



COLLABORATE Grant Program: Supporting Ageing Adults Living with Rare Diseases Independent Education Grant Request for Proposals (RFP)

Overview

Pfizer and the CanAge are collaborating to offer a new grant opportunity seeking grant proposals for programs that seek to explore innovative approaches to persistent challenges impacting older adults living with rare diseases, including, but not limited to:

- Accelerating time to diagnosis by increasing understanding of the symptoms (including the
 distinctions between ageing and illness) through enhanced clinical awareness and integration of
 genetic testing to identify underlying conditions earlier
- Supporting development of National Action Plans on Rare Disease (RD) to including solutions for the specific challenges faced by older adults and communities ageing with RD
- Gathering exisiting evidence to support advocacy for closing heatlhcare gaps and drive policy change

Grants will be awarded in support of organizations/institutions working to improve programs and policies focused on improving the care of adults living with rare disease.

CanAge will select an Expert Review Panel (ERP) to make final grant decisions, create a community of practice for the selected grantees, and share existing knowledge and tools. Organizations are invited to submit an application addressing the gaps as outlined in the RFP.

For all independent grants, the grant requester (and ultimately the grantee) is responsible for the design, implementation, and conduct of the independent initiative supported by the grant. Pfizer must not be involved in any aspect of project development, nor the conduct or monitoring of the indpendent program.

Geographic Scope/Location of Project:			
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RFP Date Issued:

Global

October 23, 2025

Applications Due:

November 24, 2025

I. Eligibility

Geographic Scope:

Global

Applicant Eligibility Criteria

- The following may apply: medical, dental, nursing, allied health, and/or pharmacy professional schools; healthcare institutions (both large and small); professional organizations; patient advocacy groups; and other entities with a mission related to healthcare improvement.
- Only organizations are eligible to receive grants, not individuals or medical practice groups
- Collaborations within institutions (e.g., between departments and/or inter-professional), as well as between different institutions / organizations / associations, are encouraged. Please note all partners must have a relevant role and the requesting organization must have a key role in the project.
- The applicant must be the Project Lead or an authorized designee of such individual. The Project Lead must be an employee or contractor of the requesting organization.

II. Requirements

Primary Area of Interest:

- Adults living with rare diseases
- Adult-onset rare diseases
- Older adults living with rare diseases

Specific Area of Interest for this RFP:

- This independent grant program emphasizes improving the policy environment and systemic factors affecting aging adults with rare diseases, recognizing the unique challenges this population faces in accessing appropriate care and support.
- It is our intent to support projects that accelerate policy changes in adequate access to care and treatment for older adults living with rare diseases.
- Proposed projects must address one or more of the following categories:
 - Assessment & Analysis: Improve and sustain care for ageing adults with rare diseases by gathering evidence to support advocacy for closing healthcare gaps and driving policy change. This can include programs that evaluate community outreach models. Application should include a thorough plan on how the evaluation data will be utilized to shape public policy.
 - Education & Awareness: Supporting the development of a <u>National Action Plan on</u>
 <u>Rare Diseases</u>. Increase education and awareness programs for healthcare providers,
 patients and caregivers, including the distinction between ageing and illness.
 Development of resources and tools to support aging adults with rare diseases.
 - Policy & Advocacy: Empower communities to advocate for better access to care through the pursuit of legislation or regulations that support ageing with RD in Patient Rights Policy frameworks, policy outreach/grassroots events, and strengthening of advocacy skill sets by connecting organizations.

- Applications must include <u>a completed grant proposal template</u> and will need to demonstrate:
 - Alignment to at least one of the categories listed above to improve the lives of older adults living with rare diseases
 - o Quantifiable program impact and ability to measure results/outcomes
 - Connection of program elements to potential policy goals (short-term/long-term)
 - Capacity to deliver quality program(s) to achieve established goals, and plan for policy advocacy

It is not our intent to support clinical research projects. Projects evaluating the efficacy of therapeutic or diagnostic agents will not be considered.

