



www.barthsyndrome.org

2009 FULL RESEARCH GRANT APPLICATION GUIDELINES AND REQUIREMENTS

Each grant application submitted to the Barth Syndrome Foundation, Inc. (BSF) must be no more than 15 pages in length (plus budget and other requested attachments), single-sided, using a font size of 12 points, and with margins of one inch. Each grant application *must* contain the following elements in order to be considered complete:

1. A completed information form (a template is provided).
2. An abstract summarizing the project, including a statement of what issue the project addresses, a description of why the work is important to either the furthering of knowledge about Barth syndrome or the treatment of individuals with the disorder, and a description of how the project will be accomplished. (*Note*: this abstract may be used for BSF publicity purposes). (1 page)
3. A section presenting the specific aims of the project, stating both the objectives and the hypotheses to be tested in the project. (1-2 pages)
4. A discussion of the background and significance of the work proposed, including a critical evaluation of previous research and existing knowledge, specifically identifying the gaps that the project is intended to fill, and explicitly stating the importance of the proposed research. (2-4 pages)
5. A *thorough* summary of research design and methods, describing the experimental design and methods that will be used to accomplish the specific aims. Include how the data will be collected, analyzed and interpreted. Describe any new methodology and its advantage over existing techniques. Discuss any potential difficulties and limitations of the proposed procedures and what alternative approaches could be used to achieve the project's aims. Provide a timetable for the project. (5-10 pages)
6. A statement indicating whether human subjects or vertebrate animals will be involved in the research. If the project will include either or both of these, then additional documentation will be required by BSF, as stated below.
7. A description of the resources and environment available for the project. This should include facilities, laboratory space and major equipment that are pertinent to the project. Also describe any procedures, materials or situations that may be hazardous to personnel and the planned precautions to be exercised.

8. A list of project personnel (name, title, institution, and role on the project), including the percentage effort that each person is expected to devote to the project.
9. A detailed budget for the proposed project (a template is provided), along with a narrative fully describing and justifying the expenses. Submit *one page for the total amount* requested as well as *one for each year of the grant* (if the proposal is for more than one year). Grant funds will be disbursed by BSF semi-annually, based on these budgets. Unless you specifically state otherwise, it will be assumed that one half of the full-year funds will be disbursed (and spent) in each of the two six-month periods comprising that year. (If you would like to request disbursement at a different rate than that, then a separate budget form for each six-month period must be completed.)

Funding requests may be as much as US \$40,000 in total (including indirect costs) and may be requested over a one- or two-year period. Indirect costs included in the project are limited to 10% of the grant amount. Salary of the PI(s) is not expected to be included, except in an extraordinary circumstance. If this request is included in the application, please provide a detailed explanation.

- **In addition to the application described above, several specific documents are required:**

1. Biographical information regarding the principal investigator(s), preferably in NIH format. If needed, an explanation of this format can be found in .PDF format at <http://grants1.nih.gov/grants/funding/phs398/biosketchsample.pdf>
2. Regulations require that all institutions maintain appropriate policies and procedures for the protection of human subjects. If applicable, please provide a copy of the informed consent form for any human subjects for the proposed project as well as proof of current or pending approval by an Institutional Review Board (IRB) (or a similar oversight group). (NOTE: Funding for the project, if the grant is approved, will not be released by BSF until the final IRB approval has been secured and a copy, including the approved informed consent form, has been received by BSF.)
3. In keeping with BSF policy, all proposals must conform to regulations for the safe and humane treatment of animals. If applicable, please provide proof of current or pending project approval by the institution's Animal Use and Protection Committee (or a similar oversight group). (NOTE: Funding for the project, if the grant is approved, will not be released by BSF until the final Animal Use and Protection Committee approval has been secured and a copy has been received by BSF.)
4. A list of three individuals (names, titles, addresses and telephone and e-mail contact information) whom you think would be appropriate outside reviewers for your grant proposal. These individuals must be qualified to review your application, have not worked with you during the last three years, and have no conflict of interest.

- Only proposals written in English can be considered.

