Fibrous Dysplasia Foundation

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Fibrous Dysplasia and McCune-Albright Syndrome Patient Registry
Consent For Adult Subject/Legally Authorized Representative of an Adult Subject/
Subject turning 18 During the Study

Sponsor / Study Title: Fibrous Dysplasia Foundation / “Fibrous Dysplasia and McCune Albright Syndrome Patient Registry”

Principal Investigator: Catherine Fairchild, JD

Telephone: 917-513-2169 (24 Hours)

Additional Contact: Deanna Portero
(Study Staff)

Address: Fibrous Dysplasia Foundation
1380 Monroe St. NW #420
Washington, DC, 20010

Please read this form carefully. Take time to ask the registry staff as many questions about the registry as you would like before you agree to take part.

Definitions

For the purpose of this Consent form, “the patient” refers to the person diagnosed with fibrous dysplasia. Registry information will be collected on patients who are diagnosed with fibrous dysplasia and McCune Albright syndrome. “You” refers to the person providing the information, who may be the patient himself or herself, or a family member or guardian who is legally responsible for the care and health of the patient. FD/MAS refers to fibrous dysplasia or McCune Albright syndrome.

If an adult patient cannot legally consent to take part, pronouns “you” and “your” should be read as referring to the person with FD/MAS rather than the person (legally authorized representative) who is signing this form for the patient. In cases where the patient’s representative gives consent, the patient should be informed about the registry to the extent possible given his/her understanding. During the course of the registry, if the patient regains the capacity to consent, informed consent should be completed and the patient offered the ability to leave the registry if desired.

Purpose

A patient registry collects and stores patient medical information, family history and other related information for use in medical and behavioral research. The purpose of the Fibrous Dysplasia and McCune Albright Syndrome Patient Registry (FD/MAS Patient Registry) is to collect and store medical and other information from individuals with the same or related disease in order to:

- Develop an understanding of the form FD/MAS takes in the population, including the scope of medical symptoms patients experience, the disease progresses, and how the disease impacts the patient’s quality of life.
- Understand how FD/MAS is currently being diagnosed and treated, including monitoring practices, and how particular treatments affect health outcomes.
- Understand the economic burden of FD/MAS on patients and their families as well as other barriers to care.
- Identify what doctors need to know about patients and caretakers, what caretakers need to know about doctors and patients, and what patients need to know about caretakers and doctors.
- Provide information to researchers that can be used to develop clinical effectiveness research, clinical trials or other research.
- Provide a convenient online platform for patients and/or caregivers to learn about other opportunities to be involved in research or clinical trials.
- Support the FD/MAS medical community in developing clinical recommendations and standards of care for patients.

In addition to what is written here, you will be given supplemental information about the Fibrous Dysplasia and McCune Albright Syndrome Patient Registry.

The Fibrous Dysplasia and McCune Albright Syndrome Patient Registry is sponsored by the Fibrous Dysplasia Foundation (FDF) and there is no cost to you to participate. The registry is on a platform provided by the National Organization for Rare Disorders (NORD). The FDF owns and controls what happens to the data in the registry. In the unforeseeable event that the FDF would not be able to continue the FD/MAS Repository program the study will be considered to have ended. All de-identified data (defined below) previously transferred to the National Organization for Rare Disorders (NORD) will be maintained and will be governed by existing Informed Consent language; all identifiable and re-identified information will be destroyed.

The Principal Investigator (PI) for the Fibrous Dysplasia and McCune Albright Syndrome Patient Registry is the President of the Board of Directors, Catherine Fairchild, JD. She is supported by the following sub-PIs who also function collectively as the Registry Oversight Committee: Dr. Alison Boyce, Dr. Andrea Burke, and Amanda Konradi, PhD. The PI and sub-PIs are subject to change; however, the PI will always be on the Board of Directors of the Fibrous Dysplasia Foundation and sub-PIs always will be closely affiliated with the FDF. Should the PI or sub-PIs change, all participants will be informed of the change.

What will happen if you join this registry?

