



Participant User Guide

Register for an Account

- Step 1: Read the Terms and Conditions and Privacy Policy and attest to the statements provided. When you are finished with this page, click “Next”.

Featuring

FD/MAS

ALLIANCE

Registration

Terms & ConditionsContact InfoNotificationsReview & SubmitConfirmation

Below are links to the IAMRARE Terms of Use and Privacy Guidelines. The purpose of these documents is to outline your rights and responsibilities when using the platform. These documents include: 1) Standard policies for all studies on this platform, 2) A privacy statement that details how your data can be used, 3) Information outlining the unacceptable uses of the platform, and 4) Information about how to address questions and issues.

Acknowledgements:

☐

You are at least 18 years of age, the age of majority in your state, province or country, and able to consent on behalf of yourself and/or an individual that you have legal responsibility for. *

☐

You agree to support the Platform’s research activities by providing truthful, appropriate information and to not do anything that will put the Services or the information in the Platform at risk. *

☐

You understand that NORD will use reasonable efforts to keep the information you enter on the Services safe, but no data transmissions over the Internet can be guaranteed to be 100% secure. The information you provide will be available to authorized users at NORD for platform maintenance and research activities, as well as to the sponsor of the studies you consent to participate in. *

☐

You agree to the [Terms and Conditions](#) and [Privacy Policy](#), and have read the [Consumer Health Data Privacy Notice](#). *

Return to login

Next

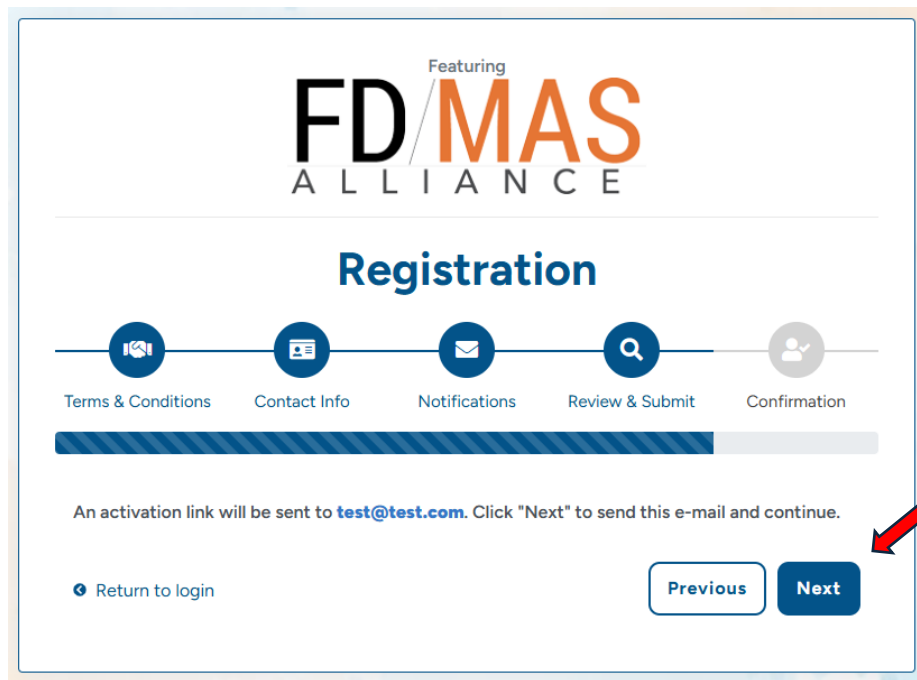
- Step 2: Enter your personal information in the spaces provided. When you are finished with this page, click “Next”.

The registration form for the FD/MAS ALLIANCE is displayed. At the top, the logo 'Featuring FD/MAS ALLIANCE' is shown. Below the logo, the title 'Registration' is centered. A progress bar with five steps is visible: 'Terms & Conditions' (completed, blue), 'Contact Info' (active, blue), 'Notifications' (pending, grey), 'Review & Submit' (pending, grey), and 'Confirmation' (pending, grey). The form fields include: 'Country of Residence *' (a dropdown menu), 'First Name *' (a text input field), 'Last Name *' (a text input field), and 'E-mail *' (a text input field). At the bottom, there is a link 'Return to login' and two buttons: 'Previous' and 'Next'.

