FD/MAS Alliance Research Facilitation Request

Introduction

The FD/MAS Alliance (incorporated as Fibrous Dysplasia Foundation, Inc.) is a community-led nonprofit working to improve the lives of people affected by fibrous dysplasia and McCune-Albright syndrome (FD/MAS). These are rare, complex diseases that affect the bones, hormones, and other systems, often causing fractures, severe skeletal deformities, chronic pain, and conditions such as precocious puberty, hyperthyroidism, and growth hormone excess. Despite the devastating effects of FD/MAS, treatment options remain limited, and most patients receive only symptom management rather than disease-modifying therapies.

FD/MAS Alliance advances evidence-based research, educates community stakeholders, and channels the voices of individuals and caregivers living with FD/MAS. Together, as families, clinicians, and researchers, we envision a future where everyone affected by FD/MAS can thrive.

Registry and Research Partnerships

The FD/MAS Patient Registry is an IRB-approved research study with over 1,400 participants. Run by the FD/MAS Alliance, the Registry is a centralized source of information on FD/MAS. We encourage researchers to utilize the registry. Researchers may use the registry to recruit participants, inform study design, access data, and conduct additional research.

The FD/MAS Alliance supports responsible and impactful use of the Patient Registry through structured research partnerships. All requests are reviewed to ensure appropriate use of data and alignment with community priorities. All requests submitted through this application are reviewed by the FD/MAS Patient Registry Oversight Committee. The Committee may approve, deny, or request modifications to any submission. Review decisions are based on:

- Scientific and methodological quality
- Ethical and regulatory compliance
- Participant privacy and data protection safeguards
- Feasibility and operational capacity
- Alignment with the FD/MAS Alliance mission and patient community benefit

Researchers can expect a response to their request within 90 days. All questions about the FD/MAS Patient Registry and requesting access can be directed to: registry@fibrousdysplasia.org

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Applicant Overview

This information will be shared with potential participants.

Primary Investigator's Name	
Organization	
Address	
Phone number	
Email Address	
Website (if applicable)	

Applicant Type

☐ Academic / University Researcher
☐ Medical Student / Trainee (Faculty Sponsor Required)
☐ Nonprofit / Foundation Partner
☐ Industry / Pharmaceutical / Biotechnology
☐ Government / Regulatory Agency
☐ Other (please specify)

Type of Request

Please select all that apply:
☐ Recruiting assistance
☐ Aggregate data access
☐ Patient-level data access
☐ Research advisory/consultation support

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Requested Registry Services
Please select all that apply. All services are subject to scope review and final approval.

Participant Recruitment & Engagement Services
☐ Email Newsletter Feature – $1,000
☐ Targeted Email Outreach – $5,000 initial / $2,500 subsequent waves
☐ Social Media Promotion – $2,000
☐ Website Listing (duration-based posting) – $2,000
☐ Mail Outreach Campaign – Variable (Performed at cost)
☐ Patient Focus Group / Advisory Recommendations & Review – $5,000
☐ Data Set - Aggregate Data – $5,000
☐ Dataset Patient Level – Variable

Costs listed are estimates and may vary depending on the scope. Fee waivers or adjustments may be considered for academic, student, or nonprofit projects.

Project Overview

Research Summary

A. Based on the selected request type(s), provide a concise description of the proposed research or activity, including the applicable items outlined below. *(Please keep your response between 800 and 2,000 words)*

- Objectives and hypotheses
- Study design and methodology
- Location where research will be conducted
- Funding source(s)
- Clear language about what is being requested of participants
- Inclusion and exclusion criteria (if applicable)
- Intended outcomes (publication, presentation, product development, etc.)
- Description of how the requested summary statistics will support project advancement

B. Provide one or two paragraphs written for a lay audience that are suitable for inclusion on the website, or in a letter. *(Please keep your response between 100 and 250 words)*

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Required Attachments

1. CV or resume, stating scientific experience and qualifications to conduct such research.
2. Proof that an Institutional Review Board or Ethics Committee has assessed the research design for compliance with ethical and safety standards (*not needed for Researchers Requesting Aggregate Data Only)*

Additional Attachments

A. **For Researchers Requesting Aggregate Data**
   - A completed form of the summary data requested: the answers to which questions, from which participants.
   - *Strongly encouraged: Proof of Human Subject Research training*

B. **Additional attachments for Researchers Requesting Patient-Level Data**
   - A completed form of the patient-level data requested; the answers to which questions, from which participants. If re-identified or identifying information data is requested, the researcher must include a justification of the need for such data to meet the study objectives.

Certification, Data Use, and Security Agreement (Required)

By submitting this request, the applicant certifies that the information provided is accurate and agrees to comply with the following terms governing the use of FD/MAS Alliance Patient Registry resources.

Any data or services provided will be used solely for the approved purposes described in this application. The applicant agrees not to share or disclose data to third parties without prior written permission and will not use the data for unauthorized or unrelated purposes, including commercial resale.

The applicant will protect the privacy and confidentiality of all Registry participants and will not attempt to identify or re-identify any individual. All data will be stored securely, with access limited to authorized personnel, and appropriate safeguards will be in place to prevent unauthorized use or disclosure.

The FD/MAS Alliance and Patient Registry will be appropriately acknowledged in any resulting publications or presentations. The applicant agrees to provide copies of such materials and understands that the FD/MAS Alliance may request a reasonable review period prior to public dissemination.

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The applicant agrees to comply with these terms and any additional requirements outlined in a formal Data Use Agreement, if applicable. The FD/MAS Alliance reserves the right to modify or revoke access if these terms are not followed.

By signing below, the applicant confirms that they have read, understand, and agree to the above, and acknowledges that submission does not guarantee approval.

Name:

Title:

Institution/Organization:

Signature:

Date: