



# FONDAZIONE TELETHON ETS FALL SEED GRANT 2025 XGS

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## CALL FOR APPLICATIONS

### Introduction

[Associazione Xia-Gibbs Italia](#) (**Associazione**) and **Fondazione Telethon ETS (FT)** agreed to collaborate to support seed research projects focused on **Xia-Gibbs Syndrome (XGS)** with one-year duration and a maximum budget of € 50,000.

The Seed Grant Call is based on the following premises:

- a. **Associazione** is a non-profit organization dedicated to promote, disseminate, and support scientific research on Xia-Gibbs Syndrome (XGS);
- b. **FT** is a non-profit organization recognized by the Ministry of University and Research, whose mission is to advance biomedical research toward cures for rare genetic diseases by funding research projects through a peer-review process compliant with the UNI EN ISO 9001:2015 standards.
- c. Associazione recognized FT's peer review process as a valid evaluation method for the identification of worth funding research projects, thus ensuring a more effective use of the financial resources within the research portfolio.
- d. Associazione expressed its interest in establishing a collaboration with FT, whereby: (i) FT is entrusted with the Call preparation, the management of the evaluation process of the submitted projects, the post award administrative procedures, the disbursement of funds and the monitoring of scientific results, and (ii) Associazione is entrusted with the dissemination of the obtained scientific results.

Therefore, Associazione and FT agreed to collaborate and pooled their respective resources to select and manage research projects aimed at supporting scientific progress for Xia-Gibbs Syndrome (XGS).

Associazione irrevocably appoints FT to act on its behalf, authorizing FT to activate the project funding in the Associazione's sole interest and own expense.

## Eligibility criteria

### *Eligible diseases and research topics*

This call is in support of research seed projects focusing only and exclusively on **Xia-Gibbs syndrome (XGS, or AHDC1-related intellectual disability-obstructive sleep apnea-mild dysmorphism syndrome, ORPHA: 412069)**, aiming at investigating new hypotheses and understanding the molecular and pathophysiological mechanisms underlying AHDC1 gene-related pathology, to pave the way for the development of new therapeutic strategies.

Research projects focusing on the following topics are **NOT eligible**: epidemiological studies, registries, biobanks.

**Preliminary results are not mandatory** as long as the underlying premise, goal, and hypothesis are plausible and testable. **The research proposal must focus on a well-defined goal achievable within the 12-month timeframe.**

Please note that, for this Call, only **single-center proposals** are admitted.

### *Eligible Host Institutions*

Only research proposals submitted by Applicants working either in public or private Italian non-profit research Institutions are eligible. Applicants from FT Research Institutes (SR-TIGET and TIGEM) are eligible.

### *Eligible applicants*

**Experience within the Xia-Gibbs Syndrome (XGS) field is not required.**

Applicants can **submit only one project** within the round **Fall Seed Grant 2025 Call**. Please note that Applicants holding an active grant from a different Fondazione Telethon funding initiative are eligible to submit a proposal. A dual appointment in a foreign Institution is allowed only if it does not impinge on the effective conduct of the Fondazione Telethon research project.

## Project duration

The duration of the proposed project is 12 months.

## Budget

**A maximum budget of € 50,000 is allowed.**

For more details about allowed and not allowed costs, please see the [Guidelines for Applicants](#) for the Fall Seed 2025 Call and the [Regolamento di Gestione del Finanziamento Seed Grant](#) documents.

A budget justification for each item must be indicated. An expenses report will be required at project closure and only project-related expenses will be approved.

Please note that the Lead Applicant's Host Institution, upon indication by the Lead Applicant in the Application, may allocate a maximum of 20% of the total budget to only one collaborator from a foreign third-party Institution. This budget must be indicated in the Application, and the involvement of the foreign collaborator must be within the scope of the project, evaluated and approved by the reviewers. If approved, the Lead Applicant's Host Institution will be responsible for transferring the budget to the foreign collaborator and collecting detailed expenditure information to be reported to FT. For more details, please refer to Section III.2 and Section V.4 in the [Regolamento di Gestione del Finanziamento Seed Grant](#) and [Guidelines for Applicants](#) for the Fall Seed 2025 Call.

## Submission deadlines

**CALL OPENING:** October 15<sup>th</sup>, 2025 on the *Fondazione Telethon Grant Management* system portal at this [link](#).

