



Research Grant Application Procedures

Overview

Smith-Lemli-Opitz Syndrome (SLOS) is an autosomal recessive genetic disorder causing a defect in cholesterol synthesis which results in delays in all areas of development and may be complicated with one or more congenital malformations. SLOS is a life-long disorder with no cure, limited treatment options and is often misunderstood. Many individuals with the syndrome go completely undiagnosed. It is a goal of the Smith-Lemli-Opitz/RSH Foundation to fund research that addresses these issues. Therefore the Foundation seeks and accepts proposals for research into furthering any knowledge related to SLOS.

Proposals and Funding

Research proposals up to \$25,000 (USD) and two years in scope (preferably only a single year) for any aspect related to SLOS are accepted and reviewed. Our main interest is in providing funding to experienced investigators for testing of initial hypotheses and preliminary data collection leading to long term funding by major granting institutions (often considered “seed money”), and continuation of ongoing research while other funding is in the final stages of acceptance. However as a secondary goal in the research arena, we wish to continually attract new investigators into the exciting realm of SLOS and welcome any proposals they may put forth.

Application Process

Grants are currently approved on a yearly deadline. For 2008, the deadline for submissions is September 15, 2008. Starting in 2009, the annual deadline will permanently be moved to February 15th. The application should be no longer than 15 pages of type 12 font and 1 inch margins (exclusive of budget and other requested documents) and must be in English. It should include the following:

- An **information** page which lists:
 - Project Title
 - Start Date and Length of Project
 - Requested funding amount
 - Research subject type (human or animal)
 - Principal investigator mailing and contact information
 - Institutional Information and Authorized Officer signing for the Organization
 - Where funds are to be sent and the exact name of who to make the checks out to
- An **abstract** summarizing the project. This should include what issue is being addressed, how the work will be accomplished, and why the project is important for treatment or increasing the knowledge base.
- A detailed description of **specific goals** including objectives and hypotheses
- A critical **evaluation** of any prior related research outlining what gaps this project is intended to fill and why this is important
- A thorough description of **research design and methods**. Include the methodology for collecting, analyzing, interpreting and reporting of data, and if it is a new methodology, explain how it is different or advantageous over previously used methods. Also include limitations, expected difficulties and possible alternative approaches.
- A description of **environment and resources**.
- A listing of **project personnel and percentage of time** they will devote to this research.
- **Evidence** of current or pending project application to the relevant Institutional Review Board for human subjects and/or Animal Use and Protection Committee for animal subjects. A statement of use of these types of subjects must be included.

- A comprehensive **Budget** outline in U.S. Dollars. It is recommended that no more than 10% of requested budget is indirect costs. If proposing a multi year project, include a budget sheet for each year in addition to a budget sheet for the total of the entire project. Include:
 - Salary and Benefits by Individual. Salary of Principal Investigator is not expected to be included. If it is, a detailed explanation must be included.
 - Equipment and Supplies by Category
 - Patient Care Itemized by Type of Expense
 - Other, Itemized
- Statements of **acceptance** (templates to follow below)

Please submit an **electronic version** of the grant application in Microsoft Word Document format with all attachments by midnight (US eastern standard time) September 15, 2008 (February 15 for following years) to research@smithlempiopitz.org **AND** mail a **paper copy** to the following address by the due date.

For standard U.S. Mail, Please send to:
 SLO/RSH Foundation
 c/o Michelle Gardner
 P.O. Box 154
 Walworth, NY 14568
 USA

For Fed-Ex or UPS, Please send to:
 SLO/RSH Foundation
 c/o Michelle Gardner
 683 Walworth-Penfield Rd.
 Macedon, NY 14502

Acknowledgement of receipt will be sent by mail and/or email within 14 days of receipt to the principal investigator.

