

Alexion Charitable Foundation Health Equity Proposal Guide

Congratulations! The Alexion Charitable Foundation invites you to apply for its new health equity grant program, which will help support innovative ways to address the inequities experienced throughout a rare disease patient's healthcare journey.

This document serves as a guide to help your organization present a high-quality and strategic grant proposal.

Background

The Alexion Charitable Foundation (ACF) is dedicated to addressing health disparities among the rare disease community and ensuring 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 Foundation's signature initiative, Rare Belonging[®], partners with organizations supporting individuals, caregivers and families impacted by rare diseases.

Rare Belonging[®] has three giving pillars—Mental Health & Wellbeing, Barriers to Care and Health Literacy. Our *Barriers to Care* pillar is focused on strengthening the diagnostic journey and access to care by minimizing mobility, language, financial and knowledge barriers for people living with rare diseases. **An expanded aspect of this pillar will now include improving equitable access to diagnostics and health outcomes for people living with rare diseases.**

Part of the broader rare disease community, undiagnosed patients can suffer years' long battles to find a diagnosis. Therefore, identifying innovative solutions is an area in which ACF is committed to being more deeply engaged.

Barriers to Care Focus Area

ACF is poised to leverage Alexion's core health equity strategy to provide another avenue of giving in our Barriers to Care pillar. By committing to fund innovative solutions resulting in faster diagnoses, ACF will help address health equity by decreasing the diagnostic journey for more patients and increasing underserved patients' access to care.

Inaugural health equity partners will ground ACF's work for rare disease patients. Prospective partners will be able to effectively identify, reach and serve the needs of BIPOC, historically marginalized, and underserved communities in urban or rural settings by launching initiatives or projects focused on:

Accelerating Diagnosis

- Enhancing data collection, analysis, and classifications for diverse and underserved populations with rare diseases.
- Improving the stratification of data diversity (i.e., causes, symptoms, health markers, etc.) to inform patient diagnosis and care.
- Leveraging innovative technology to advance rare disease research and decrease diagnosis timelines.
- Increasing utilization of rare disease health intelligence among healthcare and support services professionals.

Improving Access to Care

- Increasing physicians' and researchers' knowledge of diagnosis pathways for rare diseases.

- Enhancing evaluation protocols (testing, screening, etc.), interventions and tools to lessen the time to accurate diagnosis.
- Improving the quality of healthcare coordination with an emphasis on specialized and continuity of care from pre-diagnosis through disease management.
- Reducing structural and institutional barriers to diagnosis (bias, racism, social determinants of health, etc.).

Partnerships will have a 1-year grant term spanning from January to December 2025. Partners wishing to participate in subsequent open calls for proposals must meet all grant requirements, including submitting bi-annual updates to the Foundation via email and completing a year-end impact report in or before February 2026.

Timeline

Key Tasks	Deadline
ACF Health Equity Solicitation for Proposals Released	September 3
Applicant Q&A Period	Week of September 9
Proposals Due to ACF	September 27
Grant Agreements Executed	Late November/Early December
Grant Funds Disbursed + Project Kickoff	January 2025
Stewardship Calls	Quarterly in 2025
Impact Report Due	February 2026

Application Template

Invited applicants can access the online application via the CyberGrants platform [here](#). **Please see the information below to support the development of your application response.**

*Please Note: Prior to applying, we encourage you to carefully review the Health Equity Program Guidelines (attached) and broader [Rare Belonging® Grant Guidelines and Criteria](#). The application starts with a series of eligibility questions. Please ensure you are able to check “yes” to each of these questions. **If the answer to any of these questions is “no,” your organization is not eligible for a grant from the Alexion Charitable Foundation, and you should not proceed with the application process.** Foundation staff will also be confirming alignment to these questions in its internal due diligence process.*

Section 1: General Information

Provide a project title, summary, start and end date. In the project summary, clearly outline how you propose to leverage innovative diagnostic tools to address barriers to care within your health system. The project summary should be viewed as the Foundation’s initial point of reference in communicating a partnership.

Also in this section, please check “Barriers to Care” as the appropriate focus area for this program.

Section 2: Budget

Provide budget information including the total request amount, overall project budget and annual organization budget. This information will be part of a [larger budget worksheet](#), which outlines line-item details of expenditures for the proposed project. Please upload the filled-in budget worksheet to your application and ensure each line-item can be correlated to the project description provided in the Project Description section.

Section 3: Project Description

Need: Please outline the specific diagnostic and access to care needs and barriers faced by the rare disease community (patient, caregiver, medical professionals, etc.) your organization currently serves or has the potential to serve. Provide evidence of the need, citing independent or third-party research, studies and/or organizational observations based on services rendered to the community. If able to extrapolate, please note what percentage of the total population served by your organization represents the rare disease community.

