BATTEN DISEASE
Global Research Initiative

2026-2027 GRANT PROGRAM GUIDELINES

1. Program Objectives

The Batten Disease Global Research Initiative aims to invest in the most promising research around the world that seeks to address key research questions and areas of unmet need in Batten disease, or Neuronal Ceroid Lipofuscinoses (NCLs).

This may include, but is not limited to, one or more of the **Top Research Priority questions for Batten disease**, as identified in the worldwide Research Priority Setting Partnership survey conducted by the Batten Disease Clinical Research Consortium and published in *The Lancet Neurology* (Augustine EF, et al. 2025), Research priorities for the neuronal ceroid lipofuscinoses.

Top Research Priorities for Batten Disease

1. What are the best **gene-targeted therapy** options for Batten disease? How can this research be accelerated?
2. What are **valid, reliable biomarkers** that can inform Batten disease diagnosis, prognosis or treatment response?
3. What impact does Batten disease have on organs and body systems **outside the central nervous system**?
4. Can disease progression be **halted or reversed**?
5. How does Batten disease impact **cognition and behavior**? What are the best treatment strategies for these symptoms?
6. What strategies can be used to enhance **early diagnosis** (including newborn screening)? What are the impacts of early detection and diagnosis?
7. What interventions are best for **maintaining function** in Batten disease (including communication, learning, motor skills, mobility, etc)?
8. Which therapies have the potential for the **fastest translation** from bench to bedside? How do we accelerate therapy development?
9. What can be learned about Batten disease from **similar lysosomal disorders**? Which disease processes represent shared therapeutic targets?
10. Which **complementary health approaches** (including diet, supplements, exercise, etc) are helpful for improving symptoms or slowing progression in Batten disease?
11. What are the common causes and signs of **pain and distress** in the NCLs and how do we reliably measure, report, and treat pain and distress?
12. What are the optimal **clinical trial designs** for NCLs?

2. Funding

Grants of up to USD $50,000 will be awarded for projects of up to 12 months' duration. Requests exceeding this amount may be considered in exceptional circumstances where a compelling scientific rationale and budget justification are provided, subject to available funding.

Extensions or additional funding beyond the initial award period may be considered at the discretion of the BDGRI Committee, based on project progress, outcomes and available funding. Continued funding is not guaranteed. Funding will be provided by the Global Research Initiative, comprising the leading patient advocacy organizations Batten Disease Support, Research and Advocacy (BDSRA) Foundation, BDSRA Australia and BDSRA Canada, with in-kind support from the Batten Disease Family Association (BDFA), United Kingdom. In addition to the core funding collectively provided by these organizations, co-funding support will be sought from other interested parties. Additional organizations or individuals who contribute funding to specific projects under the Global Research Initiative Grant Program will be recognized as **Batten Disease Global Research Initiative Partners**.

3. BDCRC Pilot Award Opportunity

In 2025, the Batten Disease Global Research Initiative (BDGRI) established a strategic partnership with the **Batten Disease Clinical Research Consortium (BDCRC)**, an NIH-funded Rare Diseases Clinical Research Network consortium dedicated to advancing clinical research in Batten disease.

Through this partnership, eligible applicants may be considered for funding of up to USD $50,000 for 12 months through the BDCRC Pilot Project Award mechanism, which supports innovative, patient-focused research aligned with the BDCRC mission that includes human participants and/or human biospecimens. No cost extensions will not be permitted.

To be eligible for consideration, applicants must hold a faculty level or equivalent appointment at a US institution (for single-site projects) or a recognized international institution (for multi-site applications, with at least one site in the US). Pilot Projects may be awarded to institutions not already a member of the BDCRC. Pilot Projects should involve **human participants** or **human-derived biospecimens only**.

Applicants do not need to submit a separate application for the BDCRC Pilot Project Award. Instead, applicants may opt in for consideration through the BDGRI Expression of Interest (EOI) submission portal. Eligible applications may then be referred to the BDCRC leadership team for further review and funding consideration.

