

## II FINRETT GRANT CALL FOR RETT SYNDROME RESEARCH.

**The 6<sup>th</sup> of April 2020**

### TERMS

#### 1. PURPOSE AND BENEFICIARIES.

The purpose of the FINRETT funding described in this call is to promote scientific research projects on Rett Syndrome and other related syndromes presented by international researchers or research teams, who wish to develop research programs within the framework of universities, hospitals or research centers to which they are attached. This includes basic, translational or clinical research projects.

It is outside the scope of this call to finance projects of clinical trials with drugs as well as projects under development or in justification process for other grant applications.

#### 2. ENDOWMENT.

2.1 Aid will be granted to the institution to which the applicant researchers are assigned and where the research is being carried out. The entirety of the aid will be used solely and exclusively for the purpose for which it is granted.

2.2 These grants will be funded by donations to FINRETT which is therefore the manager of this call.

2.3 The TOTAL AMOUNT of this grant is **27.000 euros**.

2.4 FinRett may choose to finance one or more projects. Allocations will be proportionally distributed among the projects based on their respective budgets.

2.5 Any remainder not assigned in this call will be fully allocated to successive calls with equal purpose.

#### 3. APPLICATION AND DEADLINE.

3.1 In order to qualify for grants, interested parties must access the web page [www.finrett.org](http://www.finrett.org) to complete the application form and attach the following documentation:

- a. Professional curriculum vitae of the Principal Investigator and a register of the members of the team, making special reference to everything related to the submitted project.
- b. Proposal submission form of the researcher or research team, and the research project report (according to the model attached as Annex I to this Call). The research project report must contain a description in simple language that is understandable to the general public. The submission to this call implies acceptance of authorization to FINRETT to disseminate this project. (Maximum length of 30 pages including figures and excluding bibliography, with Arial font, body 11, line spacing 1.15. Whatever exceeds this length, will not be taken into account in the evaluation).
- c. Authorization for execution from the project of the head of the university, hospital, company or research center where the research will be carried out.
- d. Indication of every scholarship awards or financial aids, public or private, for this project or for the research related to it. Applications must indicate the granting institution, the specific project and the funding amounts. All pending applications must also be indicated.
- e. Necessary certificates proving compliance both by the ethics committees of the research center (which must declare the approval and viability of the proposal in all its terms), as well as by the animal experimentation committee (in the case of projects that involve experimentation in animal models).
- f. Up to date Social Security and the Tax Agency Certificates of the entity, research center, hospital or university, stamped by the holder of the authorization.

3.2 The proposal submission form, together with the corresponding annexes, and the documents referred to in section 3, must be written in English and Spanish language in the case of national projects and in English language in the case of foreign projects, and must be submitted electronically to [info@finrett.org](mailto:info@finrett.org) up to 13:00h (UTC+2) of the 6<sup>th</sup> of November, 2020. Any terms of this call submitted thereafter will be considered terminated.

3.3 Once the documentation has been submitted, if correction or provision of additional documentation is required, a period of 10 business days will be granted from the formal request by FinRett.

3.4 The application will be considered abandoned if the documentation is not provided or corrected within the established period.

3.5 The Research Center undertakes the responsibility to have these documents in original format. These original documents may be required by FINRETT at any time and must be duly updated.

## 4. PEER REVIEW.

The evaluation of the research projects that are submitted and the proposal for the delivery of research grants will be carried out by the FINRETT Follow-up Commission, at the proposal of its Scientific Committee.

### Criteria for scientific and technical evaluation of the projects (up to 70 points):

- Scientific quality: assessment of the proposed hypothesis, competence on the degree of knowledge of the subject, feasibility of the submitted proposal; clarity and concreteness of the objectives, methodological adaptation (up to 25 points).
- Scientific research capability of the Principal Investigator and scientific experience of the research team related to the subject of the project and with special relevance in the last 5 years (up to 20 points).
- Scientific and budgetary feasibility of the presented project: adequacy of the team, resources, work plan, schedule, and budget (up to 15 points).
- Existence of an adequate and sufficient plan for the dissemination and transfer of project results (up to 10 points).