Collaboration and Knowledge Sharing

Grantees are expected to:

- Participate in a COLLABORATE grantee community of practice facilitated by CanAge
- Share project updates, challenges, and learnings with other grantees
- Attend a virtual grantee kick-off meeting in Q1 2026 hosted by CanAge
- Contribute to knowledge mobilization activities managed by CanAge
- Participate in program evaluation activities
- Allow CanAge to share their project stories with CanAge members and beyond

CanAge will facilitate regular connection opportunities, provide a digital platform for grantee collaboration, and support dissemination of grantee work and outcomes.

Background

- The definition of a rare disease varies globally but is typically thought to be a disease that affects 1 in 2000 people.¹
- It is estimated that between 2–6% of the global population suffer with a rare disease, with approximately 30% of these first presenting in adulthood.²⁻⁵ There is a lack of awareness and recognition among older adults and HCPs of the symptoms related to adult-onset rare diseases, and this often leads to symptoms being missed or misattributed to the common signs of ageing⁶ thereby delaying time to diagnosis.⁷
- The number of people ageing with a rare disease is increasing globally in Italy, a three-fold increase in rare disease patients transitioning from childhood to adulthood was recently reported8-
- Life expectancy for certain rare diseases has significantly increased in recent decades and the mean age of rare disease patients in the US and Europe is now 30–40 years⁸
- Older people with rare diseases report experiencing ageism, poor communication, and inadequate provision of tailored information from their healthcare professional¹⁰ which can lead to negatively impact treatment outcomes¹¹

Expected Approximate Monetary Range of Grant Applications

- The total available budget related to this RFP is \$100,000
- Individual projects requesting up to \$25,000 will be considered.
- The amount of the grant awarded by Pfizer for any project will depend upon the external review panel's evaluation of the proposal and the costs involved and will be stated clearly in the grant agreement.
- Award amounts include direct costs, institutional overhead costs (capped at 28% per Pfizer policy), and indirect costs.

Key Dates

- RFP Release Date: October 23, 2025
- Proposal Due Date: November 24, 2025
- Review of Proposals by Review Panel: December 2025
- Anticipated Full Proposal Notification Date: December 2025/January 2026
- Grants will be distributed following a fully executed agreement.
- Anticipated approximate project timeframes (suggesting 1 year project timelines): January 20226 –
 December 2026

How to Submit

- Please go to https://www.cybergrants.com/pfizer/knowledge and sign in.
- Note: there are individual portals for each grant application type. Please be sure to use the URL above.
- First-time users should click "Create your password".
- Click the "New Grant Application" button.
- Requirements for submission:
 - Complete all required sections of the online application
 - Complete <u>this proposal template</u> and upload under the RFP Submission/Full Proposal field in the online application portal
- In the application:
 - For the question "Competitive Grant?" select "Yes"
 - Select the following Competitive Grant Program Name: 2025 RD Global CanAge RD in Adults IME

Questions

- If you encounter any technical difficulties with the website, please click <u>here</u> or the "Technical Questions" link at the bottom of the page in the grant system.
- Please click here to view "Frequently Asked Questions" regarding the Competitive Grant Program.
- If you have questions regarding this RFP, please direct them in writing to the Grant Officer, Amanda Stein (<u>Amanda.J.Stein@pfizer.com</u>) and Chief Operating Officer at CanAge, Jana Ray (jana@canage.ca) with the subject line "Adult RD IME RFP"

Expert Review Panel

Applications will be reviewed by an expert panel recruited and managed by CanAge. The panel consists of individuals with expertise in:

- Rare disease advocacy and research
- Aging and gerontology
- Healthcare policy and systems
- Community-based program delivery

The panel will also include one Pfizer Global Policy & Public Affairs colleague.

Mechanism by which Applicants will be Notified:

- All applicants will be notified via email by the dates noted above.
- Applicants may be asked for additional clarification during the review period.

Grant Agreements:

- If your grant is approved, your institution will be required to enter into a written grant agreement with Pfizer. Please click <u>here</u> to view the core terms of the agreement.
- Under Pfizer's competitive grant program, modifications to grant agreements will not be reviewed unless a genuine conflict exists as between applicable law and the terms of the relevant grant agreement.
- This RFP is supported by Pfizer Inc. and, if approved the payment will be issued by a Pfizer US based legal entity.