Funding through BDGRI and the BDCRC Pilot Project Award is mutually exclusive. Applicants may receive funding through only one mechanism for the same proposed project. Consideration for BDCRC funding does not guarantee an award and remains subject to applicable eligibility requirements, review processes and available funding.

Further information about the BDCRC Pilot Award is available here.

4. Grant Process

The BDGRI operates a two-stage application and review process, comprising an initial Expression of Interest (EOI) followed by an invited full Research Proposal. Projects eligible for funding through the BDCRC will be subject to the same application and review process, with additional eligibility assessment and funding review undertaken by the BDCRC as applicable.

Stage 1 – Expression of Interest (EOI)

Researchers are invited to submit an EOI through the online submission portal by 11:59 PM Pacific Standard Time (PST) on **Monday, 14 December 2026**.

EOIs will be assessed by the International Grant Review Panel against the published assessment criteria (Section 5), considering research quality (40%), significance and/or innovation (40%), and research team quality and capacity (20%).

Applicants whose EOIs are shortlisted will be invited to submit a full Research Proposal.

Stage 2 – Full Research Proposal

Shortlisted applicants will be invited to submit a full Research Proposal through the online submission portal, with detailed submission instructions provided at the time of invitation.

Full Research Proposals will undergo further assessment by the International Grant Review Panel, using the same assessment criteria and weightings applied at the EOI stage.

Final funding decisions will be made by the BDGRI Committee, based on the recommendations of the International Grant Review Panel and available research funding.

An invitation to submit a full Research Proposal does not guarantee funding.

5. Assessment Criteria

Research proposals will be assessed on the following criteria:

Criteria	Description	Weight
Research Quality	Are the hypotheses and objectives clearly defined? Is the project well designed and feasible? Is the proposed budget appropriate, reasonable and well justified in relation to the project objectives, proposed activities and anticipated outcomes?	40%
Significance and/or Innovation	Does the proposed research address an important knowledge gap or unmet need in Batten disease? Will it advance scientific understanding, therapeutic development, diagnosis, clinical management, care practices or patient quality of life? How readily can it be translated into clinical or practical application?	40%
Research Team Quality & Capacity	Do the researchers have the required skills and experience and capacity to carry out the project?	20%

6. Funding Decisions

The BDGRI Committee will make the final funding decision on each project, based on recommendation of the International Grant Review Panel. The BDGRI reserves the right to award no grants in any funding round.

7. Eligibility

- The Principal Investigator must have appropriate qualifications and demonstrated capacity to lead the project.
- The PI must be affiliated with an eligible research institution or organization capable of administering the grant.
- PhD students are not eligible to apply as PI but may participate as co-investigators or research team members.
- Applicants will be considered from any country.

8. Submission Requirements

Expressions of Interest (EOI) should be submitted through the online portal.

For short-listed EOIs, Principal Investigators will be invited to submit **a full Research Proposal** through the online submission portal (link provided at time of invitation).

An acknowledgement of receipt and copy of the application will be sent following submission through the portal.

Use of Generative AI

Generative AI tools may be used to assist in preparing applications. Applicants remain fully responsible for the accuracy, originality and scientific integrity of all submitted content, including references, and must certify their acceptance of this responsibility in the application form.

9. Use of Funds

Grant funds may be used for:

- Personnel
- Equipment and/or consumables that are essential to the proposed research
- Animal costs that are a direct requirement of the research project
- Travel costs directly related to achieving the objectives of the grant

Grant funds awarded through the **BDGRI program** may not be used to cover institutional overheads or indirect costs. All requested expenses must be directly attributable to the proposed research project. No cost extensions will not be permitted.

BDCRC-funded projects may be subject to different requirements regarding allowable indirect costs, in accordance with applicable NIH funding policies.

10. Confidentiality

All information contained in Expressions of Interest (EOIs) and full Research Proposals will be treated as confidential by the Batten Disease Global Research Initiative (BDGRI).

