**REQUEST FOR PROPOSALS**

**The National Organization for Rare Disorders (NORD)’s Jayne Holtzer Rare Disease Research Grants Program**

**with funding from**

**The NEHI Research Foundation**

#### *Announces Research Grant opportunity for one grant*

#### *up to $50,000 US for*

#### 

**Neuroendocrine Cell Hyperplasia of Infancy (NEHI)**

**DEADLINE FOR INITIAL APPLICATIONS: August 25, 2020 (11:59 pm PT)**

NORD, with funding from the NEHI Research Foundation, is accepting applications for a total of $50,000 US for scientific and/or clinical research studies related to neuroendocrine cell hyperplasia of infancy (NEHI). NEHI, initially described in 2005, is a subtype of children’s interstitial lung disease (chILD) with an undefined etiology. NEHI symptoms typically present by age 2 and include hypoxemia, tachypnea, retractions, failure to thrive, and crackles on chest auscultation. Classically, high resolution CT imaging shows ground-glass opacification and air trapping with a mosaic pattern. Infant pulmonary function testing also can be used to assist diagnosis. If noninvasive diagnostic techniques are not sufficient, confirmatory lung biopsy can be performed – increased neuroendocrine cells in the peripheral airways with bombesin staining and normal histology on standard staining is indicative of NEHI. Supportive treatment to address NEHI symptoms may include supplemental oxygen, nutritional management, and immunizations to reduce the risk of respiratory infections.

**Research Objectives**

The NORD Rare Disease Research Grant Program was established in 1989 to encourage meritorious scientific and clinical studies designed to improve the diagnosis or therapy of rare “orphan” diseases. Grants will be awarded to qualified 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.

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Deterding RR, Pye C, Fan LL, Langston C. Persistent tachypnea of infancy is associated with neuroendocrine cell hyperplasia. Pediatric Pulmonology. 2005;40(2): 157-165.

**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 more than 7,000 rare diseases, of which approximately 90 percent are still without an FDA-approved treatment or therapy. Rare diseases affect 25-30 million Americans. More than half of those affected are children. NORD began as a small group of patient advocates that formed a coalition to unify and mobilize support to pass the Orphan Drug Act of 1983. For more than 35 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. NORD is made strong together with over 300 disease-specific member organizations and their communities and collaborates with many other organizations on specific causes of importance to the rare disease patient community.

APPLICATION PROCEDURE

Application elements must be received by August 25, 2020 (11:59 pm PT). 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-programs@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**

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| --- | --- | --- |
| **REQUIRED ELEMENTS** | **MAX LENGTH** | **✓** |
| **Initial letter of intent** | 1 page |  |
| **Abstract of the proposal** | 1 page |  |
| **Application summary** (page 4) | - |  |
| **Biographical sketch and bibliography** (templates provided on pages 5-6) | - |  |
| **List of co-investigators, if applicable** (page 7) | - |  |
| **Statement on novelty** (page 7) | - |  |
| **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** (explain applicant’s specific interest in this grant) | ½ page |  |
| **OPTIONAL ELEMENTS** | **MAX LENGTH** | **✓** |
| **Reviewer information** (page 8) | - |  |
| **Letter of support** (page 8) | - |  |

**INCOMPLETE APPLICATIONS MAY NOT BE CONSIDERED.**

**FULL PROPOSALS**

* Full proposal invitations will be issued via email in Fall 2020
* 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 February 2021.
* 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.

APPLICATION SUMMARY

**Deadline for Initial Applications: August 25, 2020 (11:59 pm PT)**

|  |  |
| --- | --- |
| **PRINCIPAL INVESTIGATOR INFORMATION** | |
| Name |  |
| Position/Title |  |
| Email |  |
| Mailing Address |  |
| Telephone |  |
| **PROPOSAL INFORMATION** | |
| Project Title |  |
| Project Term | [ ] 1 YEAR  [ ] 2 YEARS |
| Funding Amount Requested ($ US) *not to exceed $50,000 US* |  |
| 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.

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CO-INVESTIGATOR(S)

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

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

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

STATEMENT ON PROJECT NOVELTY

Please include a statement on how your research builds upon and differs from previous research in this disease space.

REVIEWER INFORMATION (OPTIONAL)

**Please list up to five areas of scientific/medical expertise needed to review this application (optional). Do not list names of individuals.**

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

|  |  |  |
| --- | --- | --- |
| **NAME** | **INSTITUTION** | **JUSTIFICATION** |
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LETTER OF SUPPORT (OPTIONAL)

Please include a letter of support for your research from an individual advocate (e.g., patient, care partner) or patient advocacy group in this disease space (optional, but encouraged).

**To receive notification of future funding opportunities through NORD, sign up for NORD research news here:** <https://rarediseases.org/communications-sign-up/>