

Request for Proposals

National Organization for Rare Disorders (NORD)

Announces

Research Seed-Money Grants *for* Larsen Syndrome

Submission Deadline March 15, 2003

NORD is accepting applications for one-year grants for clinical research studies related to the early detection, diagnosis, or treatment of patients with Larsen syndrome. Larsen Syndrome is a rare genetic disorder thought to result from a generalized defect of collagen formation, although the specific underlying cause is unknown. Its characteristics may vary greatly in range and severity from case to case. However, primary features may include multiple joint dislocations; foot deformities; non-tapering, cylindrically shaped fingers; and/or an unusual facial appearance characterized by a prominent forehead, an upturned nose with a depressed bridge, and slightly protruding wide-spaced eyes. Other features that may be present include short stature, cleft palate, heart defects, hearing impairment, and mental retardation.

Research Objectives

The purpose of the NORD Research Grant Program is to encourage meritorious clinical studies designed to improve the diagnosis or therapy of rare “orphan” diseases. Grants will be awarded to academic researchers to initiate small clinical trials, the results of which could be used to obtain funding from NIH, FDA or other funding agencies, or to attract a corporate sponsor. Procedures or proposed therapeutic trials may be new, based on recent biochemical or pharmacological evidence, or be in preliminary states of clinical investigation. Evaluation of proposals will include careful consideration of protocol design, objectiveness of parameters measured, and statistical evaluation proposed. Protocols that will focus on early detection, diagnosis, or treatment (pharmacological, devices, surgery, or dietary) will be given priority. **Grants not to exceed \$30,000 for one year** will be awarded by NORD for the support of clinical research on Larsen syndrome.

Application Procedure – Letter of Intent Deadline March 15, 2003

- Complete pages 3 – 5 of this document
- An initial letter of intent
- A one-page abstract of the proposal
- Brief budget outline
- Cogent reasons why NORD funding is essential
- A biographical sketch and bibliography (forms provided)
- **Mail 15 copies to be received by March 15, 2003**
- Full proposal invitations by May 1, 2003
- Full proposal deadline June 16, 2003
- Award announcements September 2, 2003
- Funding to begin October 2003 through September 2004



National Organization For Rare Disorders
2003 Abstract Proposal Application
Larsen Syndrome
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FURTHER INFORMATION

- All applicants will be reviewed for scientific merit.
- The number of research grants to be awarded will depend upon the availability of funds and the quality of applications.
- Applicants will be informed if a complete proposal is appropriate and an application form will be sent by NORD to those individuals. Full proposal invitations will be announced on May 1, 2003.
- Full proposals (by invitation only) are due June 16, 2003.
- If study involves humans, copies of the Informed Consent and the Institutional Review Board (Ethics Committee) approvals will be required from each site involved in the study, before payment.
- Clinical drug trials must meet the requirements established by the Food and Drug Administration (FDA).
- If study involves human gene therapy, a copy of the NIH Recombinant DNA Advisory Committee (RAC) review or waiver of review will be required.

ABOUT NORD

National Organization for Rare Disorders (NORD) is a unique federation of voluntary health organizations and individuals dedicated to helping people with rare “orphan” diseases and assisting the organizations that serve them. NORD is committed to the identification, treatment, and cure of rare disorders through programs of education, advocacy, service, and research. Besides advocating for increased government research funding and referring patients to clinical trials and genetic investigations, NORD funds clinical research grants on new treatments for rare diseases.

To receive notification of future funding opportunities through NORD, email complete mailing address to Lcataldo@rarediseases.org



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Name of Researcher	
Researcher's Email	
Researcher's Mailing Address	
City/State/Zip Country	
Researcher's Telephone	
Researcher's Fax	
Institution(s) Where Research Will Be Conducted.	
City, State, Country of Institution(s).	
Title of Project.	
Funding Amount Requested (Not to exceed \$30,000).	
Will Research Involve Human Subjects?	[] YES [] NO
How Did You Hear About This RFP?	<input type="checkbox"/> U.S. Postal Service Notice <input type="checkbox"/> Email Subscription Service <input type="checkbox"/> Medical Journal Ad <input type="checkbox"/> Website Posting
Please Be As Specific As Possible:	
Applicant Signature (required).	

Please provide the following information and mail 15 copies of this application with attachments to be received by March 15, 2003 to:
National Organization for Rare Disorders, (NORD)
Attn: Research Grant Program,
PO Box 1968, 55 Kenosia Avenue Danbury, CT 06813-1968, USA

	Yes/No
An initial letter of intent.	
A one-page abstract of the proposal.	
Brief budget outline. Do not include PI salary, overhead, or indirect costs. Funding can be used to cover expenses such as technical assistance, supplies, and small equipment.	
Cogent reasons why NORD funding is essential.	
Biographical Sketch and bibliography. (Forms provided, see pages 4 & 5)	



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BIOGRAPHICAL SKETCH

Name Position/Title	
Education/Training Begin with baccalaureate or other initial professional education and include postdoctoral training.	<u>Institution and Location</u> <u>Degree</u> <u>Year(s)</u> <u>Field of Study</u>
Research and Professional Experience Concluding with present position, list in chronological order, previous employment, experience, and honors. Include present membership on any advisory committee.	
Honors and Awards	
Invited Talks	



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BIBLIOGRAPHY

Publications: List in chronological order, the titles, all authors, and complete references to all publications in the last three years and to representative earlier publications pertinent to this application. If the list of publications exceeds two pages, select the most pertinent publications.

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