

SMA Foundation Research Funding Program Guidelines

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Policies and Instructions for Research Funding Applications

Background

The mission of the Spinal Muscular Atrophy Foundation is to accelerate the development of a treatment or cure for SMA. We seek to fund research projects which are immediately relevant to translational research leading to a treatment and focused on drug discovery and clinical development of SMA therapeutics.

Authority for Making Funding Allocations

Research Awards are made by the Board of Directors of the SMA Foundation acting on the recommendations of the President, the Executive Committee and the Scientific Advisory Board.

The SMA Foundation reserves the right to change the Research Program Funding Guidelines at any time. The SMA Foundation reserves the right to cancel an award for cause at any time and require the return of funds.

Regulatory Standards

Research and clinical protocols must conform to legal and regulatory standards established by the FDA and other government agencies.

Eligibility to Receive Funds

Awards are given only to qualified organizations and institutions to support research on SMA. Funding is provided upon execution of Sponsored Research Agreement with the Foundation.

Basic Considerations in Making Awards

In considering research proposals, the SMA Foundation takes into account:

1. Purpose of the research program and plan of study submitted;
2. Fit with established priorities, policies and timelines;
3. Qualifications, experience and abilities of the applicants;
4. Intent and freedom to share data and/or research tools with the SMA community;
5. Spirit of cooperation for collaboration projects of the Foundation
6. Facilities available.

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Funding Period

Each application submitted should contain a detailed budget. Although program content may be approved for two or three years, funding is authorized for one year at a time, and/or contingent upon satisfactory completion of milestones and deliverables.

Renewal Request

All current awards may be eligible for competitive renewal upon application by the Principal Investigator.

Human Subjects

If human subjects are used in the proposed study, a certification form must be provided to the SMA Foundation indicating that the Institutional Review Board has approved the proposed study. Human subjects studied in the course of research conducted under a grant are under no circumstances a responsibility of the SMA Foundation. Human subjects in a program supported by the SMA Foundation shall be volunteers in any survey, study or procedure.

Consent Form

A sample of the form approved by the grantee institution for the purpose of obtaining informed consent must be submitted with the application.

Animal Studies

If animals are used in the proposed study, a certification form must be provided to the SMA Foundation indicating that appropriate precautions have been taken to assure that proper treatment, care and humane conditions have been provided.

Cost Items

Acceptable DIRECT COST Items

1. Salaries of professional staff without faculty appointments, and technical assistants.
2. Minimal but essential permanent equipment. Any permanent equipment must be directly relevant to the SMA Foundation research grant.
3. Expendable supplies.
4. Other expenses relevant to the conduct of the research.
5. Travel: Not to exceed \$1,000 per meeting to attend scientific meetings. Any travel must be directly relevant to the SMA Foundation research grant.

Indirect Costs - The SMA Foundation has an indirect cost cap of 15% and is unable to exceed this cap under any circumstances.

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Budget Items That Are Not Generally Acceptable

1. Salary for the Principal Investigator or participants with faculty appointments.
2. Construction, alteration, maintenance, or rental of buildings or building space.
3. Computer equipment, office equipment and furniture.
4. Dues for membership in scientific societies.
5. Tuition.
6. Publication costs.
7. Books and journals.
8. Service contracts.
9. Waste disposal.
10. Glassware washing.

Prohibition of Discrimination

No person shall be excluded from participation in or denied the benefits of any program or activity receiving financial assistance from the SMA Foundation because of race, ethnic origin, religion, sex, handicapping condition or disability or sexual orientation.

Amendment of Policies

The SMA Foundation reserves the right to modify or amend its policies governing research awards. The recipient agrees to abide by any changes or to terminate the award at the time when such changes become effective. Failure to abide by the policies governing awards or amendments shall be considered sufficient grounds for cancellation of the award or a refusal to consider any pending application by the recipient.

Research Award Administration Policies

Research funding awards from the SMA Foundation are made to the investigator and his/her sponsor institution. Specific terms for each award are laid out in our Sponsored Research Agreement which must be signed by all parties in order to initiate payments. Generally, the following guidelines are established:

Conformity with Budget

Transfer of funds into, within, and out of an approved line item is permitted for up to 20 percent of the approved category amount. Requests for revisions exceeding 20 percent should be received three months prior to the termination date of the research term. Such transfers may not increase SALARIED PERSONNEL or TRAVEL. Any purchase of permanent equipment not authorized in the original budget must have prior approval by the Foundation.

The SMA Foundation reserves the right to a refund, on demand, for all award funds that have been expended in unauthorized ways. The recipient institution is responsible for any unauthorized or excessive expenditures made.

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Financial Accounting

The recipient institution is required to submit to the SMA Foundation a detailed accounting report of expenditures, 90 days after completion of the research term. Periodic interim accounting reports may be requested by the SMA Foundation.

All unexpended funds must be returned to the SMA Foundation along with a final accounting report.

When a recipient investigator or institution has more than one award from the SMA Foundation, excessive expenditures in one award may not be offset by unused funds in another.

Payments to the institution for ensuing awards will be contingent on receipt of any outstanding final accounting reports and refunds as applicable.

The SMA Foundation reserves the right to audit the institution's financial records pertaining to the award.

Payment

Payments are made upon execution of the Sponsored Research Agreement and review/approval of scheduled research reports.

