

Beyond Batten Disease Foundation Progress Report Guidelines

Beyond Batten Disease Foundation (BBDF) Progress and final reports serve several functions:

Progress and Final Reports are a formal requirement for individual accountability and compliance with the Hypotheses, Specific Aims and Experimental plans as stated in the grant contract between BBDF and the recipient institution; acknowledged by the institutional designee responsible for conducting the work.

Progress and Final Reports provide BBDF the opportunity to develop a fluid understanding of BBDF-funded progress and its relationship to emerging findings relevant to progress in juvenile Batten (CLN3) disease research. Therefore, information contained therein is critically important to the continuing development of BBDF's research portfolio and pipeline of activity to therapy. For example, poor outcomes resulting from the use of existing research tools may prompt BBDF to contract with commercial entities to create new, more valuable tools providing the Investigator and the greater Batten disease research community with additional resources.

Often, Progress Reports present BBDF with an opportunity to accelerate the work by providing the Investigator with access to contracted expertise, introductions to commercial partners, or supplemental funding. As an organization dedicated to finding a cure to this disease, we are investing in the success of each program we fund.

Progress and Final Reports are NOT a source of information for reporting to either the research or nonscientific community about the achievements and outcomes of BBDF-funded programs. Because this is contradictory to some nonprofit medical research programs, we want to be certain you understand what will or will not be publicly disclosed. The Public Summary, created by the Investigator and approved by the recipient institution and located in the signed grant contract is the only source of information that will be used for reporting other than published abstracts, public presentations given by the investigator, and peer-reviewed publications. All Progress and Final reports are kept confidential.

Beyond Batten Disease Foundation Progress Report Guidelines

I. *Restate the following from the Original Grant Contract (cut and paste)*

- a. Proposal Title
- b. Specific Aims
 - i. Experimental Plans for each
- c. Personnel
- d. Start, progress, and final report date(s)
- e. Budget

II. *Using the original grant as a guide, report the progress of the Experimental Plans in each Specific Aim*

- *If the original aims remain the same, there is no need to reintroduce your grant. The original title and Specific Aims will suffice.*
- *Write this section as you would for a scientific peer-reviewed paper. Do not use lay language.*
- *Use figures and associated legends as you would when you publish your results. Ideally, these figures will be used in your future publications. If you do not anticipate publishing the data (i.e. negative data), we do want to see it but do not want you to spend time making it presentation-worthy. Excel Spreadsheets and other quick listing formats should be used.*
- *If the data does not substantiate drawing conclusions at this time, please don't draw them. Often, awardees feel pressured to report good news. The purpose of BBDF progress reports is to objectively determine whether the recipient institution and its designee are compliant with the hypotheses and experimental plans and whether there is an opportunity to increase the speed or likelihood of success of ongoing investigations in juvenile Batten (CLN3) disease.*
- *Do cite peer-reviewed publications where applicable. Ideally, each progress report will contribute to your published paper(s).*
- *Do include a referenced Materials and Methods section. This should be an expanded version of the original Materials and Methods section. Please cut, paste, revise and expand. Please don't refer your progress report reviewer back to your application.*

MATERIALS AND METHODS
1.1 AAV2/9 Virus Preparation - describe
1.2 Antibodies Used - describe
1.3 Primers Used for qPCR - describe
Etc

III. *Proposed Changes to the Grant Contract*

- *Any changes > 20% to the Specific Aims or Experimental Plan of Action must be acknowledged and agreed to by BBDF as needed. Research is ever-changing. This requirement is more relevant to keeping the foundation abreast of the status of funded proposals than approving or disapproving those changes.*
- *Include information on current or anticipated delays and their expected impact on the project. If no challenges and/or difficulties are identified in the progress reports, it is unlikely that requests for extensions, with or without cost, will be supported. All extension requests will be considered on a case by case basis, and BBDF does not guarantee that requests for extensions will be granted.*

IV. *Budget*

- *A report of the current status of the budget must accompany each progress and final report.*
- *BBDF will not approve the continual processing of invoices if the grant account is significantly underspent.*
- *Invoices for grant payments will not be honored until submission and approval of progress reports.*

V. Summary

- *The Summary should answer the “so what?” question – why do we care, and how will the achievement impact juvenile Batten (CLN3) disease research and/or therapy development. The Summary should be a single short paragraph.*