

Research Grants: Application and Approval Procedure 2014: CLN5 Batten disease RFP Guidelines



The BDFA's mission is to bring light to Batten disease by being the central point of excellence in the UK for raising awareness, supporting affected families, funding and facilitating research into the disease.

Battle Batten, is a campaign started by a family with two children affected by CLN5 disease & they have raised £20,000. All funds have been donated to the BDFA specifically for the BDFA to commission a scientific project to further the understanding of the role of CLN5 and/or for research which aims to develop effective therapies and ultimately a cure for this type of Batten disease.

The BDFA is seeking proposals for research projects and funds awarded can only be used for a project entirely focused on CLN5 research.

The award will be made in accordance with our research policy and procedures & guidelines for 2014, as stated below:

In addition the BDFA will be awarding further Research Grants for 2014-15.

BDFA Research Policy 2014-7

The BDFA seeks to facilitate scientific research into the disease mechanisms, potential cures and treatments for Batten Disease/Neuronal Ceroid Lipofusinoses (NCL). Recognition is given that research may take two forms: pure and applied. The four main areas in which applications may be made are:

1. Contributions to conferences, seminars, workshops and the publication of scientific literature. (NB Not eligible for this CLN5 award)
2. Part funding of new or existing research projects (CLN5 component of existing projects only)
3. Funding of research studentships/fellowships
4. Funding of research projects

For this CLN5 Project applications are only invited in categories 2, 3 & 4 from researchers at Universities or Research Institutions in the UK.

Any queries regarding the award process should be directed to Heather Band, BDFA Scientific Officer, heatherband@bdfa-uk.co.uk, Tel: 01243 672660.

Provisions

As a registered charity, BDFA Research Grants are conditional on recognition of the BDFA Funding contribution in the publication of subsequent research papers, other associated literature and any other form of dissemination.

All grant award(s) must be used to cover direct costs of the project/ investigation and may not be used for overhead costs.

At the conclusion of the grant funded activity, any unspent funds must be returned to the BDFA within six months. The BDFA reserves the right to relocate any equipment provided for, or purchased from, the grant if no longer used primarily for Batten Disease Research.

If a recipient's research, funded wholly or in part by the BDFA, results in any new discoveries or invention that may benefit individuals with Batten Disease/NCL, the BDFA reserves the right to use, as it deems appropriate, such discovery or invention for non-commercial research purposes.

The recipient and/or the recipients institution must inform the BFDA immediately if they are seeking to make any commercial gain, patent application or secure any property rights or to legally protect any discovery or invention (or part of) resulting directly or indirectly from the BDFA funded research.

The BDFA shall be entitled to an equitable share of any patent, proprietary right and/or commercial gain that accrues to the recipient and/or the recipient's institution resulting directly or indirectly from the BDFA funded research.

CLN5 Award £20,000

Aims of the project:

The BDFA seeks to fund excellent scientific projects & researchers to directly investigate the basic mechanisms of CLN5 Battens Disease/NCL in a variety of disciplines (e.g. biochemistry, genetics, and molecular or cell biology) or for the development of clinically related treatment approaches in the following areas:

- a) Continuation of support for existing CLN5 research projects
- b) Research Grants to part fund a PhD studentship or post doctoral researcher
- c) New or pilot studies in innovative areas of CLN5 research

The duration of the grant-funded period will, initially, be no longer than 12 months. Battle Batten is continuing to raise funds for CLN5 research with the aim of funding further research at a similar level for 2015-16 therefore proposals should also include a clear outline for a second year project extension.

The BDFA also awards funds for research in the UK into all the NCL's, which includes CLN5 research & applications can be considered under both schemes provided the criteria for each RFP are met.

For instance applications can be submitted for:

- a) Laboratory consumables for an existing funded PhD student in a recognised UK university or similar institution.
- b) Complimentary funding to complete the funding for a new PhD studentship commencing in 2014-2015 students in a recognised UK university or similar institution.

Entry Criteria:

The BDFA will only award this grant to an existing or prospective student based in an established laboratory in a recognised UK university or similar institution. The Principal Investigator and the financial status of the organisation must also meet the criteria given below in the Application procedure for the duration of the whole funding period, 2014-15.

The principle scientist must provide evidence that the new or existing studentship or Postdoc. has secured funding from their university, Institute or other recognised funding source, for their other costs for the duration of the BDFA grant funded period. The duration of the grant will be 12 months from the date of the award and will be given in agreed instalments, based on a successful interim reports.

Application Procedure- CLN5 Batten Disease Project

Submission of a completed Application Form (available from the BDFA website) together with the research proposal and other supporting information is by email to BDFA Scientific Officer heatherband@bdfa-uk.org.uk.

Closing date: 12:00HRS GMT on 31st October 2014

Evaluation of CLN5 Batten Disease Project Applications

Upon receipt of a completed application, the BDFA Scientific Officer will coordinate with the relevant assessment panel: Scientific Advisory Board (SAB) to convene a panel for peer review of the specific proposals.

This review panel will study the proposals, prioritise and make recommendations to the family and the BDFA Board of Trustees.

A formal letter will communicate the outcome of these meetings and the grant subsequently awarded, with a decision expected by 20th December 2014.

The grant awards will also be published in the BDFA newsletter & the BDFA & Battle Batten websites. The successful applicant(s) will be required to attend the BDFA conference in Autumn 2015. They must ensure that they are available for any other reasonable publicity events either personal or written for the BDFA, in collaboration with Battle Batten, that the BDFA CEO deems appropriate with respect to the grant awarded.

Review & Reporting Process

A Progress report from grant recipients will be required at six monthly intervals during the lifetime of the grant-funded project.

At the end of the funding period, a final report on the outcome must be submitted to the BDFA Scientific Officer. This report is intended for the BDFA Research Panel, relevant Advisory panel members, the family and the BDFA Trustees and can be confidential to these parties.

Regular Lay Reports will be required by the BDFA for the Board of Trustees & BDFA members, for this grant award submitted at 3 month intervals to the BDFA Scientific Officer.

For the CLN5 research project the Lay Report has a very high priority and these must be clear & informed to enable the BDFA to fully update the family & Battle Batten representatives on the progress of the project.

Lay reports may be used appropriately by the BDFA, the family & Battle Batten representatives for appropriate publicity purposes (such as newsletters or websites, further fundraising activities).

A copy of any published material shall be submitted to the BDFA Scientific Officer.

At the conclusion of the grant funded activity any unspent funds must be returned to the BDFA within six months. In all cases, a full financial breakdown, of the funds deployed, need to be submitted at the conclusion of the grant-funded period to the BDFA Scientific Officer.

Acknowledgements

All applicants are reminded that the BDFA support should be acknowledged in any publication or presentation.

Batten Disease Family Association, PO Box 504, Fleet, Hants GU51 9GE
For more information on supporting our work visit www.bdfa-uk.org.uk;
Tel: 01252 416110 Email: info@bdfa-uk.org.uk

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