Obligations of the Recipient

In accepting a funding award the applying institution undertakes that at its conclusion it will:

Submit promptly to the SMA Foundation a complete final report on the work pursued. On awards of more than one year in duration, periodic reports will be expected upon which renewal will be contingent.

Supply an accounting of funds received from the SMA Foundation and expenditures made in such detail and in such manner as may meet Internal Revenue Service procedures.

In addition, periodic progress reports may be requested via telephone by the SMA Foundation and its Scientific Advisory Board.

The progress report is confidential and available only to the SMA Foundation and the Scientific Advisory Board.

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Transfer of Award

On written request by the principal investigator, transfer of a research funding award to another institution will be considered by the SMA Foundation. The written request should include the new position, department, institution, effective date, and facilities available.

Extension of Research Period

An extension, without supplemental funds, of the termination date of a grant will be considered by the SMA Foundation on written request by the Principal Investigator. It must be requested at least three months prior to the termination date of the grant.

Responsibilities of Principal Investigator

If the principal investigator is unable to complete the research approved because of illness, departure from the institution, or other major cause, this matter must be brought immediately to the attention of the SMA Foundation.

Personnel

Personnel compensated in whole or in part with funds from a grant of the SMA Foundation shall not be considered employees or agents of the SMA Foundation. If there are changes in the professional personnel or doctoral rank participation in this research, the credentials of new personnel should be submitted to the SMA Foundation at the earliest possible date.

Patents and Discoveries During Sponsored Research Term

All inventions made with the support in whole or in part by SMA Foundation funds must be reported as per the terms outlined in the Sponsored Research Agreement. The recipient agrees to notify the SMA Foundation immediately of the decision to apply for letters of patent or other legal protection for intellectual property. The SMA Foundation agrees to keep all information regarding such application confidential.

The SMA Foundation reserves the right to share in any proceeds from an invention or discovery developed under the award as outlined in the Sponsored Research Agreement. This right may include the sharing of licensing fees and royalties.

The SMA Foundation reserves the right to share discoveries among SMA Foundation partners following a reasonable time frame for exclusivity. Because the SMA Foundation funds scientific research in order to advance its mission, any patent and royalty revenue received by the SMA Foundation will be reinvested into its research program.

Ownership of Purchased Materials

All apparatus and materials purchased and all scientific equipment and instruments paid for with grant funds of the SMA Foundation shall be the property of the grantee institution.

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Data Dissemination

SMA Foundation grantees are required to participate in an annual meeting of investigators to discuss their findings in a confidential setting.

Publications

Each recipient is obligated to furnish the SMA Foundation with one reprint or copy of any published report of research sponsored in part or in full by the SMA Foundation. Any such publication should carry a credit line reading, "Supported [in Part] by the SMA Foundation."

Publicity on Sponsored Research

The grantee institution will cooperate with the SMA Foundation in announcement through the news media of awards made, subject to the Principal Investigator's approval of the content of any news release prepared by the SMA Foundation.

The grantee will notify the SMA Foundation 30 days prior to any advertising or promotion relating to the results of the sponsored research. Notification should include a copy of the materials intended for release and detail fully the nature of the information to be divulged and the time, place and manner of its presentation.

The recipient institution, the principal investigator and personnel working under the award will cooperate fully with the SMA Foundation in the written, photographic, filmed, broadcast or other forms of materials prepared to publicize work under the award.

Research Exhibits

Any exhibit prepared for a scientific or professional meeting or assembled by anyone associated with the work covered by a grant shall be presented or described to the SMA Foundation prior to its use. Notification will be made in writing if the exhibit is to display credit, "Supported [in Part] by the SMA Foundation." This credit does not imply the endorsement of the SMA Foundation for any of the procedures or results of the project.

Payment Acknowledgement and Financial Reporting

Each institution is asked to do the following in regards to grant payment acknowledgement and financial reporting:

Payments

- Notify the Foundation upon receipt of payments. Account managers can email Kelly Howell at khowell@smafoundation.org

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upon institutional receipt of any wire or check payments.

- Notify the Foundation upon deposit of the payment into the project accounts. The departmental administrator and the investigator should confirm transfer of project funds into the active project accounts with an email to Kelly Howell at khowell@smafoundation.org
- Please cc the principal investigator and Kelly Howell at khowell@smafoundation.org on all financial correspondence.

Financial Reporting

- Per our sponsored research agreements, periodic financial reports are required along with scientific progress updates 3 or 4 times a year (depending on the individual contract). We ask that institutions provide these reports using the form attached. This form is designed to conform to the approved budget for the project and should reflect all payments received, expenditures for the current budget period, and the cumulative expenditures for the research term.
- The Foundation reserves the option to request additional budget details as needed. Generally, this detail will be needed to verify salary and major purchase expenses.
- At least once a year, the comptroller's office should approve and sign-off on a scheduled financial report, certifying that the report reflects the audited accounts of the institution.
- Financial reports should be sent electronically to the attention of Kelly Howell at khowell@smafoundation.org together with the appropriate scientific progress reports.
- Payments to the institution are dependent on satisfactory completion of all financial and research report requirements.

Should you have any questions regarding our new policy please contact Kelly Howell at khowell@smafoundation.org or (646) 253-7100.

We appreciate your help implementing these new safeguards.