FDF Research Facilitation Request for Access

The FD/MAS Patient Registry is a centralized source of information on FD/MAS overseen by the Fibrous Dysplasia Foundation (FDF). We encourage researchers to utilize the registry.

Researchers may use the registry to recruit participants, access data, and conduct additional research. Researcher requests will be reviewed by the FD/MAS Patient Registry Steering Committee. The request will be assessed for: quality, safety, and benefit to the FD/MAS community.

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

1. About the Applicant

This information will be shared with potential participants.

Primary Investigator's Name	
Address	
Email address	
URL	
Phone number	

2. Requested Services

Service	Description	Cost	Requested: Yes/No
Recruiting - Email newsletter	Feature study information in FDF quarterly newsletter to patients	Free	
Recruiting - Email outreach to potentially eligible registry participants	FDF staff will conduct targeted contact of potentially eligible participants from FD/MAS Patient Registry participants, based on data provided in the registry.	Free	
Recruiting - Social media	Feature study information in one or more FDF social media channels.	Free. If sponsored posts are requested, at cost.	
Recruiting - Mail outreach	FDF staff will prepare a mailing to potentially eligible participants	Variable. Performed at cost, including labor, materials and postage.	
Recruiting - Phone outreach	FDF staff will call potentially eligible participants	Variable. Performed at cost (labor).	
Dataset - Aggregate Data	FDF staff will share aggregate data from Registry database to support developing projects	Free	
Dataset - Patient Level Data	FDF Staff will pull patient-level, data for researchers to sort and analyze. FDF staff will support researchers to help the understand the data formatting.	Variable. Performed at cost (labor).	

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3. About the Project

A. For Researchers Requesting Recruiting Assistance

a. A 2-4 page description of the purpose and design of the planned research that includes clear language about what is being requested of the participants, and includes information about inclusion/exclusion criteria.

(Please keep your response between 800 and 2,000 words)

b. 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)

B. For Researchers Requesting Aggregate Data

a. A 2-4 paragraph description of the purpose and design of the planned research that includes clear description of how the requested summary statistics will support project advancement.

(Please keep your response between 250 and 600 words)

b. 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)

C. For Researchers Requesting Patient-Level Data

a. A 2-4 page description of the purpose and design of the planned research that includes clear language of aims and hypotheses of the proposed research, where the research will be performed, how the research will be funded, and information about inclusion/exclusion criteria.

(Please keep your response between 800 and 2,000 words)

b. 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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4. Required Attachments

A. For Researchers Requesting Recruiting Assistance

a. Proof an Institutional Review Board or Ethics Committee has assessed the research design for compliance with ethical and safety standards.
b. CV or resume, stating scientific experience and qualifications to conduct such research.

B. For Researchers Requesting Aggregate Data

a. CV or resume, stating scientific experience and qualifications to conduct such research.
b. A completed form of the summary data requested: the answers to which questions, from which participants.
c. Proof of Human Subject Research training (optional)

C. For Researchers Requesting Patient-Level Data

a. Proof an Institutional Review Board or Ethics Committee has assessed the research design for compliance with ethical and safety standards.
b. CV or resume, stating scientific experience and qualifications to conduct such research.
c. 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 their study objectives.