If you join this registry, you will be asked to provide medical information on your (or the patient’s) disease and diagnosis as well as some basic contact information about yourself. Questionnaires about mental health and well-being will also be completed. Your contact information is called “identifiable” information. Your medical records, if you wish to share them, are also identifiable information, because they can be directly linked back to you. The registry aims is to share detailed medical and other information with researchers while protecting your privacy. One way the registry protects your privacy is to remove your name, address, your date of birth, your email or other information that identifies you or your family and other “identifying” information from your medical information before providing it to researchers. This information is called “de-identified.” In some instances this de-identified information may be labeled with a unique code number. We call this data “re-identified” because the code number has replaced your actual identify. An example of why we might re-
identify information is so that when we share your data with researchers or databases we can re-submit additional data at a later date (like when you complete an annual update). The unique code number will help the researcher or database ensure that any new information you provide is accurately linked to the information that you completed previously (without disclosing your name or other identifying factors). Only authorized people who work in the registry will have access to the key to the code and will be able to identify you if needed. (For example, we need to use your identifiable information to send you a reminder that it is time to complete a new annual report or to let you know about a research opportunity.) Chesapeake IRB may also have access to the registry data.

All data that you provide will be stored on secured computers and servers and protected with encryption and passwords. Although we take measures to protect your privacy and confidentiality, because your disease is rare, there is a small risk you may be identifiable from the information in the registry.

You will be asked to update your registry information at least once per year. Based on your preference for how you would prefer to be contacted, the registry will contact you each year to remind you to update your data. The registry may also ask you to fax or upload your genetic test results and any other relevant reports or testing results. Your registry account can be updated whenever there is a change in your health, change in medication, or new symptom. If the registry tries but is unable to contact you, your account may become inactive. While inactive, your data may still be accessed in its de-identified or re-identified forms.

The protocol for the Fibrous Dysplasia and McCune Albright Syndrome Patient Registry and the management of data have been reviewed for principles of ethical research practices and proper care of data by Chesapeake IRB, Inc. All investigators involved in the Oversight Committee have completed Human Subjects training. In the unlikely event of learning that a data breach has occurred, the FDF will inform participants within 48 hours of learning about the breach by the preferred contact method the participant indicates in the consenting process.

**How will my data be accessed by researchers?**

Before any data is released, researchers must first apply to the Fibrous Dysplasia and McCune Albright Syndrome Patient Registry Oversight Committee. This committee will review the project for its reliability and validity and compliance with ethical principles.

Without contacting you, approved researchers and clinicians will be allowed to see *de-identified information* to look at the group of FD/MAS patients as a whole (like a snapshot) and *re-identified information* to look for patterns in how the disease progresses in individual patients with certain kinds of traits. The Fibrous Dysplasia and McCune Albright Syndrome Patient Registry will not share your *identifiable information* with anyone outside the registry without obtaining your authorization to do so on a case-by-case basis.

Approved researchers and clinicians may use *de-identified information* to conduct research, including research on diseases unrelated to fibrous dysplasia. They may also search the de-identified information to find patients for their studies. If a patient looks like a good match for a researcher’s study, they can submit a request form to the Fibrous Dysplasia and McCune Albright Syndrome Patient Registry.
Oversight Committee and ask that you be given information about the study and a way to contact the researcher if you wish to do so.

Your de-identified Fibrous Dysplasia and McCune Albright Syndrome Patient Registry information will also be shared with other databases such as the Global Rare Disease Patient Registry Data Repository (GRDR) that is sponsored by the National Institutes of Health. This will allow more researchers to use the information to do research.

If an investigator requests information that is identifiable, such as medical records that you have uploaded, he or she will be required to complete an agreement that specifically limits how the data is used. Before releasing any of your personal information, the Fibrous Dysplasia and McCune Albright Syndrome Patient Registry staff will contact you. You will be provided with a description of the research and why the researcher wants your information and you will be asked to consent to its release as well as the release of your name and contact information so that the researcher can contact you directly. If you grant consent to release your contact information, the researcher will call, email, or write to you and he or she will explain the research and ask for your consent. You can make your own choice about whether or not you wish to participate. You are under no obligation to participate in other studies. If you choose not to participate, your data will not be released from the Fibrous Dysplasia and McCune Albright Syndrome Patient Registry.