Granting Process

Completed proposals are reviewed by the Smith-Lemli-Opitz/RSH Foundation Medical Advisory Board for evaluation and interpretation. Final determination is made by the Board of Directors based on the recommendations of the Medical Advisory Board. Applications are evaluated on the following:

- The potential **significance** of the results of the research.
- The **feasibility** of the project given the investigators involved and the resources to be used. In addition, the feasibility of the Smith-Lemli-Opitz/RSH Foundation to be able to provide the requested funding.
- The likelihood that **long-term funding** can be obtained for additional research.

We welcome names and contact information for individuals you feel would be appropriate outside reviewers. They must be qualified to review the proposal, have no conflict of interest and have not worked with you in the last two years.

Notification of acceptance or denial is typically given 8-12 weeks after the due date. If the grant is approved a letter of approval will be sent to the applicant and funds will be available for immediate disbursement. Funded research proposals must provide the following:

- At every **six month** interval over the course of the approved project, a **progress report** of the research must be submitted to the Smith-Lemli-Opitz/RSH Foundation for review. This report must include:
 - A summary of progress made thus far in the project
 - Details of any difficulties encountered and solutions used or proposed
 - A description of any proposed changes to the project and why the changes are required.
 - An updated Budget listing expenditures to date.
- Within **60 days** after the end of the grant period, a **written report** is due that includes a layman's summary which the Smith-Lemli-Opitz/RSH Foundation may publish.
- Also with **60 days** after the end of the grant period, a **final financial report** is due.

- If the grant is for a multiple-year project, reports are due **annually** on the anniversary of grant commencement.
- **Immediate** notification of changes in Principal Investigator or Institution
- **Notification** of any patent application resulting from work performed for the funded research grant.
- On any public report of the granted research project, the Smith-Lemli-Opitz/RSH Foundation must be named as a source of funding, no matter if funding was partial or whole and a **copy** of the report must be sent to the Smith-Lemli-Opitz/RSH Foundation.

Additional Information

The Smith-Lemli-Opitz/RSH Foundation reserves the right to publish some basic information about the research grant proposals such as: title, principal investigator, institution, amount requested and/or rewarded and the abstract summary. No trade secrets or confidential information identified as such will be made public.

The Principal Investigator and the grantee Institution indemnify and hold harmless the Smith-Lemli-Opitz/RSH Foundation, its Board Members, Officers, agents, advisors and constituents from any claim judgment, award, damage, settlement, liability, negligence or malpractice arising from research related to the research grant.

The agreement between parties is a funding agreement only.

If you have any questions about the application process, please contact us at research@smithleliopitz.org or contact Michelle Gardner at 315-986-2708. Once an application has been submitted, do NOT contact us to find out status; we will notify you with a final decision.

Statements of Acceptance

Below find the templates for the statements of acceptance you must include with your grant application and progress report.

Application Statements of Acceptance

I have read the attached research grant policies of the Smith-Lemli-Opitz/RSH Foundation and certify that I both understand and will abide by these policies if this grant is awarded. I further acknowledge that I am aware that all decisions about grant applications made by the Smith-Lemli-Opitz/RSH Foundation are final and are not subject to appeal. I confirm that all of the information provided in this grant application is accurate and not misleading and I agree to accept responsibility for the scientific direction and conduct of this project.

Name of Applicant (*please print*) _____
Signature of Applicant _____
Date _____

I have read the attached research grant policies of the Smith-Lemli-Opitz/RSH Foundation and certify that I both understand and ensure the institution I represent will abide by these policies if this grant is awarded. I further acknowledge that I am aware that all decisions about grant applications made by the Smith-Lemli-Opitz/RSH Foundation are final and are not subject to appeal. I confirm that all of the information provided in this grant application is accurate and not misleading and I agree to accept legal, financial and oversight responsibility for this project.

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

Progress Report Statements of Acceptance

I confirm that the research entitled "XXXXXX" that I am conducting with funds from the Smith-Lemli-Opitz/RSH Foundation 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 Smith-Lemli-Opitz/RSH Foundation and shall continue to do so.

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 Smith-Lemli-Opitz/RSH Foundation 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 Smith-Lemli-Opitz/RSH Foundation with respect to this research project and that it shall continue to do so.

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