- Step 3: Select whether you are interested in being contacted by NORD regarding available studies. When you are finished with this page, click “Next”.

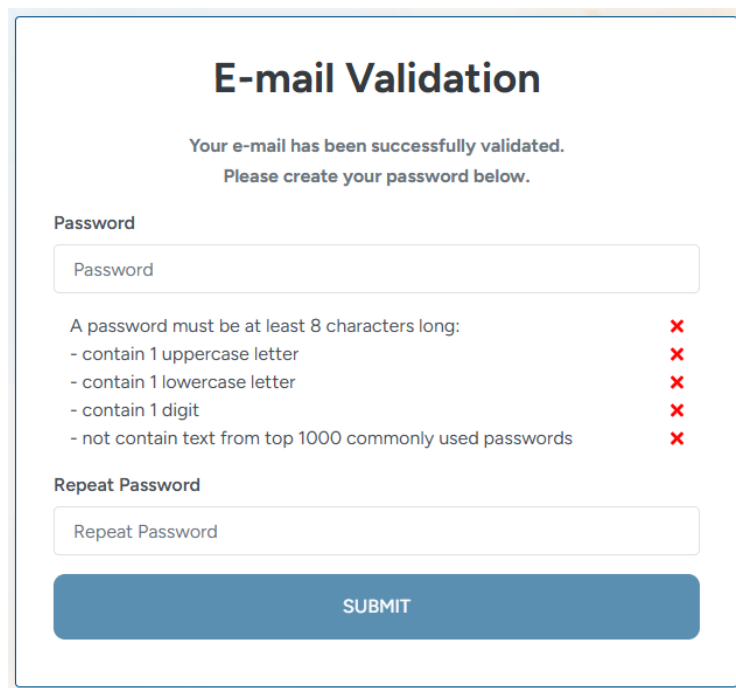
The registration form for the FD/MAS ALLIANCE is displayed. At the top, the logo 'Featuring FD/MAS ALLIANCE' is shown. Below the logo, the title 'Registration' is centered. A progress bar with five steps is visible: 'Terms & Conditions' (completed, blue), 'Contact Info' (completed, blue), 'Notifications' (active, blue), 'Review & Submit' (pending, grey), and 'Confirmation' (pending, grey). The form field includes: 'I am interested in NORD contacting me regarding available studies. *' (a statement with radio buttons for 'Yes' and 'No'). At the bottom, there is a link 'Return to login' and two buttons: 'Previous' and 'Next'.

- Step 4: Select “Next” so that an activation link is sent to your e-mail to complete registration.



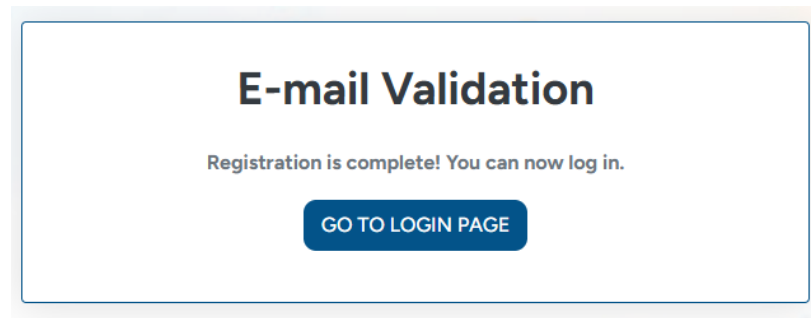
The registration screen for the FD/MAS ALLIANCE. At the top, it says "Featuring FD/MAS ALLIANCE". Below that is the title "Registration". A progress bar shows five steps: Terms & Conditions, Contact Info, Notifications, Review & Submit, and Confirmation. The "Review & Submit" step is currently active. Below the progress bar, a message states: "An activation link will be sent to test@test.com. Click 'Next' to send this e-mail and continue." At the bottom, there is a "Return to login" link and two buttons: "Previous" and "Next". A red arrow points to the "Next" button.

- Step 5: Click the link you are sent via e-mail. Please check your Spam folder if you do not see the e-mail. You will be taken to the following screen in a new tab within your browser. Set your password and click “Submit”.

