**Call for research projects 2022**

***"Research on Ichthyosis"***

**Deadline: June 5, 2022** - **5pm (Paris time)**

**Budget: 100 000 € - Duration: 6-24 months**

Contact: aap.asso@fondation-maladiesrares.com

**Context**

Due to the specificities of rare diseases, the Fondation Maladies Rares (Foundation For Rare Diseases - FFRD) and the Association Ichtyose France (AIF) have agreed on a partnership to support and stimulate biomedical research on ichthyosis.

**Association Ichtyose France** (AIF) was created in 1991 by a group of parents, with the aim of allowing better management of ichthyosis. This non-profit association has been chaired since March 2016 by Anne AUDOUZE.

The AIF’s role is to help patients to live a better life with their skin disease and to come out of isolation. The association promotes assistance between sufferers and their families. As a rare disease, ichthyosis is by nature unknown to the general public. The AIF makes every effort to raise awareness to prevent negative reactions caused by the difference. AIF organizes charity events to raise funds to support medical research.

In addition, the association works in close collaboration with caregivers, in particular those who are experts in ichthyosis. It provides financial support for research projects and clinical studies.

**FFRD**[[1]](#footnote-1) is a private non-profit organization, founded in 2012 by five members[[2]](#footnote-2),[[3]](#footnote-3) 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**

Ichthyosis is a condition that causes widespread and persistent thick, dry, "fish-scale" skin. There are at least 20 different types of Ichthyosis. Some types are inherited at birth and other types are acquired during adulthood. There is no cure for Ichthyosis. Symptoms can usually be kept manageable by daily skincare, but this routine is a heavy burden. Moreover, it was shown that Ichthyosis is associated with strong negative psychosocial consequences.

This call for projects aims to develop innovative research program to better understand Ichthyosis and develop new therapeutic approaches. All biomedical disciplines are eligible.

**Clinical research projects are not eligible for this call for projects**

**Eligibility criteria**

The project will explicitly formulate a research **question** addressing issues specifically related to Ichthyosis.

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 a **researcher,** belonging to a European research organization[[4]](#footnote-4). It is expected that the lead applicant will have a permanent position. Otherwise, the lead applicant will have to provide proof of an employment contract with the research organization managing the allocated funds. The employment contract will have to run for the entire duration of the research project plus 6 months.

**Funding**

This call for research projects provides for financial support of up to **100,000 euros for a maximum duration of 24** **month.**

Funding support can cover personnel expenses (excluding administrative staff and Master students), operations, and missions, provided they are entirely and exclusively dedicated to the project. The use of service providers for the project should only cover the execution of a very limited part of the project. Please note that indirect costs and institutional overhead are not provided.

**Funding must be realistic, reasonable, detailed post by post 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.

**Submission, selection, and schedule**

The proposal form, in English, is to be sent by email:

* Before **June 05, 2022**, 5pm (Paris time)
* At aap.asso@fondation-maladiesrares.com
* With the following email item: "AIF AAP2022 - *Your last* *name"*

The joint selection by AIF and FFRD will take place based on:

1 – validation of the eligibility criteria by FFRD

2 – adequation of the proposal with patient’s needs by AIF

3 – evaluations by independent external expert(s) (cf. appendix)

**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, and a summary of the research results will have to be produced by the main applicant 6 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 AIF website and newsletter) and scientific papers.

Laureates may be invited to present their results at a dedicated scientific day.

**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
1. *www.fondation-maladiesrares.org* [↑](#footnote-ref-1)
2. *MRNP2 : http://www.sante.gouv.fr/le-plan-national-maladies-rares-2011-14-une-ambition-renouvelee.html* [↑](#footnote-ref-2)
3. *AFM-Telethon, Alliance Maladies Rares, Inserm, Conference Directors of Chu, Conference of University Presidents* [↑](#footnote-ref-3)
4. ***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.* [↑](#footnote-ref-4)