

Funding Opportunity

Funding Organization

ARRE Foundation

Funding Opportunity Title

ARRE Grant for ASXL Research

Summary

The ARRE invites applications that propose novel studies on the molecular and genetic mechanisms underlying the function of the ASXL genes. The areas of focus include:

- 1) Developing reagents, specific antibodies, and animal models for ASXL syndromes.
- 2) Studies leading to an in-depth understanding of the molecular mechanisms and pathophysiology of ASXL syndromes.
- 3) Clinical studies that investigate the natural history of ASXL syndromes and/or improve the lives of patients with germline ASXL mutations.

Currently accepting applications

Application Due Date

November 5th 2019, by 5 PM local time of the applicant's organization.

Late applications will be accepted and considered for funding at a later date.

Purpose

ARRE invites applications that propose novel studies on the molecular and genetic mechanisms underlying the function of the ASXL genes. Constitutional mutations of these genes result in severe syndromes such as Bohring-Opitz (ASXL1), Shashi-Pena (ASXL2), and

Bainbridge-Ropers (ASXL3) syndrome. The molecular mechanism resulting in these syndromes is not fully understood.

Background

ARRE is a foundation set up by parents of patients with ASXL mutations, with scientific support from expert clinicians and investigators. Our vision is to support research that will increase our understanding of the role of ASXL genes in human development and to improve the treatment of individuals with congenital ASXL mutations.

Scope

The areas of focus include:

- 1) Developing reagents, specific antibodies, and animal models for ASXL syndromes.
- 2) Studies leading to an in-depth understanding of the molecular mechanisms and pathophysiology of ASXL syndromes.
- 3) Clinical studies that investigate the natural history of ASXL syndromes and/or improve the lives of patients with germline ASXL mutations.

Application Information

We are accepting new applications at this time. We are not considering clinical trials.

Funds Available and Anticipated Number of Awards

Total funds of \$550,000 are available. The number of awards will be based upon the number and type of meritorious applications received.

Award Budget

Application budgets are limited to \$50,000 in direct costs in any project year. Up to an additional 10% may be requested for indirect costs (facilities and administrative costs of subcontractors with collaborating organizations, etc).

Award Project Period

The maximum project period is 2 years.

Eligible Applicants

Eligible Organizations

- Institutions of Higher Education
- Nonprofits with 501(c)(3) IRS Status
- Nonprofits without 501(c)(3) IRS Status
- For-Profit Organizations

Other applications will be considered on a case by case basis.

Foreign Institutions

- Non-U.S. institutions are welcome to apply
- International groups are welcome to apply

Multiple Applications

Multiple applications can be accepted from the same organizations if they are scientifically distinct.

Submission information

1. Application Package

Download the [Research Grant Submission](#) Form now.

2. Application Instructions

- Cover page completed including title of proposal and name of principal investigator
- Summary (½ page) and abstract (½ page) of proposed research
- Specific Aims, including hypothesis, background, approach/research plan, and significance of the proposed research. (5 page maximum)
- NIH biosketch (<https://grants.nih.gov/grants/forms/biosketch.htm>)
- Description of the facilities available to carry out this study, which should be included in the Research Plan section.
- One-page detailed budget: Indirect costs of up to 10% will be allowed (these are in addition to the \$50,000 grant)
- Name and approval signatures of the institution's financial officer who confirms the availability of equipment and facilities for the project and capacity for the investigator on the proposed study
- Proposals involving human or animal subjects must be approved by institutional review boards before funding is released. Please include approval with proposal if possible.

Subject line to read: ARRE MM_20XX General RFP Submission (e.g., ARRE 09_2018 General RFP Submission)

File name to read: PI's last name_MM_20XX_Gen_RFP.pdf. (e.g., Smith_09_2018_Gen_RFP.pdf)

ARRE Medical & Scientific advisors will evaluate the relevance of the proposed research to the ASXL community. Final funding decisions will be based on scientific merit, relevance and the suitability of the research with respect to the programmatic goals of ARRE.

Questions should be directed to info@arrefoundation.org.

Use of Funds

Grants are made only for the purposes stated in the award letter, and it is agreed that these grant funds will be used only for such purposes substantially in accordance with the budget submitted with the grant proposal. It is also understood that no substantial changes will be made from the approved budget or grant proposal without the ARRE Foundation's prior approval in writing.

Grantees agree to cooperate with the AЯRE Foundation to satisfy all of the requirements of an expenditure responsibility grant in accordance with U.S. Internal Revenue Code (IRC) and the regulations thereunder and agree to the terms outlined below:

All AЯRE Foundation grant funds received by the grantee institution must be maintained in a separate account dedicated to the charitable purposes described in the award letter. The AЯRE Foundation defines a separate account as a 1) a physically separate bank account restricted to the described charitable purposes or 2) a separate bookkeeping account (limited to the described charitable purposes) maintained as part of the Institution's financial records.

- Grantees are required to maintain records of receipts and expenditures and make its books and records available to the AЯRE Foundation at reasonable times. Financial records with respect to a grant, along with any copies of annual reports submitted to the AЯRE Foundation, are required to be maintained by the awardees and their institution for at least four (4) years following the year in which all grant funds are fully expended.

- Grantees will repay any portion of the amount granted, which is not used for the purposes of the grant.

- Grantees agree not to use grant funds for any of the following restricted activities:

- To carry on propaganda, lobbying, or otherwise to attempt to influence any legislation
- In support of a candidate or party seeking elected office or to influence the outcome of any specific public election or to carry on, directly or indirectly, any voter registration drive
- To make grants to individuals for travel, study or other similar purposes by such individuals (such as scholarships, fellowships or grants for research)
- To make any grant to any other organization (other than to public charities or exempt operating foundations)
- To undertake any activity for any purpose other than the charitable purposes

The AЯRE Foundation cannot make awards to individuals, groups, institutions or organizations originating in countries or nations under economic and trade sanctions by the U.S. Office of Foreign Assets Control (OFAC) or any other persons known to support terrorism or to have violated OFAC sanctions. In accepting an award from the AЯRE Foundation, the institution must assume responsibility to screen all individuals, entities or groups supported or associated with the grant against the OFAC sanctions lists <https://www.treasury.gov/resource-center/sanctions/Pages/default.aspx>.

Reporting Requirements

The researcher must submit a progress report at six monthly intervals. This report must include a financial statement showing the expenditure of grant funds. A final report must be submitted after twelve months and all unexpended funds must be returned to the ASRE Foundation, unless a subsequent grant is awarded.

ASXL Research Network

Membership in the ASXL Research Network is not required but is highly encouraged. Open science has been gaining momentum as a way to accelerate progress especially in cutting edge research and as a way to further scientific discovery and collaboration. The ASXL network supports a sharing and publication policy for open and rapid dissemination of results, including methods, data and reagents. This sharing of knowledge is mutually beneficial and only those who choose to participate will be given access to this data. Data that includes PII (personally identifiable information) will not be included.