**SUBMISSION DEADLINE:** November 19<sup>th</sup>, 2025 at 1:00 PM (CET).

Although not mandatory, **Applicants are kindly asked to register on the platform and insert *Title, Research type, Research step, Disease Name, and ORPHA code* of the proposed project by October 29<sup>th</sup>, 2025.**

Applications must be prepared in accordance with the [Guidelines for Applicants](#) for the Fall Seed 2025 Call and to the [Regolamento di Gestione del Finanziamento Seed Grant](#). A sample PDF version of the Application form can be downloaded at this [link](#).

Please be aware that **incomplete submitted Applications**, missing any mandatory documents or not complying with the requirements set out in this Call for Applications and in the relevant Guidelines, **will not be accepted**.

## The evaluation process

FT will initially verify all submitted Applications to assess their eligibility based on administrative criteria and scientific relevance to the Call. Subsequently, FT will identify an ad hoc panel of expert reviewers to evaluate the scientific merit of all Applications that have passed the eligibility check. For Clinical trial studies, FT might also engage with experts in clinical trial design and regulations to further assess the robustness and the

feasibility of the proposed study. All the reviewers involved in the evaluation process will be bound by strict confidentiality and conflict of interest rules defined by FT.

The Panel Reviewers will be asked to evaluate and score each proposal based on the following criteria ([link](#)):

**A) Scientific merit:**

- Significance
- Originality of science
- Appropriateness of design and methods
- Feasibility and Safety
- PI and Team competence
- Budget

**B) Potential impact:**

- Added value: If the project is successful, how will the results advance current scientific knowledge in the field?
- Unmet need: How will the project contribute to fulfilling current unmet need/s of patients with rare genetic diseases?

Top scoring proposals will be discussed by an *ad hoc* panel of expert reviewers during a study section, which will take place **by the end of January 2026**. At the end of the discussion, all Panel members will score each proposal.

Applicants will be notified by email **by the end of February 2026** and will be given access to the Review Report online on the *Fondazione Telethon Grant Management* system.

FT Administration Office will communicate to the funded Applicants the administrative details and instructions to activate the approved grants.

## **Fondazione Telethon ETS Policies and Rules**

FT, as a member of the International Research Disease Consortium ([IRDiRC](#)), endorses and applies, which “emphasize the collaboration in rare diseases research, the involvement of patients and their representatives in all relevant aspects of research, as well as the sharing of data and resources.”

In addition, all FT Applicants and Grantees are bound to comply with the policies reported below.

## Safeguard of research integrity

Research integrity (RI) is the basis of responsible conduct of research (RCR); the standard principles of RI – *reliability, honesty, respect, accountability* - are shared within the international scientific community, as laid out by [the European Code of Conduct for Research Integrity](#).

FT is fully committed to preserving and promoting the RCR within the FT-funded research community, to ensure and strengthen high-quality research and to maintain public trust in its research enterprise.

Applicants, Grantees and all research personnel (investigators, trainees, administrators and staff) related to any FT Application or FT project must strictly adhere to the highest standards of good research practices, which embrace the following contexts: *research environment, training, supervision and mentoring, research procedures, safeguards, data practices and management, collaborative working, publication and dissemination, reviewing, evaluating and editing*.

Potential research misconduct will result in FT issuing a formal notification to the Applicants' Host Institution, which should then respond according to its policy for handling allegations of research misconduct.

In particular, FT expects that organizations where the FT-funded scientists' work:

- have policies, structures and training in place that enable students and researchers to understand and adopt good research practices.
- have formal, written policies for preventing and dealing with scientific misconduct, conventionally defined as *fabrication, falsification, or plagiarism* but including other unacceptable practices, including, but not limited to, manipulating authorship, 'self-plagiarism', withholding research results, misrepresenting research achievements, and misusing seniority to encourage violations of research integrity.

Please see FT guidelines on Research Integrity at the following [link](#).

## Awarding of research funds

Awarded funds must be spent to accomplish the research for which they have been approved. FT requires the funds to be used effectively and economically, and the expenses to be essential for the research for which the funds were awarded. No funds will be awarded by FT to any Host Institution until both parties have signed a specific agreement according to art. 3 of the D.P.R. 20th March 2003, n. 135.

FT reserves the right to ask for a copy of the statute of the Host Institution and of the latest available balance sheet as well as the acknowledgment of the legal status for all the Applicants working for non-profit private organizations; equally, FT can request updates of the statute and of the balance sheet in the case of

Applicants working for non-profit organizations that have already benefited from FT funds in the past. FT reserves the right to evaluate the compatibility of the statutory guidelines of the private institutions on a case-by-case basis, with the aim of ensuring social benefit and of financial reliability in order, if necessary, to dictate the conditions for the assignment/payment of the contribution.

