

Call for research projects 2024

"Research on chordoma" *Biomedical Sciences or Paramedical Sciences*

Maximum budget: **40 000 €** - Maximum duration: **24 months**

Deadline: **05/12/2024 - 5pm** (Paris time)

Your profile must be created on the application platform prior to any application (instructions p3).

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Context

Due to the specificities of the field of rare diseases, the AVAC (Association Vaincre le Chordome) and the Fondation Maladies Rares (Foundation For Rare Diseases - FFRD) have agreed on a **partnership to support and stimulate research on chordoma** (rare diseases group: rare cancers).

AVAC¹, is a non-profit association, created in 2018 by chordoma patients. Its main objectives are to:

- Inform chordoma patients, as well as their loved ones, about accessible care, and to share, with as many people as possible, the results of the experience and knowledge accumulated by each individual. The aim is to provide the most complete and objective vision of possible treatments. The association directs patients to center of expertise, so that they can make their treatment decisions with maximum information and benefit from the best medical techniques.
- Facilitate exchanges between patients suffering from the disease in order to encourage the sharing of experiences and help each patient/caregiver in their journey, so that they feel less alone. The association has developed a forum for dialogue (monthly Patients' Forum) which provides moral support to patients and others affected by the disease.
- Support research on tumour in every possible way, notably through financial participation and contributions to private or public research initiatives. The association's support can also be used to help acquire or develop expertise in the disease.

FFRD² is a private non-profit organization, founded in 2012³ by five members⁴, with the aim of helping to (i) deciphering rare diseases to facilitate diagnosis and accelerate the development of new treatments, (ii) improve the daily lives of people with disease and their loved ones. Its mission is of general interest: to lead, coordinate and support research on rare diseases. It provides free support to patient organizations in their efforts to promote rare diseases research, for example through joint calls for projects such as the one proposed here.

¹ <https://chordome.org/>

² <https://fondation-maladiesrares.org/en/>

³ PNMR2 : <http://www.sante.gouv.fr/le-plan-national-maladies-rares-2011-14-une-ambition-renouvelee.html>

⁴ AFM-Telethon, Rare Diseases Alliance, Inserm, Conference of University Hospital Directors, Conference of University Presidents

Aim of the call

According to Orphanet: *“Chordomas are rare malignant tumours arising from embryonic remnants of the notochord in axial skeleton. They are predominantly found in adults and comprise 0.2% of all central nervous system tumours and 2-4% of all primary bone neoplasms, with an estimated prevalence of 1 in 2 million people and a male-to-female ratio of 2:1.*

The clinical presentation depends entirely on the location of the chordoma. The main possible locations are the sacrum, intracranially at the clivus and along the spinal axis. Chordomas are characterized by slow growth, with local destruction of the bone and extension into the adjacent soft tissue. They can metastasize to lymph nodes, lungs, liver and bone.

Treatment should be undertaken by expert neurosurgical and radiation oncology teams. Surgery is the primary mode of treatment, but excision often remains incomplete despite repeat operations. Radiation in combination with surgery is then often used. High radiation doses (i.e. with proton beams) are required for local control. The role of chemotherapy or targeted therapies is still under investigation. Prognosis depends on the extent and completeness of the tumour excision. Long-term follow-up is required because of the high rate of recurrence of these tumours.⁵”

This call aims to support **innovative, transdisciplinary, fundamental, translational or clinical research programs on chordoma.**

All disciplines in **Biomedical Sciences** and **Paramedical Sciences** are eligible.

The association wishes to support any research aimed at understanding the pathophysiology of the disease, improving the **diagnosis**, developing **better management modalities** and/or **therapeutic strategies**, with a particular focus on:

- **articulation and combination of existing treatments,**
- **reduction of the recidivism rate (currently around 60%),**
- **management of pain, fatigue, side effects.**

Eligibility criteria

The project must explicitly formulate a **research question**, addressing issues specifically related to **chordoma**.

The project must demonstrate its **originality**, feasibility and **the expertise(s) of the** researchers involved.