If you are not currently serving the rare disease community, please provide a case statement for how you believe your work experience could be transferrable and leveraged to address needs of the rare disease community.

Project Description and Key Activities: Use this section to succinctly articulate how your organization will address the diagnostic aspects of the Barriers to Care pillar identified in Section 1. Your response should allow the Alexion Charitable Foundation to clearly understand your organization's goals, planned activities, and internal/external resources that will be leveraged for effective implementation, including collaborations if applicable.

The Alexion Charitable Foundation seeks to partner with organizations that value creativity and innovation in their approach to program design, implementation, and service delivery. When crafting your proposal, convey how your organization can uniquely address the barriers to care needs of the rare disease community.

Timeline/Milestones: Use this section to share 3-5 benchmarks of progress that will guide your efforts during the grant term. Each benchmark should reflect a reasonable point of program implementation success and have a specific deadline for achievement. The milestones will serve as the baseline for sharing bi-annual written updates and quarterly stewardship calls with the Foundation.

Organizational Capacity: Use this section to summarize how well prepared your organization is to complete the proposed project. It will also be helpful to connect how prior experience makes you a suitable partner to aid the Alexion Charitable Foundation in meeting service gaps in barriers to care for the rare disease community.

Section 4: Measurement

Measurement Approach: Use this section to share how your organization approaches measurement including protocols, processes, and tools for collecting, analyzing, and reporting impact. The Alexion Charitable Foundation is interested in both quantitative and qualitative data to validate meaningful results and impact. The Foundation also wants to understand how the data gathered and shared is used to inform program development and organizational change, as applicable.

Outputs: The Alexion Charitable Foundation defines outputs as a data point that shows the key activities outlined in Section 3: Project Description. Outputs are typically a unit of service or support rendered to the target population (i.e., number of program guides distributed, number of participants served, etc.).

In the Outputs section of the application, please outline the applicable outputs your organization will measure and report, using the "Other relevant outputs" line to share additional outputs relevant to your project.

Health Equity Outcomes: The Alexion Charitable Foundation defines outcomes as the resulting state of change or value created for the target population based on the program or service provided. Outcomes are both short- and long-term, representing a continuum of results from knowledge and awareness to skill development and behavior change. Through

our Barriers to Care Health Equity partnerships, the Alexion Charitable Foundation seeks results and impact in the areas listed below for the appropriate target audience.

In the grant application “Barriers to Care – Health Equity” outcomes section, please use the space provided to articulate the proposed program/project metric(s) of success or data points that will be used to validate progress toward the selected outcomes for your target audience and use the “Other relevant outcomes” line to share additional outcomes relevant to your project, as applicable.

Please note the information shared below is a work in progress for the overall measurement framework but provides guidance on the Foundation’s initial thinking for demonstrating success.

For Patients and Caregivers:

- A wholistic understanding of diagnostic options for patients with an unknown condition, series of symptoms that may or may not be prolonged, without explanation, or other experiences that may warrant diagnostic investigation.
- Recognition that pursuing a diagnosis leveraging innovative diagnostic interventions is a priority for the health system and providers.
- Increased opportunity for seeking diagnostic investigation, especially for underrepresented populations within the health system.

For Physicians (Medical Professionals) and Health Systems:

- Access to, and understanding of, rare disease symptoms and diagnostic tools needed.
- Stratification of data to identify healthcare disparities.
- Enhanced communication skills and practices to provide health information and diagnostic processes to patients and their families.
- Integration of evidence-based diagnostic practices and interventions for operational effectiveness.
- Improved health-related results, including diagnostic timeframes, for patients and caregivers.

For Community At Large:

- Knowledge and understanding of the importance of timely diagnosis and treatment among local community members.
- Improved health equity and quality of life for the rare disease community.

Section 5: Additional

Other Donors: Please share a list of business or foundation donors from the past two years that have provided similar levels of support to the grant request amount you seek from the Alexion Charitable Foundation. Individual donors are not required. Please provide a brief 1-2 sentence summary of how the funds were used and specifically highlight any work related to health equity programs or services.

Recognition: Please outline how the Alexion Charitable Foundation will be recognized and estimated reach of that recognition if your organization receives a Rare Belonging® grant. Please provide the estimated timing of such recognition, if known.

Board Members: Please list the names and business affiliations of your current, active board members.

Affiliation: Please describe the nature of any affiliations your organization or leadership has with the Alexion Charitable Foundation or Alexion Pharmaceuticals employees or executives.

Questions?

We thank you for your interest in partnering with the Alexion Charitable Foundation and want to serve as a resource throughout this process.

Please don't hesitate to reach out to Samantha.Gilman@alexion.com and ACF@alexion.com regarding any questions with the application process and/or Rare Belonging® grant program. Foundation staff will make every effort to respond to your email within 48 hours.