



**BATTEN  
DISEASE**  
SUPPORT & RESEARCH  
ASSOCIATION  
A LIGHT IN A WORLD OF DARKNESS



Hope 4 Bridget

*This is a sample contract to share with your university/institution as university review can be a rate-limiting step in receiving funds. Because BBDF works with several generous partners to fund contracts, this sample shows what a co-funded contract could look like.*

John Doe  
Manager, Grants and Contracts  
UMDNJ-Robert Wood Johnson Medical School  
Liberty Plaza  
335 George Street  
New Brunswick, NJ 08903

Dear Mr Doe,

It is our great pleasure to award a grant for an aggregate amount of \$100,000 US ("Grant") from Beyond Batten Disease Foundation ("BBDF"), Batten Disease Support and Research Association ("BDSRA"), and Hope for Bridget ("H4B") to University of Medicine and Dentistry of New Jersey ("UMDNJ") - Robert Wood Johnston Medical School (RWJMS) ("Grantee"). This constitutes a grant to underwrite certain costs related to research to be performed by Dr. X, as more particularly described in Grantee's 1-year grant proposal titled "Research in Neuronal Ceroid Lipofuscinosis" and briefly described in Schedule 1 ("Proposal").

Each of BBDF, BDSRA and H4B may be referred to individually as a "Foundation" or collectively as the "Foundations". The Foundations shall not be jointly and severally liable to provide the full amount of the Grant to Grantee, but each Foundation shall be obligated only to provide those amounts as more particularly set forth on Schedule 2, subject to and in accordance with the terms of this letter. In the event a Foundation fails to fulfill its commitment to fund its portion of the Grant in accordance with this letter agreement, each Foundation hereby indemnifies and agrees to hold harmless each other Foundation from and against any liability incurred by a Foundation in respect to amounts which exceed the share of Grant funds such Foundation has agreed to provide under this letter agreement (together with all costs and expenses incurred in the enforcement of the terms of this provision, including without limitation reasonable attorney's fees).

Each of the Foundations hereby appoints Danielle M. Kerkovich, PhD as its Principal Scientist for purposes of administering the Grant, determining compliance with the terms of this letter agreement, and asserting rights of the Foundations under this letter agreement. The Principal Scientist, on behalf of the Foundations, is the authorized negotiator and representative of the Foundations for this letter agreement, and as such may make such determinations, provide

such notices and take such other actions as the Principal Scientist, in her reasonable discretion, deems necessary and appropriate to administer the Grant and effectuate the intent of this letter agreement. The Principal Scientist is authorized to accept all communications from Grantee with respect to this letter agreement.

The Foundations, by unanimous agreement, may remove or replace the Principal Scientist at any time and appoint a new principal investigator or representative upon ten (10) days' prior written notice to Grantee. The Principal Scientist shall be reasonably available to consult with Grantee, and Grantee will be entitled to act in reliance upon the instructions, interpretations, and decisions of the Principal Scientist relating to this letter agreement.

Grantee shall use the Grant exclusively for the purposes and in the manner described in the Proposal. Grantee shall comply with the Expenditure Responsibility Grant Provisions attached to and made a part of this letter as Schedule 2. Foundations shall pay the Grant to Grantee in accordance with Schedule 2. If the Grantee fails to demonstrate its substantial progress toward completion of the research outlined in the Proposal, Foundations may withhold any unpaid Grant funds until Grantee demonstrates that progress toward completion has resumed. If at any time Foundations determines it to be unlikely that Grantee will complete the research outlined in the Proposal, Foundations may cancel this Grant and may withhold permanently any Grant funds then remaining unpaid.

If Grantee fails to complete the research stated in the Proposal or uses the Grant for purposes other than the research stated in the Proposal, then, within 30 days of Foundations written demand, Grantee shall refund to Foundations an amount equivalent to all of the Grant money that Foundations previously paid to Grantee, regardless of whether Grantee has expended the Grant funds. If the Grantee seeks to change his protocol in response to a recent publication, the results obtained from initial experiments, or other reasonable events, he shall make this request and any proposed changes in writing to the Foundations. Foundations may accept or reject the protocol changes recommended by Grantee. Should the Foundations accept the changes, this agreement including payment terms if appropriate, shall be changed accordingly. Should Foundations reject Grantee's proposal, Grantee must notify the Foundations within 7 days that he will abide by the terms of the original protocol or that he will cease work and return any unused Grant funds. Unused Grant funds must be returned to Foundations within 14 days.