**Your participation is voluntary**

Providing information to the registry is voluntary. You do not have to contribute information. If you do participate, you can withdraw from the registry at any time and for any reason. There will be no penalty or loss of benefits to you if you decide not to be in the registry or to withdraw from the registry. Children are encouraged to participate in answering certain sections of questions that pertain to their experiences of the disease and feelings. However, we take their right to choose whether or not they wish to participate. All minors need to complete the assent before answering questions.

**You have a right of withdrawal**

You will be told about any new information found during the study that may affect whether you want to continue to take part. Should you change your mind and wish to withdraw your information from the registry in which you are registered, you will be free to do so without having to provide any explanation. Simply contact the registry and your information will be removed from the database. Information that has already been shared with the GRDR or sent to a researcher for a specific study prior to your request for removal cannot be retrieved or removed.

**Anticipated benefit**

Participation in the registry is not likely to benefit you (or the patient) personally, medically or financially. However, participation may help members of your family and others with fibrous dysplasia and McCune Albright Syndrome or other diseases by increasing the understanding of your disease/condition and other diseases. Having an available registry of information about fibrous dysplasia and McCune Albright Syndrome may help speed up research, such research could eventually help researchers to learn whether or how treatments work, or help medical professionals improve how they
treat the disease. Participants may also receive information about opportunities to participate in research and clinical trials, as well as information about medical advances and other news from the registry.

**Risks of participating**

There is minimal risk in taking part in the registry. The registry may ask you to answer questions that can be sensitive and you may feel uncomfortable answering. You do not have to share any information that you do not want to share. Another possible but unlikely risk is potential breaches in the computer system. In the event there is a breach in the registry’s computer system, you will be notified.

**Participation of adults unable to consent**

Registry information will be collected on patients who are diagnosed with fibrous dysplasia and McCune Albright Syndrome. Patients age 18 or older who understand the consent form and legally provide their own consent (and thus do not have a legal guardian) are eligible to join the registry on their own. Otherwise, the authorized legal representative of the patient must consent for the patient to join.

**Other common questions**

**Who do I contact with questions?**

If you have any questions about the registration process or about participation in the registry, please contact the Fibrous Dysplasia and McCune Albright Syndrome Patient Registry at (registry@fibrousdysplasia.org). To report concerns about your participation in the registry, you may contact the Catherine Fairchild, Principal Investigator of the registry, at (PI.registry@fibrousdysplasia.org).

This study has been reviewed by an Institutional Review Board (IRB). This Committee reviewed this study to help ensure that your rights and welfare are protected and that this study is carried out in an ethical manner.

For questions about your rights as a research subject, contact:

- **By mail:**
  
  Study Subject Adviser  
  Chesapeake IRB  
  6940 Columbia Gateway Drive, Suite 110  
  Columbia, MD 21046

- **or call toll free:** 877-992-4724

- **or by email:** adviser@chesapeakeirb.com

Please reference the following number when contacting the Study Subject Adviser: Pro00018980.

**I want to be involved in a clinical trial. If I register, is this guaranteed?**

Although one of the main goals of the registry is to make it easier for patients to participate in clinical research, there is no guarantee that an individual patient will be eligible for a particular trial or contacted about a clinical trial. Even if you are contacted about possible eligibility based on your information in the registry, you may or may not meet the study requirements.
Please also be aware that if the registry informs you about a trial, this does not imply that the registry endorses it. Each study you enroll in will require that you sign an informed consent form for that study. Please make sure to thoroughly discuss any study you are considering with the research staff before signing its informed consent form.

I don’t want to be involved in a clinical trial. Should I still register?

Absolutely. We hope that you are still willing to register even if you don’t want to take part in a clinical trial. Your information may be useful to researchers who are trying to learn more about patients with Fibrous Dysplasia and McCune Albright Syndrome.

What are my options if I do not want to be in the Registry?

You do not have to join this registry. Participation is voluntary. You do not need to participate in this Registry to remain a member of the fibrous dysplasia and McCune Albright Syndrome community. Your decision about whether or not to participate in this registry will not affect your healthcare, your medical treatment or insurance benefits or your access to the Fibrous Dysplasia Foundation website or other resources.