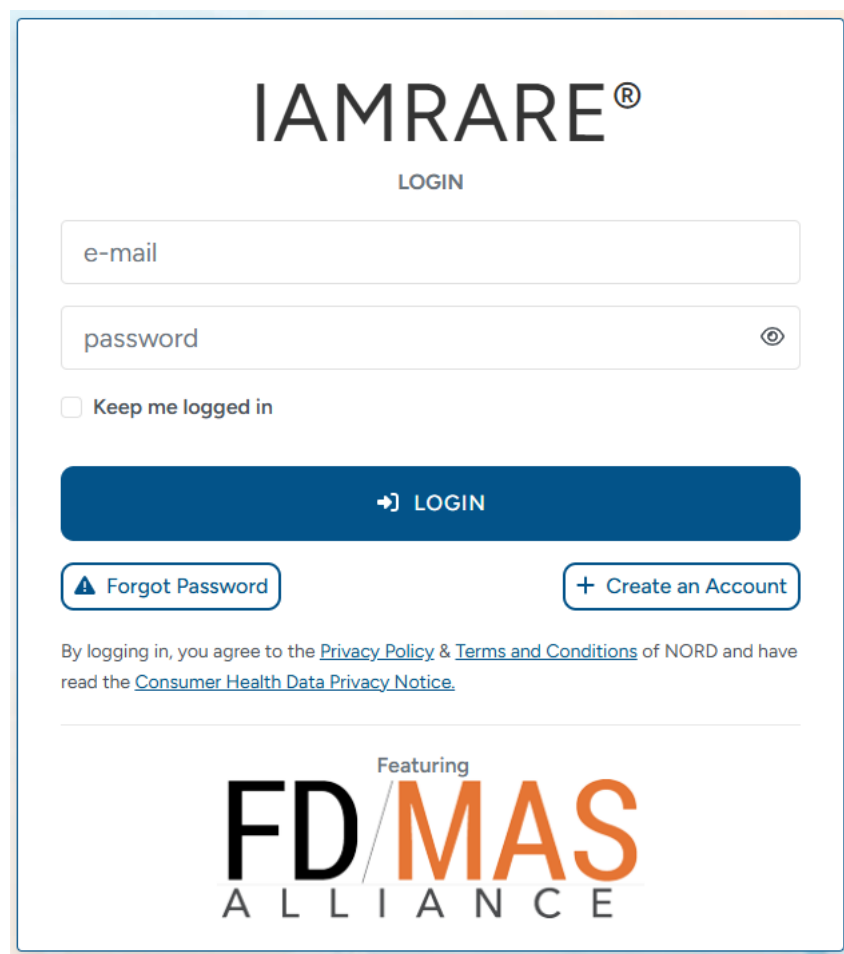


The "E-mail Validation" screen. It states: "Your e-mail has been successfully validated. Please create your password below." There are two password input fields: "Password" and "Repeat Password". Below the "Password" field, there are four requirements listed with red 'X' marks indicating they are not met: "A password must be at least 8 characters long:", "contain 1 uppercase letter", "contain 1 lowercase letter", and "contain 1 digit". Below these is a note: "not contain text from top 1000 commonly used passwords". At the bottom, there is a large blue "SUBMIT" button.

- Step 6: Your validation is now complete. Select “Go to Login Page”.