- Incomplete applications will not be accepted.
- Send an electronic version of the full application (in .doc format, please) and all the attachments to [mtoth\[at\]barthsyndrome.org](mailto:mtoth@barthsyndrome.org) by 5:00pm (US Eastern Time) on **Saturday, October 31, 2009** (with absolutely NO extensions).
- In addition, one paper copy of the grant application, with a signature, must be received by the Barth Syndrome Foundation, Inc. by **Saturday, October 31, 2009** (with absolutely NO extensions) at the following address:

Matthew J. Toth, Ph.D.
Science Director
Barth Syndrome Foundation, Inc.
132 Creemer Avenue
Iselin, NJ 08830
USA

Submissions by fax will not be accepted, and **there will be no extensions of the deadline.**

- Acknowledgement of BSF's receipt of the grant application will be sent by mail and/or e-mail to the principal investigator within 14 days of the receipt of the document.
- Grant applications will be reviewed by the BSF Scientific and Medical Advisory Board (and, when needed, selected outside reviewers), and recommendations will be forwarded to the BSF Board of Directors. The proposals will be scored on the basis of:
 1. Importance and impact – the extent to which the research outlined could make a significant contribution to the understanding of Barth syndrome or the treatment of the disorder
 2. Feasibility – the qualifications of the investigator(s) to carry out the proposed work, based on expertise, experience, commitment; as well as the availability of all the elements required for the project (such as technology, reagents, and human subjects)
 3. Prospect of Long-term Funding – the likelihood of subsequent NIH or other major funding for any potential follow-on work (if appropriate)
- Notification of the BSF Board of Directors' decision regarding whether or not to award the grant will be sent by mail on February 28, 2009. We request no telephone inquiries. All decisions are final.
- Please follow these instructions *precisely*.



Barth Syndrome
Foundation

www.barthsyndrome.org

2009 GRANT APPLICATION INFORMATION FORM

Principal Investigator:

Name (Last, First, Middle Initial) _____

Title _____

Department _____

Institution _____

Full Mailing Address _____

City _____ State _____ Postal Code _____ Country _____

Telephone _____ Fax _____ E-Mail _____

Institutional Information:

Division or Department Head:

Name _____

Title _____

Telephone _____ Fax _____ E-Mail _____

Authorized Institutional Officer Signing for Organization:

Name _____

Title _____

Mailing Address _____

City _____ State _____ Postal Code _____ Country _____

Telephone _____ Fax _____ E-Mail _____

Fiscal Official to Whom Funds Should be Sent:

Name _____

Title _____

Mailing Address _____

City _____ State _____ Postal Code _____ Country _____

Telephone _____ Fax _____ E-Mail _____

Exact Name of Institution or Account to Which Checks Should be Made Payable:

Project Title:

Proposed Starting Date for the Project: _____

Project Funding Request:

TOTAL Funds Requested \$ _____ (U.S.) – NOT TO EXCEED US \$40,000

To be Paid Over: One Year Period _____ Two Year Period _____

This Project Will Involve the Following:

Human Subjects: No ____ Yes ____ - *If yes, please submit institutional approval*

Vertebrate Animals: No ____ Yes ____ - *If yes, please submit institutional approval*

I confirm that all of the information contained in this grant application is accurate and not misleading. I agree to accept responsibility for the scientific direction and conduct of this project. I certify that I have read the attached research grant policies of the Barth Syndrome Foundation, Inc. and that I will abide by them, if this grant is awarded. I acknowledge that I am aware that all decisions about grant applications made by the Barth Syndrome Foundation, Inc. are final and are not subject to appeal.

Name of Applicant (*please print*) _____

Signature of Applicant _____

Date _____

I confirm that all of the information contained in this grant application is accurate and not misleading. I agree to accept oversight, legal and financial responsibility for this project. I certify that I have read the attached research grant policies of the Barth Syndrome Foundation, Inc. and that the institution I represent will abide by them, if this grant is awarded. I acknowledge that I am aware that all decisions about grant applications made by the Barth Syndrome Foundation, Inc. are final and are not subject to appeal.

