

## GLIA-CTN Advocacy Advancement Award FY27 Request for Applications

### I. Award Purpose

The Global Leukodystrophy Initiative Clinical Trials Network (GLIA-CTN) is a consortium of institutions, clinicians, scientists, and patient advocacy leaders working together to promote advances in the diagnosis and treatment of leukodystrophies.

The Advocacy Advancement Award is intended to serve as a mechanism for patient advocacy leaders to answer concrete questions relevant to their own constituents by leveraging shared data, expertise, and resources available through the GLIA-CTN. Award criteria were defined in deliberately broad terms in order to accommodate the diverse and evolving needs of individual leukodystrophy communities.

Potential projects may involve defining burden of disease, developing patient-facing educational materials, expanding the existing interactive dashboards, or preparing basic data for patient-focused drug development meetings with the Food and Drug Administration (FDA).

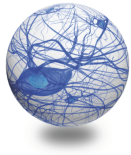
Each project must have a completion timeline of six (6) months or less, and priority will be given to projects that maximize the use of data and tools already available through the GLIA-CTN. Prospective applicants will have the option to schedule a brief consultation meeting with a GLIA-CTN technical liaison to assess project feasibility informally prior to submitting a project proposal for review.

### II. Application Deadline

Applications will be accepted on a rolling basis.

### III. Number of Awards

Up to two (2) Advocacy Advancement Awards will be granted annually, with a new project starting every six (6) months. Additional awards may be granted during a given fiscal year at the discretion of the GLIA-CTN Executive Committee, and as permitted by available resources.



#### IV. Award Period

Support will be provided for a **six (6) month** project.

#### V. Level of Support

Awardees will receive up to six (6) months' worth of in-kind support from the GLIA-CTN, including regular virtual meetings and email correspondence with the assigned administrative and/or technical contacts within the GLIA-CTN.

#### VI. Eligibility Criteria

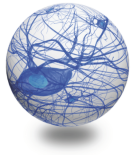
Any registered 501(c)(3) nonprofit organization focused on promoting awareness, research, and/or fundraising for leukodystrophy research is eligible to apply for the GLIA-CTN Advocacy Advancement Award.

Eligible applications will meet the following key criteria.

- i. The application must relate to a specific established leukodystrophy ([Vanderver et al., Mol Genet Metab. 2015; doi: 10.1016/j.ymgme.2015.01.006](#));
- ii. The applicant must provide a detailed explanation of how the project will support their leukodystrophy community, and, if applicable, describe how the deliverables may be translated into future research opportunities.
- iii. The applicant should be willing to meet with the GLIA-CTN Biomedical Informatics and Statistical Core (BISC) on a monthly basis for the duration of the six-month award. Meetings will be used to share progress updates, discuss conceptual and/or technical challenges, and coordinate next steps of the project. Meetings will occur virtually at a mutually convenient time;
- iv. The applicant must be willing to speak about their project at a virtual GLIA-CTN Administrative Meeting following completion of their six-month award period.

Applications should also meet the following feasibility criteria.

- i. The applicant must demonstrate that efforts have been made to evaluate project feasibility, including confirmation that of relevant data and/or technical resources exist within the GLIA-CTN, demonstration that the project goals are achievable within the six-month timeline, etc.



- ii. Preference will be given to applicants who consulted with technical representatives from the GLIA-CTN prior to submitting their initial application.

## VII. Resource Utilization

Applications that include a plan to leverage central GLIA-CTN resources in one or more of the following ways will be prioritized:

- Use of existing demographic and/or natural history previously collected through the consortium's central repository, known as the Myelin Disorders Biorepository Project (MDBP);
- Collaboration with one or more of the following GLIA-CTN Core Groups. A description of each Core Group's scope of work is available on our website at <https://theglia.org/gliactn/coregroups>.

## VIII. Reporting Requirements

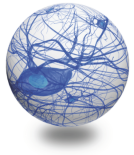
- The awardee will share a monthly progress note with the GLIA-CTN Executive Committee. This need not be more detailed than a 2-3 paragraph email summarizing key advances, challenges, etc. relevant to the project. These updates will allow the GLIA-CTN Executive Committee to more easily identify opportunities to streamline the project workflow.
- The awardee is expected to attend, and be prepared to discuss their Advocacy Advancement Award, at the GLIA-CTN Administrative Meeting following completion of their six-month award period.

## IX. Suggested Application Structure

- **Project Proposal (2-3 Pages):** Background, Approach (inc. Aims, Preliminary Data, Feasibility, and Methods), Project Timeline, and Future Directions
- **Organization Overview (1 Page):** Advocacy Organization History, Leadership Structure, Disease Focus, Nonprofit Status (If Applicable), Research Activities (if Applicable), Fundraising Activities (If Applicable), Key Initiatives/Projects

## X. Review Criteria

- Does the application meet the eligibility requirements?
- Have efforts been made to assess feasibility through consultation with GLIA-CTN technical leaders?



- Are the aims well-defined? Are data and/or tools currently available through the GLIA-CTN answer the stated aims?
- Has the applicant demonstrated how the project will advance knowledge within their leukodystrophy community?
- Can the project be completed within the standard six-month award period?

## XI. Review Process

All applications will undergo the following **two-stage** process.

- Applicants will submit a first-round application for review by the GLIA-CTN Executive Committee. Feedback will be provided to all applicants.
- Applicants with strong proposals will be invited to incorporate the Committee's feedback and submit a revised application for a final round of review.

## XII. Disorders/Topics of Interest

Proposals focused on the following key areas will be given priority during the review process: Defining burden of disease for a specific leukodystrophy, developing disease-specific educational materials, expanding the existing interactive dashboard to include new leukodystrophies and/or new domains not currently represented, or generating basic summary data to support upcoming FDA interactions such as Patient Listening Sessions and/or Patient-focused Drug Development (PFDD) meetings.

## XIII. Questions

Questions regarding the application requirements, submission guidelines, etc. may be directed to GLIA-CTN Administrative Director, Omar Sherbini, at [sherbinio@chop.edu](mailto:sherbinio@chop.edu).