FT reserves the right to visit the Host Institution before releasing any funds and at any time during the grant period.

The funds will be released in 2 tranches:

- fifty percent will be disbursed after the submission of all required documentation, as specified in the present Call for Applications and in the [Regolamento di Gestione del Finanziamento Seed Grant](#) document.
- the remaining fifty percent will be reimbursed upon completion of the project, submission of the final scientific report and approval of the administrative report demonstrating that all granted funds have been spent. Should there be any unspent residue, only the amount that has actually been spent will be reimbursed.

FT reserves the right to cancel payments whenever a conflict arises regarding the stipulations contained in this Call for Applications, or stipulations specifically made by FT to the Host Institution and/or Applicant.

### **Publications, data sharing and final scientific reports**

The Grantee is required to:

1. acknowledge **Associazione Xia-Gibbs Italia** and FT in all publications arising from the project (also by specifying the **project number** in the Acknowledgements/Funder section) and send the relative PDF file to [papers@fondazionetelethon.it](mailto:papers@fondazionetelethon.it);
2. be compliant with the FT **Open Access Policy** (<https://www.fondazionetelethon.it/en/what-we-do/support-of-research-and-patients/support-to-research/open-access/>);
3. deposit **data** generated from the research project, including source data, on appropriate open or controlled access public databases;
4. be compliant with the European General Data Protection Regulation no. 679/2016 as well as with any other applicable local law;
5. submit the **Final Scientific Report** at the end of the project;
6. support **Associazione Xia-Gibbs Italia** to disseminate **data** generated from the research project.

## Development of Fondazione Telethon funded research results

1. FT acknowledges that full ownership of all intellectual property (IP) rights arising from funded research belongs to the Host Institution/Grantee, according to IP regulations and without prejudice to the rights of potential third-party collaborators.
2. FT acknowledges the need to translate research results into therapies and to make them available to patients and recognizes that this can be achieved through the activation of industrial collaborations and partnerships that may accomplish the development, manufacturing and distribution of therapies, drugs, diagnostics and devices. FT requests that the Grantee and the Host Institution undertake all the steps required to ensure adequate protection and seek opportunities of development of such research results.
3. Accordingly, the Grantee is required to ensure that any potential therapeutic/diagnostic approach arising from the funded research project is duly protected by a patent application through the interaction and cooperation with the Host Institution's Technology Transfer Office (or other relevant office) before its disclosure (i.e., abstracts, posters, oral presentations, papers). To this aim, the Grantee must share all disclosures with the Host Institution's Technology Transfer Office in due time for the necessary assessments of patentability and patent filing procedures.
4. To allow FT to monitor the outcomes of the research funded, the Host Institution must inform FT ([tto@fondazionetelethon.it](mailto:tto@fondazionetelethon.it)) via written communication of any new patent filings related to the project.
5. In addition, the Host Institution shall promptly inform FT in writing if it decides not to proceed with the protection of a patentable result or with the exploitation or prosecution of a filed patent. In such case, FT will evaluate, together with Associazione, the type of activity to be undertaken, and the need to formalize a specific mandate to conduct such activities.

## Privacy of personal data

FT and the Host Institution will be considered as being autonomous data controller of the personal data to be processed under the Application.

The Host Institution is allowed to indicate the personal data of the Applicant as well as of any other researcher involved in the Application, on the condition that: (i) the Privacy Notice has been provided; (ii) has gathered the relevant consents; and (iii) will approve the Application ensuring that the above conditions have been respected.

In the partnership between Associazione and FT, FT is entrusted with managing the evaluation process of the research projects, the post-award administrative procedures and the scientific monitoring that are carried out through own tools and means. Therefore, only FT is allowed to know the personal data deriving from the

evaluation process and from the administrative procedures that follow the fund allocation. No personal data will be transmitted by FT to Associazione except for specific and justified reasons in which FT may communicate to Associazione the personal data acquired only after having transmitted to the interested party the information pursuant to art. 13 of the REG.EU n. 679/2016 of Associazione and acquired consent to treatment.

Therefore, for privacy purposes, FT is the data controller, while Associazione has no role (given that Associazione does not know the personal data).

**Rome - October 15<sup>th</sup>, 2025**

**FONDAZIONE TELETHON ETS**