ACT for FOP Grant Program

2026 Application Guidelines

1. Overview

The International Fibrodysplasia Ossificans Progressiva Association (IFOPA) offers the **A**ccelerating **C**ures and **T**reatments for **F**ibrodysplasia **O**ssificans **P**rogressiva (ACT for FOP) Grant Program to enable translational research in FOP and advance the development of safe and transformative therapies for FOP. The ACT for FOP Grant Program provides, through a competitive application process, funding to scientists conducting research on FOP.

Through the ACT for FOP Grant Program, the IFOPA provides up to $100,000 in research funding over a 2-year period ($50,000/year) to successful applicants. The IFOPA anticipates awarding multiple ACT for FOP Grants in 2026.

2. Research Areas of Interest

Applications for the IFOPA ACT for FOP Grant Program should focus on novel research into FOP biology, the early detection and monitoring of physiological events that precede the formation of new heterotopic bone, and novel therapeutic approaches for disease control and symptom management. In particular, the following areas of research are of high interest:

- **Drug Discovery and Drug Repurposing:** The application of therapeutic agents outside of the current FOP clinical development paradigm (i.e., ACVR1/ALK2, Activin, and MMP9 antagonists) that represent novel approaches for FOP therapy.
- **Mobility recovery research:** The application of therapeutic strategies with the potential to improve and maintain mobility in tissues and joints impacted by heterotopic bone growth.
- **Beyond Bone:** The impact of ACVR1 mutation on the normal development of non-skeletal tissue (e.g., muscle, tendon, nerves, immune cells) and how ACVR1-

altered functioning of these tissues could potentially influence the initiation and development of heterotopic bone in FOP.
- **Genetic modifiers:** ~97% of individuals with FOP have the same activating mutation in the ACVR1 gene product, ALK2 (R206H). However, the trajectory of FOP (the rate and severity of progression) can vary significantly between individuals. The identification of mutations in the MMP9 gene provided evidence that 'compensatory' genetic events could alter the trajectory of FOP. The identification of additional 'genetic modifiers' may provide alternative approaches for the treatment and management of FOP.

Proposals involving meaningful collaboration among investigators with complementary capabilities are encouraged. Awards can be split among the investigators' institutions as needed. Please note that ***ACT for FOP Grant funds cannot be used for indirect or overhead costs***.

The IFOPA may be able to assist applicants with accessing key research resources needed to accomplish their proposed research. This includes mouse models of FOP, patient-derived samples (iPSC, PBMC, and serum samples), natural history and longitudinal patient data, and drug-testing platforms.

For further information on gaining access to the IFOPA's research resources, or to discuss your grant submission, please contact Mark Hamilton, PhD, IFOPA Director of Research at **mark.hamilton@ifopa.org**. It is recommended that applicants requiring access to the IFOPA's research resources contact the IFOPA prior to submitting their application.

CONFIDENTIALITY

All research proposals submitted for the ACT for FOP Grant Program, and the identity of all applicants, are treated as sensitive and confidential information by the IFOPA, its external reviewers, and the IFOPA Scientific Advisory Board. Successful applications will be announced publicly, but all other ACT for FOP Grant Program applications will remain confidential.

3. Proposal Evaluation Process

The IFOPA utilizes an independent review process for the ACT for FOP Grant Program. All applications will be reviewed and scored by a minimum of two external Subject Matter Experts for scientific merit, significance of the proposed research, scientific rigor, and feasibility.

After the external review process, the highest-scoring applications will undergo a final review by the IFOPA Scientific Advisory Board (SAB) to ensure alignment with the IFOPA's research goals and to select the ACT for FOP awardees. The SAB's recommendations for awards undergo final review and approval by the IFOPA Research Committee and Board of Directors.

All reviewers and Scientific Advisory Board members are bound by Confidentiality Disclosure Agreements with the IFOPA to maintain confidentiality. Applications will be matched with appropriate external reviewers to minimize the possibility of conflicts of interest between reviewers and applicants.

High-scoring proposals that are not funded during the initial awards cycle may be funded if additional funds become available.

Due to limited resources, the IFOPA cannot provide applicants with written critiques of their research proposals.

4. Criteria for Proposal Evaluation

Funding decisions are based on the scientific merit of the project, including its potential for therapeutic or clinical translation, the capabilities of the investigator and the research team, and the likelihood that the project will be completed successfully within the proposed timeframe. Proposals are rated according to each of the following specific criteria:

1. **Medical Impact:** Projects should fit the goal of the program, which is to advance our understanding of FOP biology, and to identify potential, novel therapeutic approaches to the treatment and management of FOP that improve the outcomes of those living with this disorder.
2. **Scientific rationale and execution:** Proposals should have a clearly articulated scientific rationale. Applicants should provide all essential preclinical and/or clinical information supporting the study rationale, the proposed research plan (Study Aims), including experimental design, and the potential bottlenecks that could impact project success and any possible alternate approaches.
3. **Innovation:** Applicants should justify how the proposed research advances our understanding of FOP biology and its treatment.
4. **Experimental design and objectives:** Applicants should carefully describe each proposed study, keeping the following issues in mind:
   a) Study hypotheses and objectives should be clearly articulated, and proposed experimental methods should be appropriate and sufficient to achieve these goals.
   b) Key measures, statistical analysis plans (including use of appropriate power analyses), and decision-making ‘success criteria' regarding experimental steps should be described.
   c) The use of specific research tools (e.g., animal models) should be justified, and their applicability to human FOP should be articulated. If needed, successful applicants may have access to the IFOPA’s FOP Mouse Model or samples from the IFOPA Biobank.
   d) If studies involve living human subjects, evidence for adequate protection and safety monitoring should be included.
   e) Proposals which are ancillary projects to a larger project should be justified, and their relevance to the success of the parent project should be described. Sufficient details of the parent project should be included in the application to allow appropriate evaluation of the ancillary project’s rationale and importance.
   f) Potential problem areas and alternative strategies should be outlined.
5. **Investigator/Environment:** The ACT for FOP Grant Program is available to FOP researchers with a doctoral degree (MD, PhD or equivalent) at any stage of their career, worldwide. Investigators and/or research teams should be appropriately trained and competent to carry out the proposed research. The environment within which research will be performed should have sufficient access to resources to enable successful completion of the project. Provisions for adequate data management, monitoring, and analysis (e.g., biostatistical support) should be indicated.
6. **Resource Sharing Plan:** Applicants should provide details on how data and/or research tools (e.g., clinical datasets, research reagents and models) will be made available to the public for future research purposes.
7. **Study Budget:** The proposed budget should be reasonable and justified for the proposed research. Details of personnel (including non-paid collaborators), study

reagents, supplies, and all other costs should be indicated and justified. Costs should be allocated to coincide with key project milestones and not simply averaged over the entire project period. As noted previously, ACT for FOP funds cannot be used for indirect or overhead costs.
8. **Project Timeline:** Timelines for completing each study should be clearly defined and include relevant and realistic milestones. Project goals must be achievable within the award period.

IFOPA Research Portfolio: Overlap with other IFOPA research investments is considered before making any final ACT for FOP funding decisions.

5. Letter of Intent

Prior to submission of an application for the ACT for FOP Grant Program, all applicants must submit a Letter of Intent (LOI) to the IFOPA. The LOI must contain the following information:

1. Investigator name and institution
2. Names of collaborators and their respective institutions (if applicable)
3. Project title and a brief summary of the proposed research

Letters of Intent should be emailed to Mark Hamilton, PhD, IFOPA Director of Research at **mark.hamilton@ifopa.org** before March 23, 2026. Applicants will be notified whether to proceed with the application the week of March 30, 2026.

6. Proposal Content

Submitted proposals (English only) should include the following information. Please remain within the described page limits:

1. **Scientific Abstract and Project Rationale (1.5 pages):** Project title, scientific abstract, project rationale and objectives, and the expected impact of the proposed research.
2. **Lay Summary/Abstract (0.5 pages):** Plain language summary of the project rationale, objectives, and expected impact.
3. **Detailed Research Plan (3 pages maximum):** Study design and experimental approach; process for collecting and analyzing data; potential risks and mitigations; outline of research steps; study milestones and timeline
4. **Detailed Budget (1 page):** Projected project costs. These are to be linked to the research plan and milestones
5. **Curriculum Vitae/Biosketch:** The qualifications of the Principal Investigator and key personnel. Please include the curriculum vitae in NIH bio-sketch format
6. **Facility description (1 page maximum):** An outline of the facility or laboratory in which research will be conducted with a listing of existing equipment applicable to project
7. **Other sources of financial and collaborative support (1 page maximum):** This should include support already applied for (even if in process) and/or received

7. Proposal Submission

Completed applications must be submitted via email as a single PDF. Please send your completed applications to Mark Hamilton, PhD, IFOPA Director of Research, at

mark.hamilton@ifopa.org.

If you would like to review or discuss your submission to the ACT for FOP Grant Program, please contact mark.hamilton@ifopa.org.

APPLICATION SCHEDULE

ACT for FOP Program Announcement	February 12, 2026
Letter of Intent (LOI) Due	March 23, 2026
LOI Notifications	Week of March 30, 2026
Proposal Submission Deadline	July 14, 2026
Proposal Notifications	October 30, 2026

Funding for the ACT for FOP Grant Program

The ACT for FOP Grant Program was launched in 2015 by friends and family of Sona Brinkman. Today, others who are passionate about curing FOP have joined them in funding the ACT for FOP Grant Program with lead gifts from Joshua's Future of Promises, Terri Hendley, FOP Italia, FOP Australia, FOP Friends, Canadian FOP Network, friends and family of Sona Brinkman, and donors to the IFOPA's *In Pursuit of a Cure Day of Giving*.

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