



## RESEARCH GRANT APPLICATION 2020 REQUIREMENTS AND GUIDELINES

### **Introduction**

**Xia-Gibbs Syndrome** ('XGS') is caused by mutations in a gene called AHDC1, at 1p36.11-p35.3, which is the short (p) arm of chromosome 1 between positions 36.11 and 35.3.

The AHDC1 gene provides instructions for making a protein whose function is not known. The AHDC1 protein is found in the nucleus of cells, and a region of the protein is thought to allow it to attach (bind) to DNA. Based on its location and possible DNA-binding ability, researchers suspect the protein may help control the activity of other genes.

Most of the AHDC1 gene mutations involved in XGS lead to production of abnormally short AHDC1 proteins. Researchers suspect that a reduction in the amount of functional AHDC1 protein impairs normal brain development, leading to intellectual disability, speech problems, and other neurological features of XGS. Abnormal development of other body systems caused by a shortage of AHDC1 protein may account for additional signs and symptoms of the condition.

**Xia-Gibbs Society** ('The Society') is a not-for-profit corporation formed in the USA for charitable purposes.

The Society seeks to provide support to and advocate for those with Xia-Gibbs Syndrome ('XGS') and their families and to foster hope for the future. The Society also aims to raise awareness about Xia-Gibbs Syndrome among the medical and general community and to support, fund and promote scientific and medical research.

### **Xia-Gibbs Society Research Grant 2020 and Eligibility**

The Society is seeking to award a one-time research grant of US\$50,000.00 to support research into Xia-Gibbs Syndrome. The Society is currently seeking one-year project proposals, with the possibility of extending successful projects or awarding additional grants in subsequent years.

The **Xia-Gibbs Society Research Grant Award** is available to both established and early career investigators with a strong interest in XGS. All individuals should be affiliated with an academic institution, hospital system, non-profit institution or other accredited institutions. International applicants are welcome to apply; however, all materials must be submitted in English. Eligible applicants include PhD students, post-doctoral fellows, clinical fellows, researchers, physicians and other allied professionals. All applications require either a faculty level appointment or a senior scientific position/faculty member to oversee the project. The Society does not require a Letter of Intent (LOI).

## Xia-Gibbs Society Research Priority Areas

- Furthering the basic understanding of AHDC1 function and expression.
- Gaining a more in-depth understanding of the varying clinical phenotypes and clinical presentations of those with XGS.
- Advancing insight into therapeutic interventions, such as the development of novel treatments, evaluation of the efficacy of pharmacological and behavioral treatments, exploration of genetic approaches, and the identification of objective outcome markers for treatment.

### 2020 FUNDING PROGRAM

	Dates
<b>Program Opens</b>	22 <sup>nd</sup> June 2020
<b>Full Applications Due</b>	31 <sup>st</sup> July 2020
<b>Award Announcement By</b>	31 <sup>st</sup> October 2020
<b>Anticipated Project Start Date</b>	November/December 2020

### Proposal

In order to be considered for the grant, institutions should submit a proposal in writing which will:

- Outline the proposed research project, explaining its context within the overall research effort into XGS and its potential contribution to the goal of a treatment or other concrete outcome for the XGS community.
- Nominate an individual to be the recipient of the funding, providing her credentials, academic achievements and suitability for the project in question.

The proposal should be submitted, in electronic form, to [researchgrant@xgsociety.org](mailto:researchgrant@xgsociety.org), by the deadline date of 31<sup>st</sup> July 2020.

### Governance and Administration of the Award

Applications will be reviewed in detail by Xia-Gibb Society's Board members and Executive Director who will together make the final funding decision. The Board of the Society will consider the proposal and evaluate its alignment with the Society's research priority areas, goals and mission statement. The grant selection process is unbiased; awards are based solely on merit and expected contribution to the body of knowledge about Xia-Gibbs Syndrome.

### REVIEW PROCESS AND EVALUATION CRITERIA

Applications will be evaluated using the following criteria:

#### 1) Merit

Overall quality of the project proposal to achieve the Program's aims:

- The clarity, scope, originality and synergies of the team's research questions and aims against the aims of the program priority areas.

- The appropriateness of the plan that identifies critical milestones and explains how these milestones will be achieved.

## 2) The Team

- The proposal demonstrates a truly collaborative approach where the whole team will be greater than the sum of the parts.
- The appropriateness of the team member's background and expertise related to their project aims.
- The extent and appropriateness of the collaborative, team-based approach proposed.
- The appropriateness of the team leadership of the project(s), including management, coordination, and integration of activities as one team; and clarity of the team members' roles and responsibilities.

## 3) Potential Impact

- The extent, appropriateness and potential impact of the team's research objectives in relationship to the aims of the Program.
- The appropriateness of the Knowledge Translation Plan.

