

ECD Global Alliance

Supporting Those Affected by Erdheim-Chester Disease

REQUEST FOR LETTERS OF INTENT

The ECD Global Alliance is soliciting Letters of Intent for funding of research projects focused on the study of Erdheim-Chester Disease.

LOI Form is Attached

Number of Grants to be Awarded: Maximum of two (2)

Maximum Amount of Monies to be Awarded: Up to \$100,000 USD (total)

Duration of Grant: 1 Year

LOI Deadline: April 1, 2014

Eligibility Requirements: Open to all qualified researchers (international proposals welcomed)

The purpose of the ECD Global Alliance is to help those affected by Erdheim-Chester Disease. As such, the Alliance's mission is to provide support, promote research, raise awareness and share educational material related to ECD.

Erdheim-Chester Disease is an extremely rare multi-system, non-Langerhans Cell histiocytosis. ECD can affect many different organs of the body, with each patient having a different combination of organs attacked. The disorder is characterized by an excessive production and accumulation of histiocytes that infiltrate the loose connective tissue of the body. As a result this tissue becomes thickened, dense and fibrotic. Unless successful treatment is found, organ failure can result. Erdheim-Chester Disease usually affects adults, although childhood cases have been documented. It can affect both men and women. Disease involvement may include long bones of the legs and arms, skin, tissues behind the eyes, lungs, brain, pituitary gland, kidney, abdominal cavity, heart, adrenal glands and more rarely other organs.

The ECD Global Alliance is interested in receiving LOIs for any study that can lead to an increase of knowledge related to the etiology, pathophysiology, diagnosis or treatment of Erdheim-Chester Disease. Some specific projects of high interest to the organization include:

- Development and implementation of an ECD patient registry
- Clinical trials related to treatment of ECD
- Improving the quality of life for ECD patients
- Simplifying diagnosis of ECD
- Understanding the pathobiology and molecular mechanisms of the disease

All investigation proposals will be considered and all qualified and interested investigators are encouraged to submit. As appropriate, submitted studies should consider inclusion of the following:

- Collaboration among investigators from different institutions
- · Translation of findings into the clinical setting

Contact: Kathy Brewer

ECD Global Alliance, President

P.O. Box 775

DeRidder, LA 70634

1-337-515-6987 support@erdheim-chester.org

www.erdheim-chester.org 1/23/2014



LETTER OF INTENT Submission Form

Erdheim-Chester Disease Global Alliance 2014 Grant Cycle

To complete the form electronically, use the mouse pointer or the Tab key to navigate. Select and enter text for each text field.	
Title of LOI:	
Principal Investigator (PI) Name:	
PI Institution:	
Other Team Members from Your Institution:	
Names and Institutions of Collaborating Investigators from Other Institutions:	
Estimated Total Budget for Study:	
(Note: Projected budget should be realistic.)	
Estimated Budget Request for 1 Year:	
(Note : If this is a 1 year study, the total budget amount and the budget request for 1 year will be equal.)	
Proposed Sample Size:	
(Note: If research will not involve patients, please enter a zero.)	
Earliest date the study can begin:	
Will this study as a whole receive support from sources other than the ECD-GA (i.e., an institution, industry, foundations)?	
If yes, indicate the source of the funding:	
PI Signature:	Date:
PI Street Address: _	
_	
PI Country:	
PI Phone:	
PI Fax:	
PI E-mail:	
Please submit LOIs to the ECD Global Alliance	by April 1, 2014 via e-mail at:
support@Erdheim-Chester.org	
Questions: Please email support@Erdhe	eim-Chester.org.

Rationale and Background: (This section should provide the study rationale, supporting data and address the following: what is the goal of the study, why is this study important, any potential safety concerns, and how the study results might impact future treatments or research. The background information should be limited to what is relevant to the proposed study and should be presented succinctly but with sufficient detail to enable evaluation by the reviewers.)

Hypotheses: (Succinctly state the hypothesis for each primary and secondary objective.) (Attachment ok.)

Objectives: (List primary and secondary objectives. Ensure that the study design allows for these objectives to be met.)(Attachment ok)

Abbreviated Eligibility Criteria (if appropriate): (Provide key inclusion criteria. These should include patient age, performance status, any limiting factors to inclusion, and permissible and required prior therapy.) (Attachment ok.)

Study Design: (Succinctly describe the general study design. A schema or flow diagram may be used, if appropriate.) (Attachment ok)

Treatment Plan (if appropriate): (State the dose, method of administration, and schedule of each drug. State the duration of treatment, the duration of the study, and the duration of follow-up.) (Attachment ok.)

References: (Provide references for cited data and key background/concepts. Verify all references.) (Attachment ok.)