About CanAge

CanAge is Canada's national seniors' advocacy organization, working to improve the quality of life for all Canadians as we age. Through collaboration, education, and advocacy, CanAge champions the rights, dignity, and well-being of older adults across the country.

About Pfizer

Pfizer supports the global healthcare community's independent initiatives (e.g., research, quality improvement, or education) to improve patient outcomes in areas of unmet medical need that are aligned with medical, policy and/or scientific strategies.

*COLLABORATE is the name of the grant program. The resulting grants are independent grants. The grant requester is responsible for the design, implementation, and conduct of the independent initiative supported by the grant.

References

- 1. GOV.UK. (n.d.). The UK rare diseases framework. https://www.gov.uk/government/publications/uk-rare-diseases-framework/the-uk-rare-diseases-framework
- 2. Nguengang Wakap, S., Lambert, D. M., Olry, A., Rodwell, C., Gueydan, C., Lanneau, V., Murphy, D., Le Cam, Y., & Rath, A. (2020). Estimating cumulative point prevalence of rare diseases: analysis of the Orphanet database. *European journal of human genetics*: *EJHG*, *28*(2), 165–173. https://doi.org/10.1038/s41431-019-0508-0
- 3. Ferreira C. R. (2019). The burden of rare diseases. *American journal of medical genetics. Part A, 179*(6), 885–892. https://doi.org/10.1002/ajmg.a.61124
- 4. Walker, C. E., Mahede, T., Davis, G., Miller, L. J., Girschik, J., Brameld, K., Sun, W., Rath, A., Aymé, S., Zubrick, S. R., Baynam, G. S., Molster, C., Dawkins, H. J. S., & Weeramanthri, T. S. (2017). The collective impact of rare diseases in Western Australia: an estimate using a population-based cohort. *Genetics in medicine : official journal of the American College of Medical Genetics*, 19(5), 546–552. https://doi.org/10.1038/gim.2016.143
- 5. European Commission, EURORDIS, & Orphanet. (n.d.). Rare diseases in numbers. https://ec.europa.eu/health/archive/ph_threats/non_com/docs/rdnumbers.pdf
- 6. Dong, D., Chung, R. Y., Chan, R. H. W., Gong, S., & Xu, R. H. (2020). Why is misdiagnosis more likely among some people with rare diseases than others? Insights from a population-based cross-sectional study in China. *Orphanet journal of rare diseases*, *15*(1), 307. https://doi.org/10.1186/s13023-020-01587-2
- 7. Lousada, I., Comenzo, R. L., Landau, H., Guthrie, S., & Merlini, G. (2015). Light Chain Amyloidosis: Patient Experience Survey from the Amyloidosis Research Consortium. *Advances in therapy*, *32*(10), 920–928. https://doi.org/10.1007/s12325-015-0250-0
- 8. Gorini, F., Coi, A., Mezzasalma, L., Baldacci, S., Pierini, A., & Santoro, M. (2021). Survival of patients with rare diseases: a population-based study in Tuscany (Italy). *Orphanet journal of rare diseases*, *16*(1), 275. https://doi.org/10.1186/s13023-021-01907-0
- 9. Mazzucato, M., Visonà Dalla Pozza, L., Minichiello, C., Manea, S., Barbieri, S., Toto, E., Vianello, A., & Facchin, P. (2018). The Epidemiology of Transition into Adulthood of Rare Diseases Patients: Results from a Population-Based Registry. *International journal of environmental research and public health*, *15*(10), 2212. https://doi.org/10.3390/ijerph15102212
- 10. Martínez-Angulo, P., Muñoz-Mora, M., Rich-Ruiz, M., Ventura-Puertos, P. E., Cantón-Habas, V., & López-Quero, S. (2023). "With your age, what do you expect?": Ageism and healthcare of older adults in Spain. *Geriatric nursing (New York, N.Y.)*, *51*, 84–94. https://doi.org/10.1016/j.gerinurse.2023.02.020
- 11. Gertz, M., et al. (2020). Avoiding misdiagnosis: Expert consensus recommendations for the suspicion and diagnosis of transthyretin amyloidosis for the general practitioner. BMC Family Practice, 21, Article 198. https://doi.org/10.1186/s12875-020-01252-4