### Strategic and opportunity evaluation criteria of the projects, based on the added value of the work done in the network (up to 30 points):

- Multicenter project (up to 10 points).
- Participation and degree of involvement of different agents: universities, hospitals, patient organizations (up to 10 points).
- International collaboration (up to 10 points).

Decisions of the Executive Committee will not be subject to appeal.

## 5. GRANT AWARD

5.1 The grants will be delivered on the 21<sup>st</sup> of November, 2020 and will have as beneficiary the research center.

5.2 At the proposal of the Scientific Committee, the FINRETT Follow-up Commission may declare void the granting of some of the aids summoned.

5.3 Information on the assessment of applications submitted will not be provided.

5.4 The resolution of the grants, which will be communicated to each of the beneficiaries, will be made public on the website [www.finrett.org](http://www.finrett.org)

5.5 Prior to the delivery of the aid, an Agreement must be signed between FINRETT and the beneficiary or the beneficiary institution, which will regulate the terms of this concession in accordance with the provisions of the present terms which are assumed within the aid application.

## 6. DURATION.

The duration of the aid will be 12 months from the date of acceptance and signature of the Agreement.

## 7. DISTRIBUTION OF THE AID.

7.1 The amount of the aid will be delivered in two installments during the performance of the research, which will be distributed as follows:

1. 70% upon signing the protocol for acceptance of the aid.
2. 30% in the fourth month after the signing of the protocol.

7.2. The financial assistance will be exclusively devoted to cover direct expenses derived from the requested research project.

7.3 The expenses imputed to the project must be dated within the execution period and must be paid before the end of the justification period.

7.4 The financing of the project may cover the following concepts and expenses and shall be governed by the following criteria:

- Acquisition of goods and contracting of services, duly justified. The inventoriable material acquired with charge to the aid will be property of the RESEARCH CENTER.
- Purchase of consumables and supplementary expenses, such as bibliographic material or publication expenses.
- Expenses will be eligible for the total gross amount excluding taxes.
- Travel and meal expenses necessary to meet the project's objectives and to communicate results.

**NOTE:** The amount of the allowances may not exceed 15% of the total amount of justified aid and, in any case, of the amount granted unless your expenditure is absolutely necessary for the purpose of the ongoing research and undoubtedly demonstrated.

- Payment of salaries to the personnel of the RESEARCH CENTER linked to the project through a labor contract, whether temporary or indefinite. The assignment to the project must be duly based on the contract itself or on the attached documents, which will establish the time of dedication per day to the project and any other condition that demonstrates dedication to the subsidized study.
- This amount will include the amounts corresponding to the gross salary of the worker, excluding any other salary supplement, and the social security fees paid by the company of the personnel affected by the program under the conditions described above.
- Remuneration and expenses originated by members of the board or steering and administration boards of the entities involved in the development of the project cannot be included in this item.

The aid cannot be used, under any circumstances, to finance indirect expenses.

## 8. REPORTS.

8.1 There is a maximum period of one year after the date of funding delivery for the execution and realization of the proposed projects.

8.2 The beneficiaries of the aid must maintain contact with the Follow-up Commission of FINRETT, in addition to the referral to it of the report prior to the second aid delivery. In this report, the progress of the investigation will be collected, and must be sent 15 days before of the term established in these bases.

8.3 Any modification of the methodology and/or work plan must be duly justified and will not imply a deviation from the previous final objectives.

8.4 The Research Center may request, in writing, an extension of the deadline up to one month before the end of the maximum term of this call, explaining the reasons that justify it. FINRETT will expressly resolve this request.

8.5 The justification of the project must be completed by the Research Center, within a period not exceeding 3 months from the end of the project.

8.6 For such justification, an economic report must be provided in Excel format, in addition to the copies of the invoices or other documents of legal validity that certify the corresponding expenses accompanied by the payment documents which will clearly identify the provider and the Research Center as the payer.

8.7 The expenses attributed to the project must be dated within the execution period and must be paid before the end of the justification period.

8.8 The Research Center will present the list of expenses incurred, or an economic report, as well as related documents that are contributed. The concept of these expenses shall be the ones included in part 7.4 of this call. The expenses will be financed by the gross total amount, excluding taxes. The invoices will be adjusted to the legal regulations and must be issued in the name of the Research Center that receives the aid.

