



Request for Proposals

National Organization for Rare Disorders (NORD) with the Tarlov Cyst Disease Foundation

Announce

Research Seed Money Grant

For

Tarlov Cysts

Submission Deadline: May 9, 2008

NORD, in conjunction with the non-profit organization, Tarlov Cyst Disease Foundation, is accepting applications for a one-year grant for a clinical research study related to the diagnosis and/or treatment of Tarlov cysts. Tarlov cysts are fluid-filled sacs that arise out of the nerve roots of the spine, especially near the base of the spine (sacral region). Individuals may be affected by multiple Tarlov cysts of varying size. Depending on the size and specific location of the cysts, symptoms can include pain and weakness in the legs (often misdiagnosed as sciatica), paresthesias (abnormal sensations) in the legs, pain in the pelvic area, and bladder and bowel dysfunction.

The exact cause of Tarlov cyst development is unknown. A number of conditions, such as falls and other types of trauma to the spinal cord, are thought to cause the enlargement of these cysts in susceptible individuals. Currently, treatment primarily consists of pain management. Sometimes, aspirating a large cyst can provide relief, but the results are temporary, as the cysts always re-fill with fluid. Surgery is being performed by only a few neurosurgeons in the world with variable long term outcomes.

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 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.

APPLICATION PROCEDURE – Letter of Intent Deadline: May 9, 2008

- Complete pages 3 through 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)
- **14 copies of above documents, in addition to the original, to be received by May 9, 2008**

FULL PROPOSALS

- Full proposal invitations will be announced, via e-mail, the week of June 25, 2008. Applications for full proposals will accompany these announcements.
- Full proposals must be received by NORD by August 25, 2008.

AWARDING OF GRANT

- Award announcements will be made on or about November 7, 2008, via e-mail.
- Funding will begin November, 2008, providing that all necessary documents (IRB forms, patient consent forms, signed application agreements) have been received by NORD.

FURTHER INFORMATION

- If the study involves human subjects, copies of the Informed Consent form and the Institutional Review Board committee report will be required from each site involved in the study, before payment can begin.
- Clinical drug trials must meet the requirements established by the Food and Drug Administration (FDA).
- If the study involves human gene therapy, a copy of the NIH Recombinant DNA Advisory Committee (RAC) or waiver of review will be required.

ABOUT NORD

The 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: research@rarediseases.org.

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 14 copies of this application, in addition to the original, with attachments to be received by May 9, 2008 to:
National Organization for Rare Disorders, (NORD)
Attn: Stefanie Putkowski, RN, Research Program Administrator,
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)	

BIOGRAPHICAL SKETCH

Not to exceed 2 pages

Applicant may use this form or the NIH Biosketch form. Please modify the form to include, when applicable, the following:

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				
Not to exceed 2 pages				

BIBLIOGRAPHY

Not to exceed 2 pages

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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