

March 1, 2009

### **Special Announcement**

The Batten Disease Support and Research Association (BDSRA) is pleased to announce that limited funds are available to promote research and/or assist in a viable research project/s **primarily for**, but not limited to, **development of novel therapeutic approaches to treatment for NCL**, including the identification of bioactive compounds and characterization of cell-based therapeutic strategies, neuroimaging, proteomic and genomic approaches, and development of treatments that will alleviate the symptoms of Batten Disease. Also approaches exploring the neurobiology of NCL disease and determining the molecular pathogenesis in the CNS and further understanding the cell biology of the NCL proteins/enzymes. Proposals will be received for all forms of NCL with emphasis on CLN1, CLN2, and CLN3.

Multiyear proposals are generally discouraged unless there are extenuating circumstances or the study/project requires.

**BDSRA is including in its 2009 Request for Proposals, the establishment of a new postdoctoral fellowship or pre-doctoral studentship. Proposals for either must include the percentage of time the candidate will expend on the project. Proposal must also include letter from established scientist or lab in which the posstdoc or predoc will be working acknowledging the applicants position.** Note: Funding for second and/or third year will be predicated on review of previous work and likelihood of achieving goals. Funding will not accompany if individual changes institution or lab unless preauthorized by BDSRA.

All grant award(s) must be used to cover direct costs of the project/ investigation and may not be used for indirect or overhead costs. All awards, including Postdoctoral fellowship and predoctoral studentships, will be paid in six (6) month increments based on report submitted for review.

In the event of any changes, such changes will be announced on the BDSRA website - <http://www.bdsra.org>.

The submitted proposals must be concise: six to ten pages in length and include a working hypothesis, preliminary results pertinent to the specific investigation, available resources, research proposed, a short budget, collaborators, and the anticipated results and their significance. Include in proposal, or as attachment, your current funding, USPHS, NIH or NINDS grant(s) and private support and funding requested but not received to date. Supplementary support for funded NIH projects will not be supported. An original and nine copies of submissions to BDSRA must be accompanied by a curriculum vitae if this is your first submission to BDSRA or you have not submitted for five years or longer. Also include information relevant to any matching funds that may be available through your university/institution affiliation or other funding sources.

BDSRA will NOT accept proposals sent via email.

Applications will be peer reviewed based upon the quality of the proposed science, the probability of achieving the specific aims proposed and the likely-hood of securing federal funding or other funding for continued research.

As a condition of award the project/study must begin within six months of date of award and investigator must provide assurance that a report will be made to BDSRA within 12 months of the award date with a short interim report after six months. **Note also, awards may be made in six month installments based on a six month report that shows the project has made substantial progress and that the goal of the project will be attained.** Proposal preparation time should be minimal.

Recipients of awards from BDSRA, in addition to providing progress reports, are required to provide to BDSRA copies of any publications abstracts, etc. resulting in whole or in part, directly or indirectly, from research funded by the award. Appropriate acknowledgment of BDSRA funding must be noted in such publications. In addition, if a recipient's research that has been funded by the BDSRA results in any new discovery or invention that may provide benefit to individuals with Neuronal Ceroid Lipofuscinosis, the BDSRA shall retain the right to use, as it deems appropriate, such discovery or invention for non-commercial research purposes. Furthermore, the recipient and/or the recipient's institution shall immediately notify the BDSRA, if BDSRA funds have supported research that results in the recipient and/or the recipient's institution seeking to make any commercial gain, patent application or secure any other proprietary rights to legally protect any discovery or invention resulting, in whole or in part, directly or indirectly, from the research. The BDSRA shall be entitled to an equitable share of any patent, proprietary right and/or commercial gain that accrue to the recipient and/or the recipient's institution as a result, either in whole or in part, directly or indirectly, of BDSRA funding. The BDSRA's equitable share shall be based upon the level of contribution the BDSRA funding had on the research.

BDSRA requires models, cells and mice developed with BDSRA funds be openly shared with the scientific community upon description of their development or use in a peer-reviewed publication.

Note: BDSRA participates in two tissue repositories. Various tissues, primarily brain is available for research. Contact BDSRA for information.

Submitted proposals must be postmarked no later than 11:59PM , May 16, 2009.

Please submit proposals to:  
BDSRA  
166 Humphries Dr.  
Reynoldsburg , OH 43068 .

Inquiries may be directed to Lance W. Johnston, Executive Director, BDSRA, at 1-800-448-4570 or 740-927-4298. Email address: [bd سرا1@bdsra.org](mailto:bd سرا1@bdsra.org)