Name of Institutional Officer (*please print*) _____

Signature of Institutional Officer _____

Date _____

Attachment: Barth Syndrome Foundation, Inc. Research Grant Policies



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Barth Syndrome Foundation, Inc. Research Grant Policies

- Protecting the rights and welfare of human research participants is a top priority of the Barth Syndrome Foundation, Inc. (BSF). Federal regulation and BSF policy require that all institutions maintain appropriate policies and procedures for the protection of human subjects. In addition, BSF encourages a research environment in which ethical and productive investigation is valued. If applicable, a copy of the informed consent form for any human subjects for the project as well as proof of current project approval by an Institutional Review Board (or a similar oversight group) must be provided to BSF before funding for a project will be released by BSF.
- Similarly, it is a BSF policy that all projects must conform to regulations for the safe and humane treatment of animals. Specifically, BSF stipulates that animals can be used in BSF-funded research only when no other means of obtaining scientifically sound, valid and useful results are available. Furthermore, only the minimum number of appropriate animals required to obtain and validate results should be used; and in cases requiring the death of an animal, only the most appropriate and humane form of animal sacrifice consistent with the purpose of the research shall be employed. If applicable, a copy of proof of current project approval by the institution's Animal Use and Protection Committee (or a similar oversight group) must be provided to the BSF before any funding for the project will be released by BSF.
- It is BSF's expectation that any results and accomplishments from research it has funded will be made public (preferably through a high quality, peer-reviewed journal article) in order to maximize progress toward improved understanding, treatments and ultimately the discovery of a cure for Barth syndrome. BSF also expects that products resulting from research funded by the organization will be made available to other researchers on a reasonable basis. BSF considers an optional one-year period of exclusivity for the creator laboratory to be reasonable. Furthermore, it is expected that such products will be made available to non-commercial laboratories at cost and to commercial enterprises for a reasonable licensing fee.
- BSF will not challenge any decisions concerning patent applications that might be made by a grantee for inventions resulting from work performed under a BSF research grant. All inventions or discoveries made in whole or in part with funding from BSF must be reported to BSF at the earliest practical time. The grantee also must notify BSF immediately of any decision to apply for a patent or other legal protection. This information will be kept confidential.

- BSF will forward funds for the project to the institution every six months in accordance with the project's approved budget, following BSF's receipt of a signed statement from the principal investigator and an authorized institutional officer confirming adherence to BSF policies and stating that the project is proceeding in accordance with the original plan, timetable and budget (or explaining variations from the original expectations). BSF will send the required statement to the principal investigator 30 days prior to the time when the next payment of funds is anticipated, and it must be signed and returned before funds can be released. (A sample of the standard BSF form for this is included at the back of this document, for your information.)
- In any published report of research funded in part or in whole by a BSF research grant, BSF must be cited as a source of funds, and BSF must be sent a copy of the published material or paper.
- Within 60 days of the end of the grant period, it is required that a type-written report by the Principal Investigator on the research that resulted from the BSF grant be sent to BSF. In addition, a layman's summary (which can be published by BSF as is or in edited form) must be submitted. If the grant is for more than a one-year period, then a type-written progress report must be issued by the Principal Investigator at the end of each year on the grant commencement date anniversary and sent to BSF.
- A final detailed accounting of the funds spent is required to be sent to BSF within 60 days of the end of the grant period. If the grant period is longer than one year, then annual financial reports must be filed with BSF on the grant commencement date anniversary. At the end of the grant period, any unused funds must be returned to BSF, unless a letter explaining the situation and requesting an extension of the grant period (without additional funds) is submitted at least 90 days ahead of the end of the grant period and approved by BSF.
- Any change in a budget *category* equal to or greater than 10% of the total research grant amount must be requested ahead of time by the Principal Investigator to BSF in writing and must be approved by the BSF Board of Directors before being executed.
- BSF must be notified immediately if there is to be any change of either the Principal Investigator or the Institution with which he/she is associated. Furthermore, if the Principal Investigator is to be absent from the grantee Institution for a time of more than 30 days, then BSF must be notified. BSF reserves the right to request a written status report on the progress of the research project as well as an accounting of the funds spent as of the request date and to determine the final dispensation of any research grant funds remaining in any such situations.
- BSF reserves the right to suspend or cancel a grant at any time at its sole discretion for failure to abide by BSF policies governing research grants. Upon receiving notice of project suspension or cancellation, BSF's financial support of further work on the project will cease. At that point, the Principal Investigator must prepare and submit a project status report to BSF, while the grantee's institution must submit a complete accounting of funds expended to date. All unused funds must be returned to BSF immediately upon its

request. A grantee may terminate a grant by sending notice in writing to BSF, providing BSF with both a written accounting of funds expended to date and a project status report, and returning all unused funds to BSF.