By signing this form you do not give away any legal rights or benefits to which you are otherwise entitled. If you do join, you can change your mind and withdraw from the registry at any time and request to remove any of your information that has not assigned yet to any specific study. You will not be able to remove any information that already has been assigned to a specific study.

The following questions are to ensure that all relevant parties have been exposed to appropriate information and to check your understanding of your rights as a participant in this study. You must answer affirmatively to all questions in order to continue to the surveys. If you are a guardian consenting for an adult who can’t provide his or her own consent, “I” and “my” may refer to you or your child (referred to below as “the patient”).

Consent

| I am authorized to submit information to this registry, either because the information is about me, or about someone for whom I am the legal guardian or parent. | Yes☐ No☐ |
| I understand that participation in the registry is voluntary and that I (or the patient) can decide to withdraw at any time. | Yes☐ No☐ |
| I understand that the registry consists of independent surveys and I (or the patient) is under no obligation to complete them all. | Yes☐ No☐ |
| I am willing to regularly be contacted by the registry to update or correct my (or the patient’s) health information. | Yes☐ No☐ |
| I understand that my (or the patient’s) personal information will be protected and saved in the registry using a code. However, there is a very small risk that my identity could be revealed. | Yes☐ No☐ |
I am willing to provide my (or the patient’s) *de-identified* medical information to be used for clinical trials and other medical studies related to my disease. | Yes ☐ No ☐
---|---
I am willing to provide my (or the patient’s) *de-identified* information for use in any approved research study including diseases that are not associated with my disease. | Yes ☐ No ☐
---|---
I am willing to provide my (or the patient’s) *de-identified* information to be shared with other databases such as the Global Rare Disease Patient Registry Data Repository (GRDR). | Yes ☐ No ☐
---|---
I am willing to provide my (or the patient’s) *re-identified* medical information to be used for clinical trials and other medical studies related to my disease. | Yes ☐ No ☐
---|---
I understand that my (or the patient's) *identifiable* information will not be released unless the Registry staff contact me to obtain my consent. | Yes ☐ No ☐
---|---
I understand that I am (or the patient is) under no obligation to participate in other studies, should I be contacted to give consent. | Yes ☐ No ☐
---|---
I understand that I (or the patient) may not personally benefit from participating in the registry or from the use of de-identified medical information in any research study. | Yes ☐ No ☐
---|---
I understand that I (or the patient) can withdraw from the registry at any time and remove personal information. | Yes ☐ No ☐
---|---
I also understand that any of my information (or the patient’s information) provided to researchers before withdrawing cannot be removed. | Yes ☐ No ☐
---|---
I understand that I will be informed if there is any breach in the computer systems that contain my (or the patient’s) data. | Yes ☐ No ☐
---|---
I understand that the questions I am asked may make me (or the patient) uncomfortable. | Yes ☐ No ☐
---|---
I understand that my participation in the registry does not guarantee my involvement (or the patient’s involvement) in any clinical trials. | Yes ☐ No ☐
---|---
I understand that I can obtain further information about the study by contacting registry@fibrousdysplasia.org or PI.registry@fibrousdysplasia.org. | Yes ☐ No ☐
---|---
I understand that I can inquire about my rights (or the patient’s rights) as a participant in the registry by contacting the Study Subject Adviser at Chesapeake IRB: adviser@chesapeakeirb.com. | Yes ☐ No ☐
---|---
I understand the content of this form and all my questions were answered. | Yes ☐ No ☐
---|---
I wish to consent (or consent for the patient) to participate in the Registry. | Yes ☐ No ☐
---|---

**Informed Consent for Participating in**

**Fibrous Dysplasia and McCune Albright Syndrome Patient Registry**

for Parent / Legal Guardian enrolling FD/MAS minor patients up to 17 years old
Definitions

For the purpose of this Consent form, “the patient” refers to the person diagnosed with fibrous dysplasia. Registry information will be collected on patients who are diagnosed with fibrous dysplasia and McCune Albright syndrome. The person providing the information for the registry may be the patient himself or herself, or a family member or guardian who is legally responsible for the care and health of the patient. FD/MAS refers to fibrous dysplasia or McCune Albright syndrome. If you are the parent or legal guardian of a child who may take part in this registry, your permission and the permission of your child will be needed. When “you” appears in this form, it may refer to you or the child for whom you are providing consent.

