

Request For Proposals

Through funds made available from the Leland McSpadden Memorial Fund for Medical and Scientific Research, the LSA is able to periodically solicit proposals for research grants by interested scientific and medical researchers.

While many criteria are used to judge research proposals, of primary concern to the LSA Board of Directors and its Medical and Scientific Advisory Board is:

- Achieving a better understanding of the metabolic basis of Lowe syndrome
- Developing a better understanding and better treatments for the major complications of Lowe syndrome.

Request for Proposals

The Lowe Syndrome Association, Inc., requests research proposals aimed at achieving a better understanding of the metabolic basis of Lowe syndrome and/or developing a better understanding and better treatments for the major complications of Lowe syndrome. Grant award up to \$25,000 for one year.

Application deadline will be posted to NORD (<http://www.rarediseases.org/medical-professionals/research-grants>). Grant guidelines and application instructions follow.

LOWE SYNDROME ASSOCIATION, INC.

The Leland McSpadden memorial Fund for Medical & Scientific Research Guidelines for Preparation of Research Proposals

For more information contact: [[Contact the LSA](#)]

I. Deadline.

The deadline for receipt of research proposals will be posted to NORD (<http://www.rarediseases.org/medical-professionals/research-grants>). .

II. Contact for Further Information.

For further information,
[[Contact the LSA](#)]

III. Policies Governing Research Grants.

A. Background

The Lowe Syndrome Association, Inc., (LSA) is an international, voluntary, non-profit organization made up of parents, professionals, and others who are interested in Lowe syndrome. It was founded in 1982 and incorporated in 1986.

The primary purposes of the LSA are to: foster communication among families, promote a better understanding of Lowe syndrome and the potentials of individuals with this condition, provide information, and encourage and support medical research relating to Lowe syndrome. The primary activities of the LSA include publishing a triannual newsletter, On the Beam, and other publications, and sponsoring international conferences. The official slogan of the LSA is "Care today, cure tomorrow."

The LSA, is governed by a Board of Directors. In scientific and medical issues, the Board relies upon the advice and information of the LSA Medical and Scientific Advisory Board, which is made up of physicians and scientists representing various backgrounds.

For more information visit the LSA Web site at <http://www.lowesyndrome.org>.

B. Areas of Research Interest

The LSA will support research which will lead to a better understanding of the metabolic basis of Lowe syndrome, to better treatments of the major complications of Lowe syndrome, to the prevention of Lowe syndrome, and/or to a cure for Lowe syndrome.

Specifically, the LSA would consider supporting research aimed at one or more of the following:

1) achieving a thorough understanding of the metabolic basis of Lowe syndrome, especially how a phosphatidylinositol enzyme deficiency leads to the various features of Lowe syndrome;

2) developing a better understanding and treatment of the major complications of Lowe syndrome including but not limited to neurologic and behavioral problems, corneal keloid, degenerative bone and joint disorders, and renal diseases. Proposals for the establishment of a clinical research database and/or a longitudinal study of the progression of renal and/or neurological features will be given special consideration.

C. Size and Time Period of Grant

The LSA is prepared to provide funds in an amount up to \$25,000 for one year to support an appropriate research project. The researcher may re-apply for a second year of funding t, if offered.

D. Funding Eligibility Requirements

The LSA invites applications from researchers of all types, including but not limited to universities, hospitals, and other non-profit organizations with interest in research in the previously specified areas.

E. Grant Funding Restrictions

The LSA grant money may not be used as salary for the principal investigator, for honoraria for consultants, for the purchase of standard, non-consumable laboratory equipment, to purchase services from other research laboratories, or for overhead or indirect costs. Also, grant funds must be held in interest-bearing accounts payable to the grant.

F. Reporting Requirements

The researcher must submit a progress report at the end of eight months. This report must include a financial statement showing the expenditure of grant funds. Consideration for re-application for a subsequent grant will depend on satisfactory progress demonstrated in the eight month progress report. A final report must be submitted after twelve months and all unexpended funds must be returned to the LSA.

G. Safeguarding the Rights and Welfare of Human Subjects

If any human subjects are involved in research supported by the LSA, the researcher must obtain the informed consent of each subject, or the informed consent of a parent or guardian for each minor subject, prior to the participation of human subjects in any study or procedure.

No research involving human subjects shall be made unless the research is given initial and continuing review and approval by an appropriate committee of the researcher's institution. The institution must provide written assurance that the research project complies with the regulations of the United States Department of Health and Human Services (see IV.A.10 below).

IV. Guidelines for Proposals.

A. Application

The total application must be no more than 12 pages (8" x 11") long, not including curriculum vitae and bibliography. Each application must contain the following items:

1. The name of the applicant, the title of the research project, the name and address of the institution, the name and approval signature of the institution's financial officer, the name

and address of the chairman of the department in which the research will be done, and the name and address of the supervisor of the research.

2. A brief (about one paragraph) summary of the purpose, nature, and potential significance of the proposed project, written as much as possible in lay language for a non-scientific reader.

3. A scientific summary (no more than 1 page long) of proposed research, including a statement of what the researcher proposes to learn, how the researcher proposes to conduct the research, and the expected duration of the study.

4. A summary of the qualifications of the researcher, including his or her qualifications to carry out the study and including studies he or she has done previously that make him or her competent to do the study.

5. A description of the facilities available to carry out this study.

6. A detailed budget, including identification and explanation of all proposed expenses.

7. A statement listing all sources, amounts, and purposes of governmental or philanthropic support the researcher is receiving for this study.

8. A detailed research plan, including all information necessary for reviewers to understand fully the proposed research. The plan should provide a clear statement of the research question and the theoretical base for the project. The plan should summarize similar and relevant work by the applicant and others as reported in the scientific literature or known to be in progress. The plan should also state the specific aims and hypotheses of the research. The plan should describe the strategies to be employed, including the nature and sources of data to be collected.

9. Curricula Vitae of investigators to be involved in the study.

10. A statement by the institution's review board assuring that the proposed study has been reviewed and approved.

11. A letter from the applicant's supervisor of research (or from the applicant's department chairperson if the applicant is supervising his or her own research), approving the research, confirming the availability of equipment and facilities for the project, and describing the capacity of the investigator to carry out the proposed study.

12. A statement by the researcher agreeing to provide an 8-month progress report and a final 12-month report, to return unexpended funds to the LSA after twelve months, and to acknowledge the support of the LSA in all publications resulting from this grant.

13. A statement by the researcher agreeing to make available to the scientific community any reagents and/or data generated using the support of the LSA, once they are published.

B. Submission of Application

Proposals can be submitted by email on or before the deadline to: to:

Christine Knight, Director of the Medical & Scientific Advisory Board

<http://lowesyndrome.org/contact/>