The Xia-Gibbs Society will be responsible for contract award activities, transfer of funds and evaluation of project outcomes. The recipient will be responsible for day to day project implementation, monitoring budget expenditure against the award amount and preparation and submission of project reports as per the schedule outlined (see pg 5).

### Application Instructions

Please read the **priority areas** listed above before completing the application and supplemental materials.

Applications must be submitted by end of day Central Standard Time (CST) on 31<sup>st</sup> July 2020, via email to [researchgrant@xgsociety.org](mailto:researchgrant@xgsociety.org) and must include the following:

1. A completed application form and signature page, including Signature of an official authorized to sign for the institution. (Please use blank form at the end of this document)
2. Lay Summary/Mission Statement: A brief summary; describe your project goals, aims, and impact to the XGS community. (300 words)
3. Scientific Abstract. (200 words or ½ page)
4. Specific Aims/Deliverables. (300 words)
5. Background, Preliminary data, and Clinical Impact / Research Significance. (500 words or 1 page)
6. Research Design & Methods. (500 words or 1 page)
7. Budget: the budget maximum for this 2020 program is \$50,000, awarded to one applicant for **direct costs only** (see allowable costs and excluded costs below). Please include an itemized list

of how funds will be used (for example: materials, animals, salary, laboratory supplies, research expenses, etc.). All expenses must be expressed in US dollars. Please provide detailed budget information, including the following:

- a. Total budget requested from Xia-Gibbs Society.
  - b. Please include an NIH-formatted "Other Support" page that includes all current and pending support.
8. Biographical Sketch/Investigator Qualifications: Please provide your background information including education, training, positions, honors and recent research publications for Principal Investigator and Co-Principal Investigator. An NIH Biosketch style is preferred. A link to a website biography is allowable.
9. References: Submit up to 2 letters of recommendation from mentors, department heads or collaborators. Letters of support are only required for early career investigators, including postdoctoral or clinical fellows or faculty within their first year.
10. IRB/IACUC Requirement: We require proof of IRB and/or IACUC approval from your institution prior to awarding funding. If this is not available at the application stage, it can be provided later.

#### **ALLOWABLE COSTS**

The following expenditures will be considered eligible for funding received through this opportunity:

- Research operating costs for the proposed collaborative research program: this must be distinct in their objectives from those for which team members currently receive other sources of funding.
- Costs of data collection, database and maintenance: this refers to information holdings directly related to the program of work.
- Costs of national quality improvement forums and networking: including collaborations, planning and knowledge translation activities.
- Salaries for research trainees, research assistants, coordinators, administrative staff, and other personnel: must be deemed essential to enhance the collaborative research productivity of the team.
- Costs involved in linkage with downstream translation and dissemination of research findings: applicants are encouraged to link with other award recipients (where appropriate) to leverage outcomes as well as share the results of their research with the broader clinical quality community.

#### **INELIGIBLE EXPENDITURE**

The following expenses are ineligible for funding:

- Institutional overhead costs.
- Tuition and professional membership fees.
- Funding for clinical or research staff that are already funded through other sources
- Projects or research activities already covered by other research or funding arrangements.

## Application Submission

A PDF copy of the proposal should be electronically submitted to [researchgrant@xgsociety.org](mailto:researchgrant@xgsociety.org) by 31<sup>st</sup> July 2020. Applications will be kept confidential. The required format for submission is as follows:

- All documents should be merged into one PDF file. This includes all items listed above in numbers 1-11.
- Documents requiring signatures (cover sheet, IRB or IACUC letter or equivalent letter, letters of recommendation) need to be signed first, scanned and then merged into the full application file. Digital signatures will not be accepted.
- The PDF file should be saved as “investigator first and last name\_institution\_2020.” An example would be to name the file “John Smith\_Univ of Texas\_2020”

No extensions of the deadline can be made. No late applications allowed. Post-submission materials will only be allowed upon request.

**Inquiries:** Questions regarding these guidelines should be directed to [researchgrant@xgsociety.org](mailto:researchgrant@xgsociety.org).

Final decisions on funding will be made by the Society’s Board of Directors by 31<sup>st</sup> October 2020 and grant applicants will be notified by email. All decisions about grant applications made by the Society are final and are not subject to appeal.