Purpose

A patient registry collects and stores patient medical information, family history and other related information for use in medical and behavioral research. The purpose of the Fibrous Dysplasia and McCune Albright Syndrome Patient Registry (FD/MAS Patient Registry) is to collect and store medical and other information from individuals with the same or related disease in order to:

- Develop an understanding of the form FD/MAS takes in the population, including the scope of medical symptoms patients experience, the disease progresses, and how the disease impacts the patient’s quality of life.
- Understand how FD/MAS is currently being diagnosed and treated, including monitoring practices, and how particular treatments affect health outcomes.
- Understand the economic burden of FD/MAS on patients and their families as well as other barriers to care.
- Identify what doctors need to know about patients and caretakers, what caretakers need to know about doctors and patients, and what patients need to know about caretakers and doctors.
• Provide information to researchers that can be used to develop clinical effectiveness research, clinical trials or other research.
• Provide a convenient online platform for patients and/or caregivers to learn about other opportunities to be involved in research or clinical trials.
• Support the FD/MAS medical community in developing clinical recommendations and standards of care for patients.

In addition to what is written here, you will be given supplemental information about the Fibrous Dysplasia and McCune Albright Syndrome Patient Registry.

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What will happen if you join this registry?

If you join this registry, you will be asked to provide medical information on your (or the patient’s) disease and diagnosis as well as some basic contact information about yourself. Questionnaires about mental health and well-being will also be completed. Your contact information is called “identifiable” information. Your medical records, if you wish to share them, are also identifiable information, because they can be directly linked back to you. The registry aims is to share detailed medical and other information with researchers while protecting your privacy. One way the registry protects your privacy is to remove your name, address, your date of birth, your email or other information that identifies you or your family and other “identifying” information from your medical information before providing it to researchers. This information is called “de-identified.” In some instances this de-identified information may be labeled with a unique code number. We call this data “re-identified” because the code number has replaced your actual identify. An example of why we might re-identify information is so that when we share your data with researchers or databases we can re-submit additional data at a later date (like when you complete an annual update). The unique code number will help the researcher or database ensure that any new information you provide is accurately linked to the information that you completed previously (without disclosing your name or other identifying factors).
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You will be asked to update your registry information at least once per year. Based on your preference for how you would prefer to be contacted, the registry will contact you each year to remind you to update your data. The registry may also ask you to fax or upload your genetic test results and any other relevant reports or testing results. Your registry account can be updated whenever there is a change in your health, change in medication, or new symptom. If the registry tries but is unable to contact you, your account may become inactive. While inactive, your data may still be accessed in its de-identified or re-identified forms.

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Approved researchers and clinicians may use de-identified information to conduct research, including research on diseases unrelated to fibrous dysplasia. They may also search the de-identified information to find patients for their studies. If a patient looks like a good match for a researcher’s study, they can submit a request form to the Fibrous Dysplasia and McCune Albright Syndrome Patient Registry Oversight Committee and ask that you be given information about the study and a way to contact the researcher if you wish to do so.

Your de-identified Fibrous Dysplasia and McCune Albright Syndrome Patient Registry information will also be shared with other databases such as the Global Rare Disease Patient Registry Data Repository.
(GRDR) that is sponsored by the National Institutes of Health. This will allow more researchers to use the information to do research.

If an investigator requests information that is identifiable, such as medical records that you have uploaded, he or she will be required to complete an agreement that specifically limits how the data is used. Before releasing any of your personal information, the Fibrous Dysplasia and McCune Albright Syndrome Patient Registry staff will contact you. You will be provided with a description of the research and why the researcher wants your information and you will be asked to consent to its release as well as the release of your name and contact information so that the researcher can contact you directly. If you grant consent to release your contact information, the researcher will call, email, or write to you and he or she will explain the research and ask for your consent. You can make your own choice about whether or not you wish to participate. You are under no obligation to participate in other studies. If you choose not to participate, your data will not be released from the Fibrous Dysplasia and McCune Albright Syndrome Patient Registry.

