

**ORPHAN DISEASE CENTER
MILLION DOLLAR BIKE RIDE
PILOT GRANT PROGRAM**

The ODC MDBR Pilot Grant Program provides a one-year grant to support research related to a rare disease represented in the 2026 Million Dollar Bike Ride. Number of awards and dollar amounts vary per disease based on fundraising totals by each disease team. The respective disease team, not the ODC, will execute the Notice of Award (NOA) and will be responsible for disbursing the awarded funds.

Eligibility

This RFA is open globally. International applicants are invited to apply. All individuals holding a faculty-level appointment at an academic institution or a senior scientific position at a non-profit institution or foundation are eligible to respond to this RFA. Prior MDBR award recipients must have current and updated project reporting to be eligible for selection.

Letter of Interest Instructions:

Please visit our [website](#) to submit your Letter of Interest (LOI), which can also be found [here](#). This one-page LOI is due no later than **Friday, September 18, 2026 by 8pm (EST)**.

Full Application Instructions and Review Procedure

NOTE: Full Application is by invitation only after review of Pre-Application

Proposal Due Date: **Monday, October 19, 2026 no later than 8pm (EST)**

Full application documents are to be uploaded on our website, by invitation only.

FORMAT for documents:

Font and Page Margins: Use Arial typeface, a black font color, and a font size of 11 points. A symbol font may be used to insert Greek letters or special characters. Use 0.5 inch margins (top, bottom, left, and right) for all pages, including continuation pages. Print must be clear and legible; all text should be single-spaced.

Header: There should be a header at the top right on all pages of the PDF indicating the full name of the PI (e.g., **PI: Smith, John D.**).

For your convenience, a continuation page template is included at the end of the application document.

File names: ALL files to be uploaded should start with the LAST NAME of the PI followed by the brief name of the document. Examples: SMITH CV, SMITH Cover Page, SMITH Budget. **If files are not labeled properly, you will be asked to resubmit the PDFs before your application can be considered.**

CONTENT to be uploaded:

☐ **Cover Page/Checklist/Institutional Signature Page [PDF].**

☐ **NIH-style Biosketch with Other Support of PI and key personnel (5 pages max/PI, including Other Support). [PDF]**

The PI must include accurate and complete information regarding all other sources of grant support (current and pending), including title, abstract, annual and total amount of grant,

inclusive funding period, and percent effort.

☐ **Detailed Budget and Justification. [combined into one PDF]**

Complete Excel budget sheet (to be provided). Describe justifications in a Word document. Award will be for one year. Proposed funding period: February 1, 2027 – January 31, 2028. Total Budget depends on disease RFA:

Disease	# of Awards	Award Total
CADASIL	1	\$106,000
CDG	1	\$50,000

*No Indirect Costs (IDCs) may be taken from award totals.
Awarded amounts will not exceed Award Totals listed above.*

Allowable direct costs

- Salary for PI*
- Salary/stipend and related benefits for graduate student/postdoctoral fellow/technical support
- Travel (up to \$1,500)
- Laboratory supplies and other research expenses

Unallowable costs

- Consultant costs
- Tuition
- Professional membership dues
- Equipment >\$5,000
- General office supplies, institutional administrative charges (e.g., telephone, other electronic communication, IT network, etc.)
- Pre-award charges
- Any other expenses not directly related to the project
- Indirect Costs

* Beginning in May 2020, PI salary on all ODC Pilot awards will be applicable to the National Institutes of Health Executive Level II Salary Cap. The current NIH Salary Cap for the year 2026 is \$228,000. For background and guidance, please refer to the following link: https://grants.nih.gov/grants/policy/salcap_summary.htm

☐ **Research Plan (5 pages max) and Bibliography (1 page max). [combined into one PDF]**

Include the following sections: Specific Aims, Background and Significance, Preliminary Studies/Data, Research Design and Methods. Research plan should address the following questions: 1) Do you require access to reagents, cell lines, animal models, IRB/ethical board approvals, and/or equipment necessary to complete work? If so, please describe your plan to gain access within the timeframe of this grant period. 2) Have you identified qualified personnel to complete this project within the grant period? If not, please provide your plan to do so. Text citations should use a numbered format. Include all author names in the reference list.

☐ **Appendix [combined into one PDF]**

Limited to 5 pages of supplemental information pertaining to proposal or preliminary data only. In addition to 5 pages of supplemental information, a maximum of 3 relevant reprints are also acceptable. Include IRB and/or IACUC approval letters if relevant.

Project Disclosures and No Cost Extensions (NCE):

- NCEs will be granted at the discretion of the disease team who is funding the project.
- Awardees will be limited to 1 NCE request for their award.
- Maximum NCE time awarded will be 6 months.
- NCEs will be granted after a formal request prior to the NCE deadline with adequate justification.

