BATTEN DISEASE
Global Research Initiative

2025-2026 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 Priorities for Batten Disease**, as identified in the 2024 Research Priority Setting Partnership survey conducted by the Kennedy Krieger Research Institute in partnership with the BDSRA Foundation, in accordance with the James Lind Alliance Method.

Top Research Priorities for Batten Disease

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

2. Funding

Grants of up to USD $50,000 will be awarded for a one-year period, with potential of renewal based on outcomes in the first year. Exceptional applications may be funded at a higher amount if the budget request is justified. Awards will be granted based on available research funds.

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. Grant Process

The Global Research Initiative invites researchers to submit an Expression of Interest (EOI) per the stipulated requirements (see below). EOIs for the 2025-26 round, must be submitted no later than **midnight** in the applicant's local time zone on **September 30, 2025.**

EOIs will be reviewed by the International Grant Review Panel and short-listed on the basis of relative merit and feasibility; alignment with the objectives of the grant program; and available research funding. Principal Investigators of short-listed projects will be invited to submit a full Research Proposal using the standard application form (provided at time of invitation), which will be subject to review by the Grant Review Panel.

4. Funding Decisions

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

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?	40%
Significance and/or Innovation	Will the research increase our understanding of Batten disease, develop potential therapeutic strategies, and/or improve our current diagnosis, treatment, education and/or management practices or family support practices? How readily can it be translated into clinical or practical application?	40%
Research Team Quality and Capacity	Do the researchers have the required skills and experience and capacity to carry out the project?	20%

6. Eligibility

Eligible applicants must hold relevant professional qualifications in the proposed field of research and hold a relevant current position of employment at any level (clinician or other healthcare practitioner, assistant/associate/full professor, post-doctoral research scientist, allied healthcare professional, educator, etc) with the exception of PhD students.

Biotech industry companies are eligible to apply; however, applications must be submitted in partnership with an academic institution, with an academic investigator serving as a Principal Investigator.

Applicants will be considered from any country.

7. Submission Requirements

Expressions of Interest (EOI) should be submitted according to the requirements set out in the *Expression of Interest – Information for Applicants* document.

For short-listed EOIs, Principal Investigators will be invited to submit **a full Research Proposal** using the standard application form (to be provided at time of invitation).

All Expressions of Interest and full Research Proposals are to be submitted in PDF format by **email only** to: research@bdsrafoundation.org

An acknowledge of receipt for all submitted EOIs and full Research Proposals will be issued by email within two business days. If you do not receive an acknowledgement email, please follow up promptly.

8. 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 may not cover institutional overheads or indirect costs

9. Confidentiality

Subject to clause 10, information contained in EOIs and applications is regarded as strictly confidential unless otherwise indicated and will be received and treated as confidential by the Global Research Initiative.

10. 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**

Failure to comply with the reporting requirements will result in the grant recipient's ineligibility for the following three grant rounds.

The Batten Disease Global Research Initiative reserves the right to publish the above reports and documents.

11. 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.

12. 2025-2026 Funding Timeline

Grant round opens **Wednesday August 20, 2025**

Deadline for submission of Expressions of Interest (EOI) is **Tuesday September 30, 2025,** by midnight in applicant's local time zone.

Successful EOIs will be notified in **mid-November 2025**

Deadline for invited full Research Proposals: **Thursday January 15, 2026,** by midnight in the applicant's local time zone.

Funding announcements will be made in **March 2026**

13. Additional Conditions of Award

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

1. Each grant shall be named 'Batten Disease Global Research Initiative Grant'.
2. Applicants may only be nominated as Principal Investigator on ONE project per grant round.
3. 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.
4. Funding will commence upon execution of the grant agreement, per the agreed Schedule of Payments. Projects are to commence within three months following initial grant payment.

5. Members of the Global Research Initiative Committee and/or Grant Review Panel are not excluded from applying but must recuse themselves from reviewing any application in that grant round.

14. Further Information

Queries should be directed to research@bdsrafoundation.org