**Your participation is voluntary**

Providing information to the registry is voluntary. You do not have to contribute information. If you do participate, you can withdraw from the registry at any time and for any reason. There will be no penalty or loss of benefits to you if you decide not to be in the registry or to withdraw from the registry. Children are encouraged to participate in answering certain sections of questions that pertain to their experiences of the disease and feelings. However, we take their right to choose whether or not they wish to participate. All minors need to complete the assent before answering questions.

**You have a right of withdrawal**

You will be told about any new information found during the study that may affect whether you want to continue to take part. Should you change your mind and wish to withdraw your information from the registry in which you are registered, you will be free to do so without having to provide any explanation. Simply contact the registry and your information will be removed from the database. Information that has already been shared with the GRDR or sent to a researcher for a specific study prior to your request for removal cannot be retrieved or removed.

**Anticipated benefit**

Participation in the registry is not likely to benefit you (or the patient) personally, medically or financially. However, participation may help members of your family and others with fibrous dysplasia and McCune Albright Syndrome or other diseases by increasing the understanding of your disease/condition and other diseases. Having an available registry of information about fibrous dysplasia and McCune Albright Syndrome may help speed up research, such research could eventually help researchers to learn whether or how treatments work, or help medical professionals improve how they treat the disease. Participants may also receive information about opportunities to participate in research and clinical trials, as well as information about medical advances and other news from the registry.

**Risks of participating**
There is minimal risk in taking part in the registry. The registry may ask you to answer questions that can be sensitive and you may feel uncomfortable answering. You do not have to share any information that you do not want to share. Another possible but unlikely risk is potential breaches in the computer system. In the event there is a breach in the registry’s computer system, you will be notified.

**Participation of minors**

Registry information will be collected on patients who are diagnosed with fibrous dysplasia and McCune Albright Syndrome. For patients under the age 18, the legal guardian or parent of the patient must consent for the patient to join. The minor may indicate their assent to be in the registry and to answer specific sets of questions that pertain to how she or he experiences daily life. When a minor participant becomes 18 (and if they are able), consent will be obtained directly from them for continued participation.

**Other common questions**

**Who do I contact with questions?**

If you have any questions about the registration process or about participation in the registry, please contact the Fibrous Dysplasia and McCune Albright Syndrome Patient Registry at (registry@fibrousdysplasia.org). To report concerns about your participation in the registry, you may contact the Catherine Fairchild, Principal Investigator of the registry, at (PI.registry@fibrousdysplasia.org).

This study has been reviewed by an Institutional Review Board (IRB). This Committee reviewed this study to help ensure that your child’s rights and welfare are protected and that this study is carried out in an ethical manner.

For questions about your child’s rights as a research subject, contact:

- By mail:  
  Study Subject Adviser  
  Chesapeake IRB  
  6940 Columbia Gateway Drive, Suite 110  
  Columbia, MD 21046
- or call **toll free:** 877-992-4724
- or by email: adviser@chesapeakeirb.com

Please reference the following number when contacting the Study Subject Adviser: Pro00018980.

**I want to be involved in a clinical trial. If I register, is this guaranteed?**

Although one of the main goals of the registry is to make it easier for patients to participate in clinical research, there is no guarantee that an individual patient will be eligible for a particular trial or contacted about a clinical trial. Even if you are contacted about possible eligibility based on your information in the registry, you may or may not meet the study requirements.

Please also be aware that if the registry informs you about a trial, this does not imply that the registry endorses it. Each study you enroll in will require that you sign an informed consent form for that study.
Please make sure to thoroughly discuss any study you are considering with the research staff before signing its informed consent form.

I don’t want to be involved in a clinical trial. Should I still register?

Absolutely. We hope that you are still willing to register even if you don’t want to take part in a clinical trial. Your information may be useful to researchers who are trying to learn more about patients with Fibrous Dysplasia and McCune Albright Syndrome.

