**REquest for proposals**

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

**Alveolar Capillary Dysplasia Association, The David Ashwell Foundation, and**

**William Akers, Jr. & Georgia O. Akers Private Foundation, Inc.**

#### *Announces Research Grant Money*

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

#### 

**Alveolar Capillary Dysplasia with Misalignment of the Pulmonary Veins (ACD/MPV)**

**DEADLINE FOR INITIAL APPLICATIONS: June 18, 2019 (11:59 pm ET)**

NORD, with funding from the Alveolar Capillary Dysplasia Association (ACDA), The David Ashwell Foundation, and William Akers, Jr. & Georgia O. Akers Private Foundation, Inc., is accepting applications for a total of $50,000 US for scientific and/or clinical research studies related to alveolar capillary dysplasia with misalignment of the pulmonary veins (ACD/MPV). ACDA and The David Ashwell Foundation are respectively USA- and UK-based not for profit charitable organizations founded by parents of infants with ACD/MPV. Funds are raised by parents, families, and friends globally with the aim of increasing scientific knowledge about ACD/MPV.

Histologically, ACD/MPV is characterized by failure of formation and inward growth of alveolar capillaries, causing lack of contact with alveolar epithelium. Muscular thickening of small pulmonary arterioles, thickened alveolar walls, and anomalously-situated pulmonary veins are hallmarks of ACD/MPV. The disorder leads to hypoxia and persistent pulmonary hypertension of the neonate or infant. Additional features of ACD/MPV include multiple congenital anomalies affecting the cardiovascular, gastrointestinal, genitourinary, and musculoskeletal systems, as well as disruption of the normal right-left symmetry of intrathoracic or intraabdominal organs. Affected infants present with respiratory distress, hypoxia and pulmonary hypertension. The disease is uniformly fatal without bilateral lung transplantation. Most affected infants have a sporadic mutation in the *FOXF1* gene, or loss of genetic material on chromosome 16 that includes the *FOXF1* gene or genes that regulate the expression of the *FOXF1* gene.

**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.

Application Procedure

All of the following application elements must be received by June 18, 2019 (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 3)
* Biographical sketch and bibliography for principal investigator (templates provided on pages 4-5)
* List of co-investigators, if applicable (page 6)
* Reviewer information, optional (page 7)
* 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 2019.
* 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 2019.
* 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 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 280 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 SUMMARY

**Deadline for Initial Applications: June 18, 2019 (11:59 pm ET)**

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| --- | --- |
| **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 |  |

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

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

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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application checklist

**Deadline for Initial Applications: June 18, 2019 (11:59 pm ET)**

|  |  |
| --- | --- |
| **Application summary** (page 3) |  |
| **Biographical sketch and bibliography** (templates provided on pages 4-5) |  |
| **List of co-investigators, if applicable** (page 6) |  |
| **Reviewer information, optional** (page 7) |  |
| **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, send email address to:** [**research@rarediseases.org**](mailto:research@rarediseases.org)