8.9 The Research Center must provide a Final Scientific Report of the project that will contain at least the following sections: summary of the executed project, objectives and results obtained, conclusions, transferability of the results, diffusion report explaining the origin of the aid granted, expressed in simple language for the dissemination of results by the Research Center.

## 9. MAIN RESPONSIBILITIES.

### 9.1 FROM THE RESEARCH CENTER.

9.1.1 The RESEARCH CENTER will be responsible for the ethical performance of any of the activities supported by the funded grants.

9.1.2 THE RESEARCH CENTER will ensure compliance with the guidelines of this call by reviewing the data submitted and ensuring that the execution of the project has the necessary authorizations and ethical certificates in accordance with the provisions of section 11 of this Call.

9.1.3 The RESEARCH CENTER will administer the support received from FINRETT to the execution of the project.

9.1.4 The RESEARCH CENTER is responsible for both the economic management of the project and the justification of the received aid and must prepare and send to FINRETT an economic and scientific report within 3 months of project completion.

9.1.5 An incorrect justification in time and form of the received financial aid may result in the withdrawal of the same.

9.1.6 The RESEARCH CENTER agrees to return the amounts of the subsidy not invested in the project, if any, to FINRETT.

### 9.2 FROM FINRETT

9.2.1 FINRETT will be responsible for managing this call, especially with regard to the following tasks:

- i. Initial assessment of compliance with the formal requirements of the applications submitted by the Research Centers.

- ii. Transfer of the valuation to the Scientific Committee so that it may evaluate the scientific, technical, and strategic merits of the application.
- iii. Publication of the resolution of the call and
- iv. Formalization and signature of the Agreement that will regulate the general and specific terms between FINRETT and the beneficiary RESEARCH CENTER, once this call is resolved.

9.2.2 FINRETT will be responsible for delivering the financial aid to the RESEARCH CENTER to which the successful applicant is associated.

## 10. VOLUNTARY RETURN AND / OR REIMBURSEMENT:

10.1 VOLUNTARY RETURN of granted funds will be from the RESEARCH CENTER without prior request from FINRETT and may occur at any time during the execution period.

10.2 REINTEGRATION: In the event of total or partial non-compliance with the established conditions in the Agreement signed between the parties, the RESEARCH CENTER shall refund the amount received and, if applicable, the generated income and interest accrued by the payment of the financed project.

## 11. PUBLICATIONS.

FINRETT, or any of the associations signing the Agreement, the Spanish Association of Rett Syndrome and the Catalan Association of Rett Syndrome, may publish and disseminate the work throughout the world and for an indefinite period of time through its publication in specialized journals, in book or electronic book format, and on the website [www.finrett.org](http://www.finrett.org). Any scientific publication resulting from it must quote FINRETT in the list of acknowledgments.

## 12. RESCISSION.

By submitting to this call, the participants assume the requirements set out in this policy, as well as those that FINRETT has established, in each case, to monitor the development of the research project.

In case of non-compliance the aid will automatically be left without effect, and the total amount received up to date must be returned.

## 13. LEGISLATION.

Research projects that qualify for grants must respect the fundamental principles set out in the Declaration of Helsinki, in the Council of Europe Convention on Human Rights and Biomedicine, in the Universal Declaration on the Human Genome and the Human Rights of the UNESCO, and must meet the requirements established in Spanish legislation in the field of medical research in general and especially those required in relation to the specific research on which the project is to be seen, on the protection of personal data in accordance with the Organic Law 3/2018, of December 5, Protection of Personal Data and guarantee of digital rights, and other applicable Spanish legislation.

## 14. INTELLECTUAL AND INDUSTRIAL PROPERTY

All of the industrial and intellectual property rights that may derive from the financed projects will be distributed according to the policy and Agreements of the RESEARCH CENTER.

## 15. DATA PROTECTION.

The data provided to FINRETT will be included in a file of personal data and will be used solely and exclusively for the specific purposes that have been provided in this document.

At any time, applicants may exercise the rights of access, rectification, cancellation and opposition contemplated in the current regulations on data protection, stating this in an irrefutable manner at [info@finrett.org](mailto:info@finrett.org)