- If granted a NCE, you are still required to submit an interim scientific report 6 months into the duration of the original award period, regardless of your new project end date.
- In your letter of interest, you will be required to certify that you have identified qualified personnel to complete this project within the grant period **PRIOR** to the start date of the award. If you have not, you will be required to provide your plan to engage said personnel. Only under extenuating circumstances will personnel issues be considered for NCE requests.
- In your letter of interest, you will also be required to state whether or not you require access to reagents, cell lines, animal models, IRB/ethical board approvals, and/or equipment necessary to complete your work. If so, you will be required to describe your plan to gain access within the timeframe of this grant period.

Research Focus Areas for Pilot Grants:

1) CADASIL - Grant Amount: \$106,000

CADASIL (Cerebral autosomal dominant arteriopathy with subcortical infarcts and leukoencephalopathy) is the leading genetic cause of stroke, vascular cognitive impairment and vascular dementia and is linked to cysteine-altering mutations in NOTCH3. The precise mechanisms driving vascular dysfunction, leukodystrophy, or neurodegeneration in CADASIL are not clear. Moreover, clinical markers that can be used to assess treatment efficacy are sparse. cureCADASIL seeks applications for research that will advance the understanding of mechanisms of the disease or clinical phenotyping that will facilitate future treatment trials (e.g. identification of biomarkers or clinical predictors). Disease model initiatives and drug repurposing projects are of interest. Both basic laboratory and clinical projects will be considered. Because this community-funded grant is intended to support a one-year project, we encourage applicants to propose a clearly defined set of aims - whether a standalone project or a well-defined component of a larger research program - that can be achieved within this time frame. This grant is made possible by cureCADASIL and the individual donors and participants in the Million Dollar Bike Ride 2026.

2) CDG - Grant Amount: \$50,000

Congenital Disorders of Glycosylation (CDG) are a genetically and clinically diverse group of rare inherited metabolic disorders caused by defects in glycosylation, a fundamental cellular process essential for normal growth and function. Individuals with CDG often experience complex, multisystem disease with significant unmet medical needs, and for many CDG types there are currently no approved therapies. CDG CARE is seeking applications that will advance the understanding, diagnosis, clinical management, or treatment of CDG across the basic, translational, and clinical research continuum. Areas of interest include, but are not limited to, disease mechanisms, biomarker discovery, natural history, model development, drug repurposing, precision medicine, novel therapeutic approaches, gene-based therapies, and studies that improve clinical care or clinical trial readiness. Projects may utilize cell-based, animal, or human models. CDG CARE encourages innovative, collaborative projects with strong scientific merit and the potential to meaningfully advance the field and improve outcomes for individuals and families affected by CDG. One grant of \$50,000 is made possible by Team CDG and the individual donors and participants in the Million Dollar Bike Ride 2026. Per CDG CARE policy, indirect costs

and institutional overhead fees are not allowable and may not be requested as part of the proposed project budget.

Grant Review Process:

- 1) Grants will be reviewed for scientific content and relevance to the goals of the RFA.
- 2) Full applications proceed through a two-step review process. The first step includes external review and rating with an assessment of the strengths and weaknesses of each application based on the defined review criteria described below. During the second step, funding recommendations are determined based on an assessment of the reviewer scores and written comments. Final decision of funding will be made by the rare disease funding organization.
- 3) Proposal Content and Review Criteria: The following criteria will be utilized in proposal review.
 - **Project Proposal** - Is the proposed project of high scientific quality? Is the budget fully justified and reasonable in relation to the proposed project?
 - **Background** - Is the fundamental objective of the study and hypothesis to be addressed clearly defined?
 - **Scientific Approach** - Will the proposed specific aims answer the study hypothesis? Will the scientific approach effectively test and answer each specific aim? Are the study goals supported by existing data?
 - **Clinical Impact** - Is the answer to the study hypothesis important to our ability to treat or reduce rare disorders/disease incidence and/or mortality? Will the proposed research lead to substantial advances and/or contribute to large leaps of understanding or knowledge that will contribute to reductions in disease incidence and/or mortality within the decade?
 - **Research Significance** - Does the study address an important question that is not likely to be addressed without this funding? Does the proposed study offer a unique opportunity to explore an important issue and/or employ a novel approach to this disease research? Will the study outcomes advance our knowledge of this disease and/or contribute to changes in the focus of future research questions or the way we conduct research on this issue?
 - **Investigator Qualifications** – Does the investigator hold a track record of outstanding accomplishment as evidenced by peer-reviewed publications and funding awards? Does the investigator have access to the resources and environment necessary to complete the study as outlined?

Anonymous reviewer feedback is shared upon the request of the applicant at the discretion of the rare disease funding organization.

Confidentiality:

The MDBR Grant Program is a confidential process and all content of the LOIs and Full Applications will be kept confidential by the ODC; our expert reviewers sign a CDA in advance of the review process. As the funding organization, the disease team will have access to the LOIs and Full Applications throughout the review process and is likewise bound by confidentiality regarding this content.

Fund Disbursement:

Funds will be issued through a cost reimbursement mechanism executed by the rare disease funding organization. Details of invoicing schedules and reporting requirements will be made available upon award. For additional information, please contact Leslie Silverman at lsilve@upenn.edu