## Terms and Conditions

*Please note – This is only a partial list of our terms. A complete list of the full terms and conditions will be forwarded to Grant recipient(s) upon notification of Grant approval or may be supplied upon request to any applicant.*

- **Payment terms:** The award will be paid in two installments. The first grant payment of 50% will be forwarded upon receipt of the signed contract. The second 50% payment will follow after submission of a satisfactory progress report at the 6-month mark as described below.
- **Reporting:** We will require a non-scientific status update at the 6-month mark, maximum of one page in length, detailing out progress thus far of the research, in layman’s terms. At one year, we will require a final scientific report of outcomes of the research (and final budget report detailing how the money was spent).
- **Publication Policy:** It is expected that the results of research supported by Xia-Gibbs Society will be published as soon as is practical in literature, consistent with high standards of scientific excellence and rigor. The responsibility for publication lies exclusively with the Principal Investigator – however, the results of any work supported through Xia-Gibbs Society may not be published without prior review by Xia-Gibbs Society. Any publication arising in whole or in part from an Award funded by Xia-Gibbs Society shall acknowledge funding support by Xia-Gibbs Society.
- **Sharing Policy:** Xia-Gibbs Society-funded investigators may be asked to make reagents (e.g. animal models, expression plasmids, antibodies, permanent cell lines) and detailed protocols for their use available, upon request, to qualified scientists for non-commercial purposes. Protocols may also be included on the Xia-Gibbs Society website. Recipients will be expected to bear shipping costs and to acknowledge the source of the reagents in resulting publications.

- **Publicity:** Xia-Gibbs Society shall be permitted to use the Principal Investigator's name, image and likeness, as well as the name of the affiliated institution, in connection with all statements, printed materials or electronic media related to the grant award or related to Xia-Gibbs Society's program. The Principal Investigator will provide appropriate photographs and biographical information to Xia-Gibbs Society.
- **Laboratory/Clinic Visits:** As a condition of support, the Principal Investigator agrees that a representative of Xia-Gibbs Society may visit the laboratory, clinic or institution where the grant is being funded upon reasonable prior notification and during normal business hours.
- **Conference Attendance:** The Principal Investigator would be expected to attend the Xia-Gibbs Society Family Conference and present their findings.

### **Variations**

The Xia-Gibbs Society may vary the requirements set out in this call for full applications and seek further information from the Applicants. Applicants shall supply this information on reasonable request.



## 2020 RESEARCH GRANT APPLICATION FORM

### RESEARCH INFORMATION

Title of Research Project \_\_\_\_\_

### APPLICANT INFORMATION

Principal Investigator's Name (First, MI, Last) \_\_\_\_\_

Title \_\_\_\_\_ Degree(s) \_\_\_\_\_

Institution \_\_\_\_\_ Division/Department \_\_\_\_\_

Mailing Address \_\_\_\_\_

Phone \_\_\_\_\_ Fax \_\_\_\_\_ E-mail \_\_\_\_\_

### INSTITUTION & SUPERVISOR INFORMATION

*If research is to be conducted at a different site:*

Institution \_\_\_\_\_ Division/Department \_\_\_\_\_

Mailing Address \_\_\_\_\_

Phone \_\_\_\_\_ Fax \_\_\_\_\_ E-mail \_\_\_\_\_

*If a supervisor or co-investigator is involved:*

Supervisor Name \_\_\_\_\_ Title/Degree(s) \_\_\_\_\_

Supervisor Phone \_\_\_\_\_ E-mail \_\_\_\_\_

Co-investigator Name \_\_\_\_\_ Title \_\_\_\_\_

Institution \_\_\_\_\_ Division/Department \_\_\_\_\_

Co-investigator Phone \_\_\_\_\_ E-mail \_\_\_\_\_

RESEARCH PROJECT BUDGET

Total research project budget: \_\_\_\_\_

Xia-Gibbs Society funding requested (\$50,000 maximum) \_\_\_\_\_

Grant payment checks should be payable to: \_\_\_\_\_

Grant payment checks should be mailed to (i.e. grants administration office address): \_\_\_\_\_

\_\_\_\_\_





## 2020 RESEARCH GRANT APPLICATION FORM (cont.)

### APPLICANT'S STATEMENT

I hereby certify that the information provided in this application is, to the best of my knowledge, true and correct. I have not knowingly withheld any facts or circumstances that could otherwise jeopardize consideration of this application. I agree to accept responsibility for the scientific direction, conduct and financial and legal oversight of this project.

I certify that I have read Xia-Gibbs Society's grant terms and understand the grant requirements if awarded funding by Xia-Gibbs Society. Please note, digital signatures will not be accepted.

Applicant's Name \_\_\_\_\_

Applicant's Signature \_\_\_\_\_

Applicant's Title \_\_\_\_\_

Date \_\_\_\_\_

### INSTITUTIONAL ASSURANCES

We require written assurance from an official authorized to sign for the Institution. Please note, digital signatures will not be accepted.

Institutional Official and/or Faculty or Senior Researcher

I certify that the information provided by the applicant(s) is accurate and that the funds will be administered in accordance with all appropriate institutional policies and all requirements of Xia-Gibbs Society.

Signing Official's Name \_\_\_\_\_

Signing Official's Signature \_\_\_\_\_

Signing Official's Title \_\_\_\_\_

Date \_\_\_\_\_