**REquest for proposals**

**National Organization for Rare Disorders (NORD) with funding from**

**The NORSE Institute**

#### *Announces*

# *Research Grant Money (up to $100,000 U.S.)*

*for*

**New Onset Refractory Status Epilepticus (NORSE) and**

**Febrile Infection-Related Epilepsy Syndrome (FIRES)**

**DEADLINE FOR INITIAL APPLICATIONS: July 16, 2018 (11:59 pm ET)**

NORD, with funding from the NORSE Institute and public donations, is accepting applications for grants from $30,000 U.S. up to a total of $100,000 U.S., for scientific research studies related to new-onset refractory status epilepticus (NORSE) and/or febrile infection-related epilepsy syndrome (FIRES), a subcategory of NORSE. Preference will be given to translational research in the areas of inflammation, immunology, infection and genetics. Scientists are invited (but not limited) to submit proposals that will utilize biological specimens collected in the ongoing NORSE prospective, observational clinical study conducted through the Critical Care EEG Monitoring Research Consortium (CCEMRC), an international multi-center consortium.

Investigators wishing to conduct research utilizing the biological materials and/or clinical data from this consortium study will submit a request to the Critical Care EEG Monitoring Research Consortium (CCEMRC) through NORD [research@rarediseases.org](mailto:research@rarediseases.org) with the subject line “NORSE RFP request for consortium biological samples.”

Approval of requests will be at the discretion of the NORSE study Principal Investigators: Dr. Lawrence Hirsch and Dr. Nicolas Gaspard. Dr. Hirsch, Dr. Gaspard and the project study manager will assure appropriate IRB approvals are in place prior to distributing de-identified data to other researchers. The consortium study protocol specifically allows third party use of the data.

The biological samples available are: CSF (10cc), serum (10cc) and DNA. Amounts given are in total. There is no restriction for use provided researchers obtain IRB approval.

If CCEMRC data is used, co-authorship with CCEMRC Principal Investigators is not required. What is requested is the following acknowledgement: “The authors are grateful to the NORSE Institute and the Critical Care EEG Monitoring Research Consortium (CCEMRC) for granting access to the biological samples used in this study.”

**Consensus definitions of NORSE and FIRES**

According to the proposed consensus definitions recently published, NORSE is not a diagnosis, but rather a clinical presentation “in a patient without active epilepsy or other preexisting relevant neurological disorder, with new onset of refractory status epilepticus without a clear acute or active structural, toxic or metabolic cause.”[[1]](#footnote-1) In a complementary definition, Hirsch et al. propose that FIRES should be considered an age-agnostic subcategory of NORSE, applicable when a patient presents with febrile infection prior to the onset of refractory status epilepticus.[[2]](#footnote-2) Because refractory status epilepticus does not respond to standard first- and second-line anticonvulsant medications, treatment of these disease states typically involves using additional seizure medications and/or inducing a coma with anesthetic drugs. Although the cause of these clinical presentations is unknown, treatment may also include immunomodulatory therapies due to the suspected involvement of inflammation.

**Research Objectives**

The purpose of the NORD Rare Disease Research Grant Program is to encourage meritorious scientific and clinical studies designed to improve the diagnosis or therapy of rare “orphan” diseases. Grants will be awarded to academic researchers to initiate small scientific research studies or clinical trials, the results of which could be used to obtain funding from the 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 stages 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 cause, early detection, diagnosis, or treatment (pharmacological, devices, surgery, or dietary) will be given priority.

**Application Procedure**

**Deadline for Initial Applications: July 16, 2018 (11:59 pm ET)**

All of the following application elements must be received by July 16, 2018 (11:59 pm ET). Incomplete applications may not be considered. For electronic submission (preferred), all application elements should be merged into a single PDF file and sent to [research@rarediseases.org](mailto:research@rarediseases.org) with “NORD Abstract Proposal” as the subject line. Alternatively, applications can be mailed to:

**NORD Rare Disease Research Grant Program**

**55 Kenosia Avenue**

**Danbury, CT 06810 USA**

* Application summary (page 4)
* Biographical sketch and bibliography for principal investigator (templates provided on pages 5-6)
* List of co-investigators, if applicable (page 7)
* Reviewer information, optional (page 8)
* Initial letter of intent (maximum one page)
* Abstract of the proposal (maximum one page)
* Brief budget outline
* Cogent reasons why NORD funding is essential (explain applicant’s particular interest in this grant)

**INCOMPLETE APPLICATIONS MAY NOT BE CONSIDERED.**

**FULL PROPOSALS**

* Full proposal invitations will be issued via email in August 2018.
* Application requirements for full proposals will accompany these invitations.

