

## Call for research projects "Research on cerebellar syndromes"

**Deadline: June 22, 2023 - 5pm (Paris time)**

**Budget: max 30 000 € - Duration: max 24 months**

**Contact: [aap.asso@fondation-maladiesrares.com](mailto:aap.asso@fondation-maladiesrares.com)**

### Context

Due to the specificities of rare diseases, the Fondation Maladies Rares (Foundation For Rare Diseases - FFRD) and the French Association 'Comprendre les Syndromes Cérébelleux' (CSC) have agreed on a partnership to **support and stimulate biomedical research on cerebellar ataxia**.

**CSC**<sup>1</sup> is a non-profit association of general interest, open to all, especially to people with cerebellar syndromes, their families and caregivers, or their friends. CSC was created in June 1995 by Evelyne DELION.

The 4 objectives of CSC: To help research (all donations to the association are dedicated to medical research), to inform about what our rare diseases are (as much the public, the patients, as the health professionals), to support the patients, their families, and their caregivers, and to represent its members.

It is supported, in the field of research, by a Scientific Council composed of medical doctors and researchers involved in this disease.

**FFRD**<sup>2</sup> is a private non-profit organization, founded in 2012<sup>3</sup> by five members<sup>4</sup> with the aim of helping to (i) decipher rare diseases to facilitate diagnosis and accelerate the development of new treatments, (ii) improve the daily lives of sick people and their loved ones. FFRD carries a mission of general interest: to animate, coordinate and support research on rare diseases.

### Aim of the call

Cerebellar syndromes are a very heterogeneous group of pathologies characterized by balance disorders, speech problems and coordination disorders of voluntary movements (ataxia).

This call for projects aims to **develop innovative biomedical research programs** (basic, translational, clinical) **in cerebellar syndromes exclusively due to a rare disease**.

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<sup>1</sup> <https://www.csc.asso.fr/home>

<sup>2</sup> [www.fondation-maladiesrares.org](http://www.fondation-maladiesrares.org)

<sup>3</sup> MRNP2: <http://www.sante.gouv.fr/le-plan-national-maladies-rares-2011-14-une-ambition-renouvelee.html>

<sup>4</sup> AFM-Telethon, Alliance Maladies Rares, Inserm, Conference Directors GChu Nationals, Conference of University Presidents

CSC is interested in supporting any research that advances **physiological understanding** of the disease and/or **development of therapeutic** strategies. Due to the lack of research on those topics, special attention will be given to innovative projects which will address **pediatric research**.

## Eligibility criteria

The project will explicitly formulate a research **question** addressing issues specifically related to **cerebellar syndromes exclusively due to a rare disease**. Projects studying cerebellar syndromes not exclusively related to a rare disease are not eligible (head trauma, stroke, alcoholism, Alzheimer's, Parkinson's, Multiple sclerosis, addictions, infections, non-rare neoplastic syndromes...).

The project will have to demonstrate its **novelty**, its **feasibility** and the **expertise(s)** of the researcher(s) involved.

The principal investigator ("lead applicant") must be an **academic researcher, with a permanent position**, belonging to a European research organization<sup>5</sup>.

## Funding

This call for research projects provides for financial support of up to **30 000 euros for a maximum duration of 24 month**.

Funding support can cover:

- personnel expenses – **except for permanent and/or administrative staff**,
- operations, equipment, missions: each is limited to 2 000 € (exceptional greater financial needs have to be clearly justified in the proposal),

provided they are **entirely and exclusively dedicated to the research project**.

The use of service providers should only cover the execution of a very limited part of the project (max 10% of total budget).

Please note that indirect costs and institutional overhead are not provided.

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

An agreement will be established between the research program management organization (the lead applicant's research organization) and FFRD. **The management organization will not be able to charge any management fee on the amount awarded.**

Co-financing of the selected project is possible if there is no conflict of interest.

**The lead applicant will manage the allocated funds**, including, if necessary, the agreement and allocation to the partners teams.

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<sup>5</sup> **Research organization:** is considered a research organization, an entity such as universities or research institutes, or research structures dedicated to research within the health institution associated with a university or research institute, regardless of its legal status (public or private body) or its method of funding, 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.

## Submission, selection, and schedule

The proposal form (download [here](#)), in English with a popularized presentation in French for the association, is to be sent by email:

- Before **June 22, 2023**, 5pm (Paris time)
- In **PDF** format (no scan)
- At [aap.asso@fondation-maladiesrares.com](mailto:aap.asso@fondation-maladiesrares.com)
- With the following email item: "**CSC AAP2023** - *Your last name*"

The joint selection by CSC and FFRD will be based on:

- validation of the eligibility criteria by FFRD
- adequation of the proposal with patients' needs by CSC
- evaluations by independent external expert(s) (cf. appendix)
- evaluations by CSC/ASL-HSP/AFAF joint scientific advisory board

## Scientific and financial follow-up

**A precise scientific and financial report** will have to be produced **at the mid-term of the project**.

**A final scientific research report**, a comprehensive and readable report for patients (understandable by a middle school student), and a summary of the research results will have to be produced by the main applicant **1 months after the end of the project**.

The work carried out and the results obtained are expected to be valorized in the form of mainstream publications (at least for CSC website and newsletter) and scientific papers.

Laureates will participate to CSC meeting, to present their funded research.

## **Annex**

### **Evaluation criteria**

#### **1. Excellence**

- Clarity and pertinence of the objectives,
- Credibility of the proposed approach and methodology,
- Soundness of the concept,
- 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
- Benefit to patients, their families, and carers

#### **3. Quality and efficiency of the implementation**

- Coherence and effectiveness of the work plan
- Complementarity of the participants
- Plan for sustainability of infrastructures or resources initiated by the project,
- Budget and cost-effectiveness of the project