What are my options if I do not want to be in the Registry?

You do not have to join this registry. Participation is voluntary. You do not need to participate in this Registry to remain a member of the fibrous dysplasia and McCune Albright Syndrome community. Your decision about whether or not to participate in this registry will not affect your healthcare, your medical treatment or insurance benefits or your access to the Fibrous Dysplasia Foundation website or other resources.

By signing this form you do not give away any legal rights or benefits to which you are otherwise entitled. If you do join, you can change your mind and withdraw from the registry at any time and request to remove any of your information that has not assigned yet to any specific study. You will not be able to remove any information that already has been assigned to a specific study.

The following questions are to ensure that that all relevant parties have been exposed to appropriate information and to check your understanding of your rights as a participant in this study. You must answer affirmatively to all questions in order to continue to the surveys. “I” and “my” may refer to you or your child (referred to below as “the patient”).

Consent

<table>
<thead>
<tr>
<th>Statement</th>
<th>Yes</th>
<th>No</th>
</tr>
</thead>
<tbody>
<tr>
<td>I am authorized to submit information to this registry, either because the information is about me, or about someone for whom I am the legal guardian or parent.</td>
<td>Yes</td>
<td>No</td>
</tr>
<tr>
<td>I understand that participation in the registry is voluntary and that I (or the patient) can decide to withdraw at any time.</td>
<td>Yes</td>
<td>No</td>
</tr>
<tr>
<td>I understand that the registry consists of independent surveys and I (or the patient) is under no obligation to complete them all.</td>
<td>Yes</td>
<td>No</td>
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<tr>
<td>I am willing to regularly be contacted by the registry to update or correct my (or the patient’s) health information.</td>
<td>Yes</td>
<td>No</td>
</tr>
<tr>
<td>I understand that my (or the patient’s) personal information will be protected and saved in the registry using a code. However, there is a very small risk that my identity could be revealed.</td>
<td>Yes</td>
<td>No</td>
</tr>
<tr>
<td>I am willing to provide my (or the patient’s) de-identified medical information to be used for clinical trials and other medical studies related to my disease.</td>
<td>Yes</td>
<td>No</td>
</tr>
<tr>
<td>I am willing to provide my (or the patient’s) de-identified information for use in any approved research study including diseases that are not associated with my disease.</td>
<td>Yes</td>
<td>No</td>
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</tbody>
</table>
I am willing to provide my (or the patient’s) *de-identified* information to be shared with other databases such as the Global Rare Disease Patient Registry Data Repository (GRDR).  

<table>
<thead>
<tr>
<th>Yes</th>
<th>No</th>
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I am willing to provide my (or the patient’s) *re-identified* medical information to be used for clinical trials and other medical studies related to my disease.  

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<thead>
<tr>
<th>Yes</th>
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I understand that my (or the patient’s) *identifiable* information will not be released unless the Registry staff contact me to obtain my consent.  

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<thead>
<tr>
<th>Yes</th>
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I understand that I am (or the patient is) under no obligation to participate in other studies, should I be contacted to give consent.  

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<tr>
<th>Yes</th>
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I understand that I (or the patient) may not personally benefit from participating in the registry or from the use of de-identified medical information in any research study.  

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I understand that I (or the patient) can withdraw from the registry at any time and remove personal information.  

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<th>Yes</th>
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I also understand that any of my information (or the patient’s information) provided to researchers before withdrawing cannot be removed.  

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I understand that I will be informed if there is any breach in the computer systems that contain my (or the patient’s) data.  

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I understand that the questions I am asked may make me (or the patient) uncomfortable.  

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I understand that my participation in the registry does not guarantee my involvement (or the patient’s involvement) in any clinical trials.  

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I understand that I can obtain further information about the study by contacting registry@fibrousdysplasia.org or PI.registry@fibrousdysplasia.org.  

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I understand that I can inquire about my rights (or the patient’s rights) as a participant in the registry by contacting the Study Subject Adviser at Chesapeake IRB: adviser@chesapeakeirb.com.  

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I understand the content of this form and all my questions were answered.  

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I wish to consent (or consent for the patient) to participate in the Registry.  

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