**AWARDING OF GRANT**

* Award announcements will be made via email and posted on NORD’s website in December 2018.
* Funding will begin after all necessary documents (e.g. IRB forms, patient consent forms, signed grant agreements) have been received by NORD.

**FURTHER INFORMATION**

* If the study involves human or animal subjects, copies of governance documents will be required from each site involved in the study before payment can be issued.
* Clinical drug trials must meet requirements established by the U.S. Food & Drug Administration (FDA).
* Duplicate/overlapping funds from any other private or public source are not to be used.

**ABOUT NORD**

The National Organization for Rare Disorders (NORD)® is the leading independent advocacy organization representing all patients and families affected by rare diseases. NORD is committed to the identification, treatment and cure of the 7,000 rare diseases that affect 30 million Americans, or 1 in every 10 people. For more than 30 years, NORD has led the way in voicing the needs of the rare disease community, driving supportive policies and education, advancing medical research, and providing patient and family services for those who need them most. 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.

**APPLICATION SUMMARY**

**Deadline for Initial Applications: July 16, 2018 (11:59 pm ET)**

|  |  |
| --- | --- |
| **PRINCIPAL INVESTIGATOR INFORMATION** | |
| Name |  |
| Position/Title |  |
| Email |  |
| Mailing Address |  |
| Telephone |  |
| **PROPOSAL INFORMATION** | |
| Project Title |  |
| Project Term | [ ] 1 YEAR  [ ] 2 YEARS |
| Funding Amount Requested ($) *not to exceed $100,000 U.S.* |  |
| Institution(s) where research will be conducted |  |
| City, State/Province, Country of Institution(s) |  |
| Will research involve human subjects? | [ ] YES  [ ] NO |
| Will research involve animals? | [ ] YES  [ ] NO |
| How did you hear about this RFP? | NORD Member Organization Website Posting  Email Subscription Service Referral from Colleague  Medical/Research Publication  Other (please specify below) |
| Please be as specific as possible: |  |
| Principal Investigator Signature  **REQUIRED** |  |

**Biographical Sketch**

Please provide a biographical sketch and bibliography for the principal investigator. 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. | Institution and Location | Degree | Year(s) | Field of Study |
|  |  |  |  |
| **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** |  | | | |

**Bibliography**

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

|  |
| --- |
|  |

**Co-Investigator(s)**

|  |  |
| --- | --- |
| Name of Co-Investigator |  |
| Position/Title |  |
| Institution |  |
| Email |  |

|  |  |
| --- | --- |
| Name of Co-Investigator |  |
| Position/Title |  |
| Institution |  |
| Email |  |

|  |  |
| --- | --- |
| Name of Co-Investigator |  |
| Position/Title |  |
| Institution |  |
| Email |  |

**REVIEWer information**

**Please list up to five areas of scientific/medical expertise needed to review this application (optional).**



**Please list below any individuals who should not review this application (optional).**

|  |  |  |
| --- | --- | --- |
| **NAME** | **INSTITUTION** | **JUSTIFICATION** |
|  |  |  |
|  |  |  |
|  |  |  |
|  |  |  |

**application checklist**

**Deadline for Initial Applications: July 16, 2018 (11:59 pm ET)**

|  |  |
| --- | --- |
| **Application summary** (page 4) |  |
| **Biographical sketch and bibliography** (templates provided on pages 5-6) |  |
| **List of co-investigators, if applicable** (page 7) |  |
| **Reviewer information, optional** (page 8) |  |
| **Initial letter of intent** (maximum one page) |  |
| **Abstract of the proposal** (maximum one page) |  |
| **Brief budget outline.** Do not include PI salary, overhead, or indirect costs. Funding can be used to cover expenses such as staff salary, technical assistance, supplies, and small equipment. |  |
| **Cogent reasons why NORD funding is essential** |  |

**To receive notification of future funding opportunities through NORD,**

**please contact** [**research@rarediseases.org**](mailto:research@rarediseases.org)

1. Hirsch LJ, Gaspard N, van Baalen A, et al. Proposed consensus definitions for new-onset refractory status epilepticus (NORSE), febrile infection-related epilepsy syndrome (FIRES), and related conditions. Epilepsia. 2018;59(4):739-744. [↑](#footnote-ref-1)
2. Ibid. [↑](#footnote-ref-2)