The principal investigator of the project ("lead applicant" – P.I.) must be a **researcher**, belonging to a⁶ French or foreign public research organization. It is expected that the bearer will be statutory and hold a permanent position.

There must be a clear match between the main methodology used in the project and the expertise of the principal investigator.

⁵ <https://www.orpha.net/en/disease/detail/178>

⁶ **Public research organization:** entity such as a university or research institute, or a structure dedicated to research within a health institution and associated with a university or research institute, whose primary purpose is to carry out basic research or applied research or experimental development activities and to disseminate their results through teaching, publication, or technology transfer.

Financing

This call for research projects provides for financial support up to **40 000 €**, for a **maximum duration of 24 months**.

Funding support can cover, **if it is entirely and exclusively dedicated to the research experiments**, the costs of:

- Fixed-term contract staff (excluding administrative staff).
- Equipment, up to a maximum of €2,000 (any excess to be justified precisely in the response form),
- Consumables, up to a maximum of €2,000 (any excess to be justified precisely in the response form),
- Travels, up to a maximum of €2,000 (possible overage to be justified precisely in the response form),
- Provision of services, if they relate only to the execution of a very limited part of the project (maximum 10% of the budget).

No environmental costs or management fees are eligible.

Funding must be **realistic, reasonable, detailed line by line**, and **fully justified**.

An agreement will be established between the organisation managing the research programme (organisation of the main leader) and FFRD. **The management organisation will not be able to charge any management fee on the amount granted.**

Co-financing of the selected project is possible as long as no conflict of interest exists.

The lead applicant will be responsible for the management of the allocated funds, including, where applicable, the agreement and distribution to the partner teams.

Submission Process, Selection and Scheduled

The application form, in English, must be completed on <https://ffrd.syntosolution.com/> before **December 5th 2024, 5pm** (Paris time).

You must have already created your profile on the application platform before submitting (a delay may be necessary). Technical support for the platform is available from 9am to 6pm until December 4th 2024.

The joint selection by AVAC and FMR will take place on the basis of:

- validation of the eligibility criteria by the FMR,
- of the priorities of the AVAC association,
- evaluations by independent external experts (see Annex),
- of the final scientific opinion, issued by the scientific committee (SC) of AVAC.

The members of the board of the AVAC Association and the external experts sign a confidentiality and a non-conflict-of-interest agreement.

The reports, documents and files sent to the members of the board and of the SC of the AVAC Association are confidential.

Scientific and financial follow-up

AVAC is committed to this approach with gravity and a strong sense of responsibility. The budget that its Board of Directors will commit to the selected projects comes exclusively from donations. These include donations from members, as well as funds donated by friends and families, sometimes following the death of one of their own, in a gesture of solidarity with those who are waiting and hoping. PI are expected to adhere to this commitment.

Half of the grant will be paid at the start of the project.

For projects longer than one year, the PI will have to share briefly by email, every 6 months, on the progress of the project (a few lines).

A complete scientific and financial report must be produced by the PI at mid-term, in order to justify the correct progress of the work and trigger the payment of 40% of the grant.

A final scientific and financial report must be produced by the PI 1 month after the end of the project in order to trigger the payment of the remaining 10% of the grant.

Each report must be accompanied by a report in French, understandable by all members of the association, regardless of their scientific knowledge.

It is expected that the work carried out and the results obtained at the end of the project will be promoted, in the form of publications, and scientific and mainstream communications. The project leader will make himself available for the presentation of his results at a meeting organized by the AVAC association.

Annex

Evaluation criteria

1. Excellence

- Clarity and pertinence of the objectives,
- Credibility of the proposed approach and methodology,
- Feasibility of the project,
- Competence and experience of participating research partners

2. Impact

- Potential of the expected results for exploitation and for future relevant applications
- Effectiveness of the proposed measures to exploit and disseminate the project results
- Innovative potential

3. Quality and efficiency of the implementation

- Coherence and effectiveness of the work plan
- Budget and cost-effectiveness of the project