- To properly evaluate the applications, each research grant proposal will be reviewed by members of the BSF Scientific and Medical Advisory Board (SMAB) who have not also submitted applications in that grant cycle. Outside reviewers may be utilized as well if the subject matter of a particular application warrants enlisting outside expertise. The applicant should furnish BSF with a list of three individuals who would be appropriate outside reviewers. These individuals must be qualified to review your application, have not worked with you during the last three years, and have no conflict of interest. In addition, the applicant should make known to BSF at the time of application submission if there are any BSF SMAB members or other outside experts whose review of the application would constitute a conflict of interest.
- Some information about research grants awarded by BSF will be made available to its constituents and to the general public. This information will include the title of the project, the Principal Investigator, the grantee Institution, the amount of the grant award, and the abstract provided as part of the grant application. No privileged or confidential information or trade secrets previously identified as such to BSF will be divulged.
- The nature of this arrangement is a funding agreement; no employment or agency relationship is hereby created.
- The Principal Investigator and the grantee Institution indemnify and hold harmless BSF, its Board, officers, agents, advisors and constituents from any claim, judgment, award, damage, settlement, liability, negligence or malpractice arising from research or investigation related to this BSF research grant.

BARTH RESEARCH GRANT APPLICATION BUDGET FORM

Complete one Budget Form for the **TOTAL** project budget and a separate one for each year of the project (NOTE: the annual figures will serve as the basis for funds distribution -- one half of the annual amount will be disbursed semi-annually unless explicit six-month budgets are submitted in addition); **list all amounts in US \$.**

Budget Categories as listed: _____ **Time Period:** _____

Salaries and Benefits (listed by individual): (NOTE: Salary of PI(s) is not expected to be included, except in an extraordinary circumstance)	
SUBTOTAL	
Equipment and Supplies (listed by category):	
SUBTOTAL	
Patient Care (itemized by type of expense):	
SUBTOTAL	
Other (itemized by type of expense):	
SUBTOTAL	
TOTAL DIRECT COSTS	
TOTAL INDIRECT COSTS (not to exceed 10% of total)	
TOTAL (Direct + Indirect) COSTS	
NOT TO EXCEED US \$40,000	



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**STATEMENT REQUIRED TO BE SIGNED EVERY SIX MONTHS
BEFORE DISBURSEMENT OF BARTH SYNDROME
FOUNDATION, INC. RESEARCH GRANT FUNDS**

I confirm that the research entitled "XXXXXX" that I am conducting with funds from the Barth Syndrome Foundation, Inc. and/or its affiliates is proceeding as was outlined in the research grant proposal in terms of the project design, methods and personnel and that it is on schedule and within budget. I certify that I have abided by the research grant policies of the Barth Syndrome Foundation, Inc. and shall continue to do so. I have described any deviations from expectations in any of these facets below:

Changes in research design, methods or personnel: _____

Changes in schedule: _____

Changes in budget or spending: _____

Name of Principal Investigator (*please print*) _____

Signature of Principal Investigator _____

Date _____

I confirm that the research entitled "XXXXXX" that is being conducted by "YYYYYYY" with funds from the Barth Syndrome Foundation, Inc. and/or its affiliates is proceeding as was outlined in the research grant proposal. I verify that the work is being executed according to the timetable described in the research grant proposal and that funds are being expended according to plan in terms of the use of funds, amounts and timing of expenditures. I certify that the institution I represent has abided by the research grant policies of the Barth Syndrome Foundation, Inc. with respect to this research project and that it shall continue to do so. I have described any deviations from expectations in any of these facets below:

(Continued)

Changes in timetable: _____

Changes in spending: _____

Name of Institutional Officer (*please print*) _____
Signature of Institutional Officer _____
Date _____