

Section 1. Overview Information

Participating Organizations

Galactosemia Foundation (the Foundation)

Funding Opportunity Title

Galactosemia Foundation Biennial Research Grant 2025 - 2026

Announcement Type

Recurrent – Biennial

Funding opportunity Purpose

The Galactosemia Foundation provides funding for scientific and medical research related to the identification, treatment, and therapies related to classical galactosemia. The goal of this research initiative is to improve the lives of people with galactosemia. All proposals will be given equal consideration in the review process; however, for this round of funding, the foundation is especially interested in receiving projects related to the following:

- *Premature ovarian insufficiency/failure (POI/POF)*
 - *Advances in hormone therapy or related treatments to address POI/POF throughout life (pre-puberty through menopause)*
 - *Advances in fertility options*
 - *Women’s physical and mental health-related issues living with classic galactosemia*
- *Motor/neurological deficits*
 - *Tremors (including study of onset, prevalence, relationship to age and viable treatments)*
 - *Seizures (including study of onset, prevalence, relationship to age and viable treatments)*
 - *Movement disorders (including onset, prevalence, relationship to age and viable treatments)*
 - *Neurological changes associated with classic galactosemia throughout the lifespan (including onset, prevalence, relationship to age and viable treatments)*
- *Cognition*
 - *Cognitive changes and deficits in the patient with classic galactosemia (including onset, prevalence, relationship to age and viable treatments)*
 - *Longitudinal studies comparing natural history data on same subjects through the lifespan over period of time*
- *Advancements in Diet-related issues*
 - *Galactose content related to liberalization of diet, outcomes and quality of life*
 - *Enzyme activity for residual enzyme production as it relates to liberalization of diet*
- *Bone density and bone health in classic galactosemia (male/female) including advances in treatments and relationship with hormones and/or metabolism*

The foundation will accept projects that answer an outstanding question or address an unmet need of our community. We are particularly interested in advancing identification and treatment of complications related to classic galactosemia and variability of outcomes. These may include, but are not limited to treatments or cures as well as advancing our knowledge of the sequela of classic galactosemia through the lifespan.

Key Dates

Posted Date

August 1, 2024

Application and Announcement Dates

Stage 1 submission deadline: September 30, 2024

Stage 1 results announcement: November 15, 2024

Stage 2 submission deadline: January 13, 2025

State 2 results announcement: April 2025 Award

disbursement: May 2025

Completion of Grant June 2026

Section 2. Award Information

Funding Instrument

Grant

Application Types Allowed

New Progression of prior
research

Project categories

Research projects
Clinical trials
Educational projects
Collaborative projects or meetings

Award Budget

Awards are provided for amounts between \$10,000 and \$50,000 typically. 1 year Partial awards are available (see Cost Sharing below). Authorized uses of grant monies will include direct costs as set forth by the funding guidelines. Unauthorized expenses include:

1. Salaries, travel, and/or housing related to sabbatical leaves
2. Purchase or rental of office equipment (i.e., , computers furniture, and copy machines).
3. Expenses normally covered by the indirect cost of the grantee's institution.
4. Fees for tuition.
5. Membership dues, subscriptions, books, or journals.

Institutional overhead is not allowed. All monies awarded should be direct costs.

Section 3. Applicant Eligibility

Eligible Organizations

Higher Education Institutions

Public/State Controlled Institutions of Higher Education Private
Institutions of Higher Education

Nonprofits Other Than Institutions of Higher Education

Nonprofits with 501(c)(3) IRS Status (Other than Institutions of Higher Education)

Nonprofits without 501(c)(3) IRS Status (Other than Institutions of Higher Education)

For-Profit Organizations

Small Businesses

For-Profit Organizations (Other than Small Businesses) Foreign

Institutions

Non-domestic (non-U.S.) Entities (Foreign Institutions)

Non-domestic (non-U.S.) components of U.S. Organizations

Foreign components, as defined in the NIH Grants Policy Statement

Program Directors/Principal Investigators (PD(s)/PI(s))

The PD/PI must have support from their organization. Previously research experience is desired but not required. The PD/PI does NOT need to have a background or previous experience with galactosemia. Historically, projects that have been funded have been led by medical doctors, doctorate level researchers, registered dietitians, and PhD candidates. Partnerships, especially bringing together galactosemia expertise with other relevant fields, are encouraged. If there is more than one PD/PI, please identify the individual who will execute the project and with whom the Foundation should communicate as well as his or her organization or institution.

Cost Sharing

Applications will not be accepted for projects for which funding has already been distributed by another source unless the anticipated costs of the project exceed the awarded funds. In this case, the Galactosemia Foundation may provide partial funding up to the remaining reasonable estimation of total costs not to exceed \$50,000 as described above in Award Budget.

Number of Applications

Applicant organizations may submit more than one application, provided that each application is scientifically distinct.

Section 4. Application and Submission Information

Requesting an Application Package

Stage 1 application guidelines may be found on our [website](http://www.galactosemia.org) or may be requested by emailing research@galactosemia.org.

Stage 2 applications are to be submitted by request only and may be found on our [website](http://www.galactosemia.org) or may be requested by emailing research@galactosemia.org.

