a disease agnostic basis, and to organizations that work to positively impact and support the Rare Disease community that maximizes the impact of the grant funds across the Rare Disease community. Ultimate selection of individual or organizational grantees will be left to the sole discretion of the primary grantee organization and the Alexion Charitable Foundation will not be involved in the selection process.
 - Determining what kind of information needs to be collected from the applicant for a specific grant.
 - Determining whether there are any tax implications associated with the grant.
 - Providing and implementing a process for how the qualifying individuals and/or organizations are paid.
 - Promoting the availability of the grants to the Rare Disease community.
 - Receiving applications from individuals living with or affected by a Rare Disease and/or organizations working to positively impact and support the Rare Disease community.
 - Appropriately reviewing, examining and approving applications to ensure they meet the criteria for the grant.

- Communicating directly with applicants, including infrastructure to handle inbound questions and regular check-ins and follow-up communications with grantees.
- **Expertise:** All primary grantee organizations must have demonstrated expertise with 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 don't exist.
 - Ability to direct patients to other organizations if needed.
- **Reach:** All primary grant recipients must have at least national reach in the country in which they are based.
- **Other Restrictions:** Additionally, the following types of organizations and activities are **INELIGIBLE** for grants awarded directly from the Alexion Charitable Foundation and, with the exception of 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.

Consistent with its mission to fund initiatives that serve the Rare Disease community on a disease-agnostic basis, the Alexion Charitable Foundation will not provide funding for activities or initiatives that focus only on one or more specific diseases. Specifically, the activities or initiatives must be intended to benefit individuals (whether patients, parents, siblings, or caregivers) living with or affected by any Rare Disease or organizations focused on any Rare Disease. Support cannot by definition (i.e., terms of eligibility or application) or in practice be directed to patients, parents, siblings, or caregivers living with or affected by specific diseases or organizations serving specific diseases. Although the Alexion Charitable Foundation recognizes that the individual beneficiaries of activities or initiatives may have, or otherwise may be living with or be affected by, one Rare Disease, individuals living with or affected by any Rare Disease should be eligible for and 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.

Funding is not available for the 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) 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).

Given the association of the Alexion Charitable Foundation with Alexion Pharmaceuticals, to avoid any appearance of impropriety, the Alexion Charitable Foundation will not provide funding for any activity or initiative for which (or to any organization to which) Alexion Pharmaceuticals could not provide funding.

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/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).

Other than noting that the ultimate beneficiaries of the Rare Belonging™ grants are all living with or affected by Rare Diseases (without identifying the specific Rare Disease), if applicable, the Impact Report shall not make any references to specific disease states. Additionally, no directly identifying information about individual beneficiaries (such as pictures or full names, addresses or similar information) or specific description of their condition will be provided as part of the Impact Report. If individual stories are shared, grant recipient is responsible for obtaining all necessary consents to do so from the grant recipient.

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 from the Alexion Charitable Foundation.

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 any Rare Belonging™ grant is in the sole discretion of the Alexion Charitable Foundation and 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 Rare Belonging™ grant.

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. Foundation staff will make every effort to respond to your email within 48 hours.