Applications will be shared only with authorised members of the BDGRI Committee, International Grant Review Panel and other individuals directly involved in the assessment and administration of the grant program, who are subject to appropriate independent peer review, confidentiality and conflict-of-interest obligations.

Where applicants have opted for consideration under the Batten Disease Clinical Research Consortium (BDCRC) Pilot Core funding opportunity, relevant application information may also be shared with authorised BDCRC personnel and reviewers for the purposes of eligibility assessment and funding consideration.

Information relating to funded projects may be publicly disclosed in accordance with the Reporting Requirements (Section 11) and the terms of the Research Agreement.

11. Reporting Requirements

A **mid-year progress report** is to be submitted to Global Research Initiative Committee (max. 1000 words).

On completion of the 12-month project the following documents must be submitted:

- A **final report** (max. 1000 words), plus a copy of any publications, published conference abstracts, conference posters and presentations; and
- A **short description** (max. 250 words) or poster written in language able to be understood by a lay person, setting out the objectives and results of the project, and accompanied by figures or images suitable for inclusion in newsletters and on the Global Research Initiative website; and
- A **financial acquittal report**
- Projects funded through the BDCRC may be subject to additional reporting requirements

Failure to meet reporting requirements without reasonable justification may affect eligibility for future BDGRI funding. The BDGRI Committee reserves the right to suspend further payments or decline future applications where reporting obligations remain outstanding.

BDGRI reserves the right to publish and disseminate non-confidential summaries of funded research, including project objectives, progress and outcomes. All materials intended for public dissemination will be provided to the Principal Investigator or grant recipient for review prior to publication, to ensure scientific accuracy and protection of confidential information, unpublished findings and intellectual property. Full scientific and financial reports will remain confidential unless otherwise agreed.

12. Acknowledgements

Acknowledgement of the support of the **Batten Disease Global Research Initiative** and any **partner organizations** responsible for co-funding, is required wherever possible, such as in publications, posters or conference presentations arising from the funded research.

13. 2026-2027 Funding Timeline

Grant round opens **Wednesday 21 October, 2026**

Deadline for submission of Expressions of Interest (EOI) is **Monday December 14, 2026** by 11:59 PM Pacific Standard Time (PST)

Successful EOIs will be notified in **March 2027.**

Deadline for invited Full Research Proposals: **Wednesday, 2 June 2027** at 11:59 PM Pacific Daylight Time (PDT).

Funding announcements will be made in **August 2027,** with an anticipated Award start date in **September 2027**.

14. Additional Conditions of Award

Research grants shall be awarded under the conditions specified above, together with the following additional conditions:

1. Applicants may be named as Principal Investigator (PI) on only one application per grant round but may participate as a Co-Investigator or collaborator on multiple applications.

2. The decision to award any grants shall be wholly at the discretion of the Batten Disease Global Research Initiative Committee, based on the recommendations of its International Grant Review Panel and available funding.

3. Successful applicants will be required to enter into a formal Research Agreement setting out the terms and conditions of funding, including ethical and regulatory requirements, financial management, reporting obligations and other applicable conditions.

4. Funded research must comply with all applicable institutional, ethical and regulatory requirements, including obtaining necessary approvals before commencement of relevant research activities.

5. A signed Research Agreement must be returned within **eight (8) weeks** of receipt of the draft Agreement. Failure to meet this deadline may result in withdrawal of the funding offer, at the discretion of the BDGRI Committee, unless an extension has been agreed in writing.

6. Funding will commence upon execution of the Research Agreement, per the agreed Schedule of Payments.

7. Projects are to commence within three months following initial grant payment.

8. Members of the BDGRI Committee or International Grant Review Panel are not automatically excluded from applying for funding. However, any member with an actual, potential or perceived conflict of interest must declare that conflict and be excluded from the assessment, discussion

and funding decision relating to the relevant application, in accordance with BDGRI conflict-of-interest procedures.

15. Further Information

Queries should be directed to research@bdsrafoundation.org