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

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

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

#### Announces

# Research Seed Money Grant (up to $50,000)

for

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

Deadline for Initial Applications: June 23, 2017 (11:59 pm ET)  
[research@rarediseases.org](mailto:research@rarediseases.org)

NORD, with funding from The David Ashwell Foundation, Alveolar Capillary Dysplasia Association (ACDA), and William Akers, Jr. & Georgia O. Akers Private Foundation, Inc., is accepting applications for a total of $50,000, for scientific and/or clinical research studies related to alveolar capillary dysplasia with misalignment of the pulmonary veins (ACD/MPV). The David Ashwell Foundation & ACDA are respectively UK & USA 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 purpose of the NORD 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 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: June 23, 2017**

**All of the following application elements must be received by June 23, 2017 (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 (PDF required for document security) 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 Research Grant Program**

**55 Kenosia Avenue**

**Danbury, CT 06810 USA**

* Tables on pages 3 through 5 of this document, completed in full
* Initial letter of intent (1 page)
* Abstract of the proposal (1 page)
* Brief budget outline
* Cogent reasons why NORD funding is essential (explain applicant’s particular interest in this grant)
* Biographical sketch and bibliography for Principal Investigator (forms provided)
* List of co-investigators (if applicable)

**FULL PROPOSALS**

* Full proposal invitations will be announced via email in August 2017.
* Application requirements for full proposals will accompany these announcements.
* The deadline for full proposals will be early October 2017.

**AWARDING OF GRANT**

* Award announcements will be made in December 2017.
* 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 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 requirements established by the U.S. Food & Drug Administration (FDA).
* If the study involves applicable human gene transfer protocols, a copy of the NIH Recombinant DNA Advisory Committee (RAC) review or waiver of review will be required.
* 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 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.

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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 |  | | |
| Term of Project (*should reflect proposal*) | 1 Year 2 Years | | |
| Funding Amount Requested (not to exceed $50,000) |  | | |
| Will Research Involve Human Subjects? | [ ] 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: |  | | |
| Applicant Signature (required) |  | | |
| Application Checklist | | | Yes/No |
| **Initial letter of intent** (1 page) | | |  |
| **Abstract of the proposal** (1 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** (explain applicant’s particular interest in this NORD grant opportunity) | | |  |
| **Biographical sketch and bibliography** (forms provided, see pages 4 & 5) | | |  |
| **List of co-investigators** (if applicable) | | |  |

**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)**

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| --- | --- |
| Name of Researcher |  |
| Researcher’s Title |  |
| Researcher’s Institution/Company |  |
| Researcher’s Email |  |

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| Name of Researcher |  |
| Researcher’s Title |  |
| Researcher’s Institution/Company |  |
| Researcher’s Email |  |

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| Name of Researcher |  |
| Researcher’s Title |  |
| Researcher’s Institution/Company |  |
| Researcher’s Email |  |

**To receive notification of future funding opportunities through NORD, send email address to:** [**research@rarediseases.org**](mailto:research@rarediseases.org)