



CONCEPT MEMORANDUM REQUEST

The Blue Lips Foundation (Foundation) is committed to funding ground-breaking research into novel diagnostic tools and screening methods for pulmonary arterial hypertension (PAH), with particular emphasis on idiopathic PAH.

PAH is a progressive and lethal disease characterized by increased pulmonary vascular resistance due to vascular proliferation and remodeling of pulmonary arterioles, eventually leading to right ventricular failure. Patients with PAH face several challenges fighting this devastating disease. NIH registry in the pre-treatment era showed a median survival of 2.8 years. But the more recent REVEAL registry suggests a much improved median survival of more than 7 years. For those who are detected early in the course of their illness stand a much better chance of responding to therapy and likely will have more favorable outcome. The nonspecific symptoms at presentation, rarity of the disease and the lack of familiarity by the primary care providers make it all the more difficult for the early and prompt diagnosis of the disease. 2D echocardiogram is the mainstay of screening test for a suspected case and right heart catheterization remains the pivotal study in confirming diagnosis. Is it possible to identify a simpler and more easily accessible screening tool in a suspected case?

Symptoms associated with PAH are often undetected for months or years while the disease is in early stages (WHO Class I). Generally, as the disease progresses, symptoms become more noticeable to the patient (WHO Classes II-IV), but often remain undiagnosed until late stages (WHO Classes III, IV). As a general matter, approximately 2.8 years pass between symptom onset and definitive PAH diagnosis. 74% of PAH patients are diagnosed in advanced stages of the disease (WHO Classes III or IV). Five year mortality rates are measured at approximately 50% for PAH patients diagnosed in Classes III or IV. On average, symptomatic PAH patients will not be referred for diagnostic echocardiography for over two years after symptom onset.

While continual education of the public and “medical gatekeepers” is necessary to recognize the signs and symptoms of PAH - i.e., at-risk patients, family practice

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www.bluelipsfoundation.org

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EIN: 47-4689048



physicians, pediatricians, geriatric specialists, etc., the Foundation is dedicated to providing medical practitioners with novel diagnostic and early screening tools to “Rule-In” PAH candidates early and efficiently. Primary care physicians require at their disposal novel tools and screening methods to identify PAH patients during routine medical examinations.

There is currently insufficient dedication to early diagnosis screening tools and methods associated with PAH. This Concept Memorandum Request (Memorandum) seeks proposals for funding into this area of research that will deliver robust advancements into early detection and diagnosis of PAH.

To apply, please submit a Concept Memorandum that includes the following:

Project Summary

- One-half page maximum to include basic information about aims, needs, preliminary data, methods and data analysis.

Study, Design, Scope and Approach

- Description of the proposed research study, inclusive of study design, methods, indicators to be measured, and statistical analysis.
- Summary of formative and feasibility research completed to date (if applicable)
- Describe the length of time anticipated to complete the study; and if anticipated to extend beyond 12 months, the benchmark advancements to be expected in annual increments

Relevance and Applicability

- Description of how the findings from the research study could be applicable at a program level

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- Communications plan that describes the approach for publication and research uptake
- Description of how formative research will translate into a large-scale intervention study

Organizational Fit

- Summary of the lead investigator - and applicant organization's previous experience and/or expertise that is relevant to the requested research
- Description of any collaborative partners (if applicable)

Budget

- Summary of requested budget for proposed activities
- List any support for project from other sources

Concept Memorandums should be addressed to Randy Wilharber, Board of Directors – Blue Lips Foundation and submitted via email to randy@bluelipsfoundation.org, or regular mail to Randy Wilharber, Board of Directors – Blue Lips Foundation, 3201 163rd Street, Urbandale, Iowa 50323. Upon receipt, the Foundation shall review the Memorandums internally, with appropriate vetting via the Foundation's Scientific Advisory Board.

Memorandums received by the Foundation does not bind the Foundation to fund any work proposed by the applicant. Once you have submitted your Memorandum, you will receive confirmation that we have received it – and that your proposal will be reviewed. Memorandums are reviewed by the Blue Lips Foundation on a continual basis throughout the year.

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