The results and data developed as part of the Proposal shall be jointly owned by the parties. Each party grants to the other party a non-exclusive, royalty-free license to use the results and data developed solely by each other provided that each party uses such results and data only for its own internal research and educational purposes. UMDNJ - RWJMS will be responsible for filing, maintenance, and enforcement of any intellectual property and will keep Foundations reasonably informed as to any progress and developments. The parties agree to negotiate in good faith in the event that either party desires to grant a commercial license to a third party. Such negotiation and eventual sharing of any proceeds will take into account the relative contributions of UMDNJ - RWJMS and Foundations to the creation, development, and maintenance of any intellectual property.

There will be no restrictions on the joint publications of part or all of the data and/or discoveries made during the research investigation except as they may be necessary to protect

confidential information or to file patent applications. To this end, all publications will be reviewed prior to submission on behalf of the Foundations by the Principal Scientist and on behalf of Grantee by its Principal Investigator (currently Dr X). Any delay requested by either party will not exceed 90 days for the purpose of filing patent applications.

We request that the Grantee identify the Foundations as a source of funding for the Program in various communications, publications and media to staff, supporters and the public, and Grantee may use the Foundations name and logos for such purposes. We request that, to the extent it is reasonably practical and appropriate to do so, Grantee provide the Foundations with copies of such communications. We request that the grantee provide Foundations with copies of peer-reviewed publications and notifications of patents, grants and other scientific products stemming directly from this work. We also request that any listing of contributors or acknowledgements list the grant as having been awarded by Beyond Batten Disease Foundation (BBDF), Batten Disease Support and Research Association (BBDF), and Hope for Bridget (H4B).

Limited availability of platform technology such as animal models and cell lines can inhibit the timely development of new knowledge and their application to medical practice. Therefore, any materials such as these, antibodies or other research tools resulting from this funding must be entered into the commercial sector once they are published by the investigator as a condition of this funding.

Please indicate your agreement with the terms of this grant by signing the acknowledgment on the enclosed copy of this letter and returning it to me for our records. We appreciate the opportunity to support the important work of UMDNJ - RWJMS through this Proposal, and we look forward to following your progress.

Accepted and Agreed to for Beyond Batten Disease Foundation

Name: \_\_\_\_\_

Title: \_\_\_\_\_

Signature: \_\_\_\_\_

Accepted and Agreed to For Batten Disease Support and Research Association

Name: \_\_\_\_\_

Title: \_\_\_\_\_

Signature: \_\_\_\_\_

Accepted and Agreed to For Hope for Bridget

Name: \_\_\_\_\_

Title: \_\_\_\_\_

Signature: \_\_\_\_\_

Accepted and Agreed to for University of Medicine and Dentistry of New Jersey (“UMDNJ”) -  
Robert Wood Johnston Medical School (RWJMS)

Name: \_\_\_\_\_

Title: \_\_\_\_\_

Signature: \_\_\_\_\_

Accepted and Agreed to by the Principal Investigator

Name: Dr. X

Title: \_\_\_\_\_

Signature: \_\_\_\_\_

SAMPLE CONTRACT

Schedule 1

*Research Proposal for Beyond Batten Disease Foundation, Batten Disease Support and Research Association, and Hope for Bridget*

**Research in Juvenile Neuronal Ceroid Lipofuscinosis**

Dr X, PhD, University of Medicine and Dentistry of New Jersey (UMDNJ) - Robert Wood Johnston Medical School (RWJMS)

**PUBLIC PROPOSAL SUMMARY/ABSTRACT (Application page 5, May be shared/disseminated by the Foundations once this grant contract has been executed)**

Clinical trials for the neuronal ceroid lipofuscinoses (NCLs) include gene therapy for late infantile NCL (LINCL), stem-cell therapy for infantile NCL (INCL) and LINCL, and small molecule therapies for INCL and juvenile NCL (JNCL). Clinical trials are also planned for enzyme replacement therapy in LINCL and there are

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SAMPLE CONTRACT



## Schedule 2

### *Expenditure Responsibility Grant Provisions*

1. *Separate fund.* All Foundations grant monies received by Grantee must be maintained in a separate fund dedicated to the charitable purposes described in this letter. Such a separate fund may be either (1) a physically separate bank account restricted to the described charitable purposes, or (2) a separate bookkeeping account (limited to the described charitable purposes) maintained as part of your financial records. The Foundations encourage, whenever feasible, the deposit of grant funds in an interest-bearing account.