Content and Form of Application Submission

The Galactosemia Foundation enacted a two-stage in 2019 to help expedite the selection process for award candidates. Stage 1 should be brief and not exceed two pages. Review of this first stage will be done by Galactosemia Foundation Research Team and board representative(s). Notification of the outcome of Stage 1 will be sent out by the Research Team by November 15, 2024.

Invitations to submit an application for stage 2 will be sent to the individuals by November 15, 2024. Stage 2 applications must follow the funding guidelines carefully. Previous receipt of a grant does not constitute a commitment to continue funding in future years. Submission of an application in Stage 1 does not constitute automatic approval into the Stage 2 process. If you do not submit an outline/proposal for Stage 1, you will not be considered for Stage 2. Invitation into Stage 2 does not mean you will automatically be funded. Applications for Stage 2 will be due January 13, 2025.

All applications must be received by midnight, US Eastern Time, on their respective due dates. Applications must be submitted in English, in PDF format, and with a standard font type that can be photocopied (i.e., Times New Roman, Arial, etc.). Font shall not be smaller than 11 point. The application must be signed by the applicant, the department chair (or comparable), the financial officer or appropriate representative from the office of sponsored programs.

Section 5. Application Review Information

Staged Review Process

Stage 1 applications will be reviewed by the Foundation Research Team and/or board members focusing on potential impact and foundation priorities. The decision for which applications to invite for stage 2 will be at the discretion of the Research Team and there is no quota for stage 2 applications.

Stage 2 applications will be reviewed by the Research Team and external expert peer reviewers. All peer reviewers will be required to agree to a non-disclosure agreement and further be evaluated for conflict of interests. Additionally, professionals who submit a proposal during this funding cycle will not be used as a reviewer for other proposals during this same cycle. The external expert reviewers will review each proposal individually using the criteria listed below and will not take funding priorities into consideration.

The Research Team will decide which of the stage 2 applications will be selected for funding nomination, and the Foundation's governing board will decide which of the nominated applications will be selected for funding. This decision is primarily made based on available funds and results from the review process.

Stage 2 Review Criteria

Introduction

Does the proposal provide adequate background information? Are the goals/purpose of the research clearly stated? Is there an attached literature review? Is any related preliminary work clearly described?

Significance

Does the study address an important problem facing the galactosemia community? Does the project employ novel concepts, approaches, or methods? Are the aims original and innovative?

Design and Methods

Does the project have clear, realistic goals and objectives? Is the target population clearly defined? Are the proposed activities well thought out and able to meet the objectives? If applicable, is the recruitment strategy, potential risk, and methods for maintaining patient confidentiality described? Is there an appropriate plan for data analysis? If applicable, are survey tools or questionnaires provided?

Institutional Support and Staffing

Does the PD/PI have adequate background and/or an adequate mentor to complete the project? Is there adequate staffing? Is there institutional support? Do the proposed experiments take advantage of the scientific environment or employ useful collaborative arrangements?

Anticipated Problems

Does the applicant anticipate problems and provide strategies to consider alternative tactics?

Budget

Is the budget realistic? Do the line items meet the criteria established by funding guidelines?

Information sharing

Is there a plan to share information obtained by this project?

Timeline

Is the timeline realistic? Research projects are expected to be completed within the time frame selected for the research as proposed on the application, but not to exceed 12 months, unless a no-cost extension is approved in advance by the research team.

Foundation Funding Decisions

The Research Team will decide which of the stage 2 applications will be selected for funding nomination, and the Foundation's governing board will decide which of the nominated applications will be selected for funding. This decision is primarily made based on available funds, results from the Stage 2 review process, and consideration given to foundation funding priorities. Award of grants is at the discretion of the Galactosemia Foundation.

Section 6. Award Administration Information

Award Notices

Those projects chosen from stage 2 which have been approved for funding will be notified via email no later than April 30, 2025. Recipients must comply with the funding restrictions established by funding guidelines, and the Foundation reserves the right to terminate funding to any project for any reason at the sole discretion of the board.

The transaction of funds is the responsibility of the Galactosemia Foundation Treasurer. The Research Team would like to be notified of any issues with the transaction of funds as this may impact or delay projects. The recipients of the Stage 2 grant will receive half of the awarded amount initially at the start of the project and receive the remaining half of the awarded amount after a mid-year report has been submitted to the team. Financial agreements will be managed by the Galactosemia Foundation Treasurer.

Reporting

Recipients are required to submit semi-annual progress reports, financial reports, and a final research report consisting of a summary in lay language of the research accomplished must be provided within 90 days of conclusion of the research project. This final report is in addition to any interim progress reports submitted. The reports shall be sent to the Research Team chair via email at research@galactosemia.org. Additionally, recipients are required to present their research findings at our biennial Galactosemia Foundation Conference. Details of that process will be made available to all award recipients. At times, the Foundation may request the PD/PI to provide a laymen update that may be posted on the GF Newsletter or related postings.

Section 7. Agency Contacts

We encourage inquiries concerning this funding opportunity and welcome the opportunity to answer questions from potential applicants. Questions may be sent to the Research Team via email at research@galactosemia.org. Questions regarding the administration of the Foundation may be submitted via email to outreach@galactosemia.org.