2. *Reporting.* Written reports signed by an appropriate officer of Grantee must be furnished to the Foundations from time to time but no less frequently than as set forth below in Progress Report Schedule. Within two (2) months following the fiscal year end in which Grantee completes its use of all grant funds, a final written report is to be furnished to the Foundations with respect to all expenditures under the grant. Written reports must be submitted to Foundations designee (currently Danielle M Kerkovich, PhD).

Each written report, including the final written report, must contain two parts: a narrative account and a financial account of what was accomplished by the expenditure of the grant funds during the period covered by the report.

A. Narrative Account. The narrative account should provide a detailed description of what was accomplished by the grant, including a description of the progress made toward achieving the goals of the grant and an assurance that the activities under the grant have been conducted in conformity with the terms of the grant.

B. Financial Account. The financial account should provide a financial statement reporting, in U.S. dollars, all expenditures of Foundations grant funds and any income earned on those funds. The financial statement should include only Foundations funds received and expended under this grant during the period covered by the report. It is assumed that the financial statement will be prepared from books and records maintained on a fund accounting (cash) basis. Only expenditures made in support of the grant purposes should be charged against the grant, and records should be maintained of such expenditures adequate to enable the use of such funds to be checked readily.

If written reports are not submitted to Foundations on a timely basis, United States law requires that Foundations withhold further payments, if any, to Grantee and prohibits Foundations from awarding any new grants to Grantee.

C. Progress Report Schedule:

Grant Start Date: [December 1, 2012]

Mid-Progress Report: [April 15, 2013]

Final Report: [January 15, 2014]

Publications, Patents, Grants [see page 3]

3. *Record Maintenance and Inspection.* Grantee shall maintain records of receipts and expenditures of the Grant in sufficient detail to show that Grantee expended the Grant for the purposes and in the manner outlined in the Proposal. Grantee shall make its books and records relating to the Grant available to Foundations for inspection at reasonable times.

4. *Right to Audit.*

- a. Financial Audits. During the term of this Grant and for a period of up to two years after expiration or termination of this Grant, Foundations shall have the right to audit, upon reasonable notice, any of Grantee's records related to this Grant, including contracts with third parties and financial records relating to Grantee's performance under this Grant. Grantee shall refund any sums determined to be due to Foundations as a result of such an audit immediately after delivery of the audit report to Grantee.
- b. Operational Audits. Foundations shall have the right, upon reasonable notice to Grantee, to observe and to audit Grantee's adherence to the Proposal. Such an audit may include on-site inspection of Grantee's facilities, equipment, records and other documentation related to Grantee's performance of this Grant and also may include in-person or remote interviews of personnel working on the Grant. .

5. *Payment Schedule.* Foundations shall pay Grantee the Grant funds in accordance with the following schedule. Foundations reserves the right to withhold any payment if it determines that Grantee has failed to make substantial progress toward completion of the work outlined in the Proposal:

## Sample Values

Payment Schedule	Foundation	Amount in USD	Date
Start-Up Payment: \$	BBDF	21,110	December 1, 2012
Start-Up Payment: \$	BDSRA	5,000	December 1, 2012
Start-Up Payment: \$	Hope for Bridget	8,619.50	December 1, 2012
Final Payment: \$	BBDF	21,110	June 1, 2013
Final Payment: \$	BDSRA	5,000	June 1, 2013



Final Payment: \$	Hope for Bridget	8,619.50	June 1, 2013
<b>Totals</b>	<b>Foundation</b>	<b>Amount in USD</b>	
Foundation 1 Total	BBDF	42,220	
Foundation 2 Total	BDSRA	10,000	
Foundation 3 Total	Hope for Bridget	17,239	
Grant Total		69,459	

6. *Return of Unused Funds.* Any grant funds, and any income earned on those funds, that are not spent or committed for the purposes of the grant, must be returned to the Foundations.

SAMPLE CONTRACT