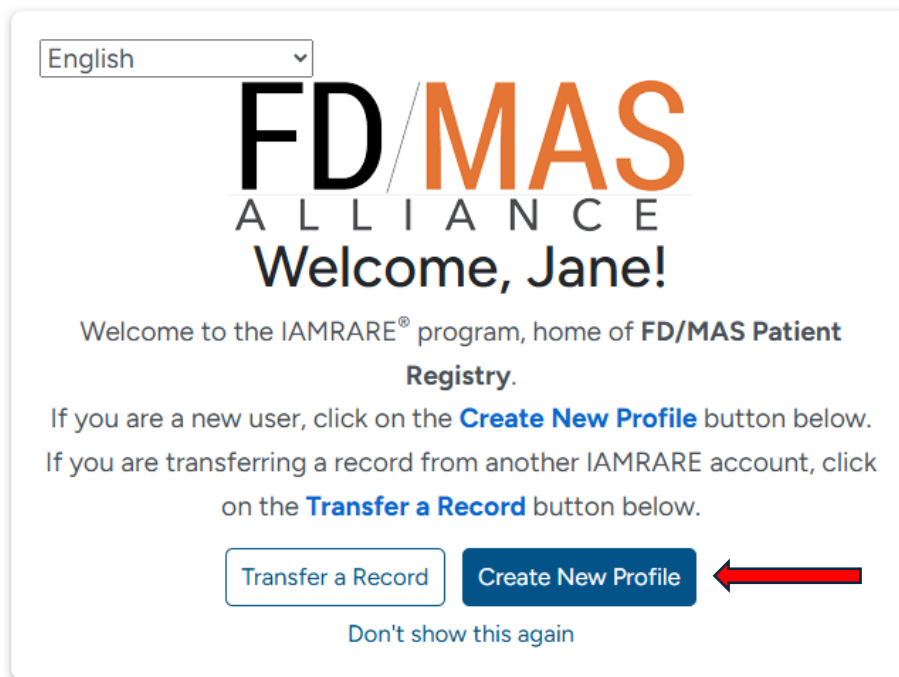


- Step 7: Log in using your new e-mail and password.

A screenshot of the IAMRARE LOGIN page. The page has the IAMRARE logo at the top, followed by the word "LOGIN". Below this are two input fields: "e-mail" and "password". The password field has an eye icon to toggle visibility. Below the input fields is a checkbox labeled "Keep me logged in". A large blue button with a right arrow icon and the text "LOGIN" is positioned below the checkbox. At the bottom of the login section are two links: "Forgot Password" (with a warning triangle icon) and "Create an Account" (with a plus icon). Below these links is a line of text: "By logging in, you agree to the [Privacy Policy](#) & [Terms and Conditions](#) of NORD and have read the [Consumer Health Data Privacy Notice](#)." At the very bottom of the page is the "Featuring FD/MAS ALLIANCE" logo.

Add a Participant

- Step 1: To start, click Create New Profile.



English

FD/MAS

ALLIANCE

Welcome, Jane!

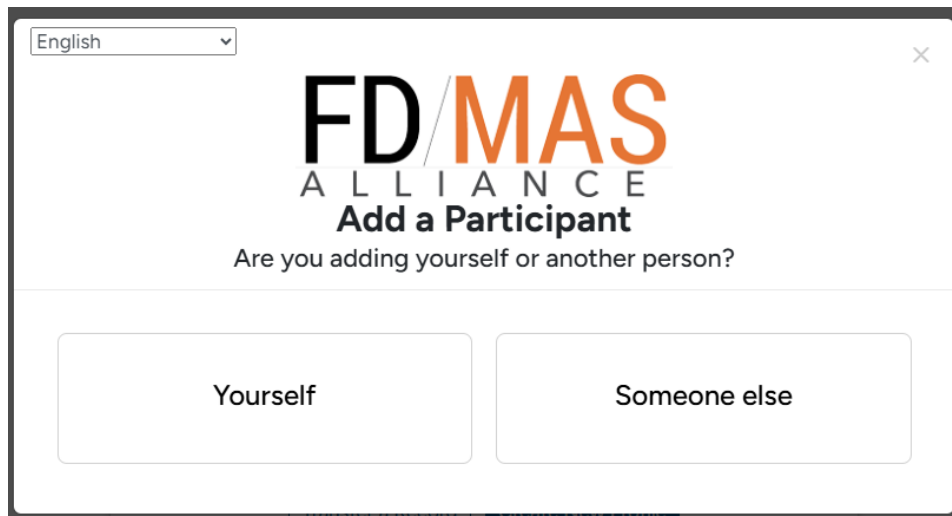
Welcome to the IAMRARE® program, home of **FD/MAS Patient Registry**.

If you are a new user, click on the [Create New Profile](#) button below.
If you are transferring a record from another IAMRARE account, click on the [Transfer a Record](#) button below.

[Transfer a Record](#) [Create New Profile](#) ←

[Don't show this again](#)

- Step 2: Select who you will be providing information about.



English

FD/MAS

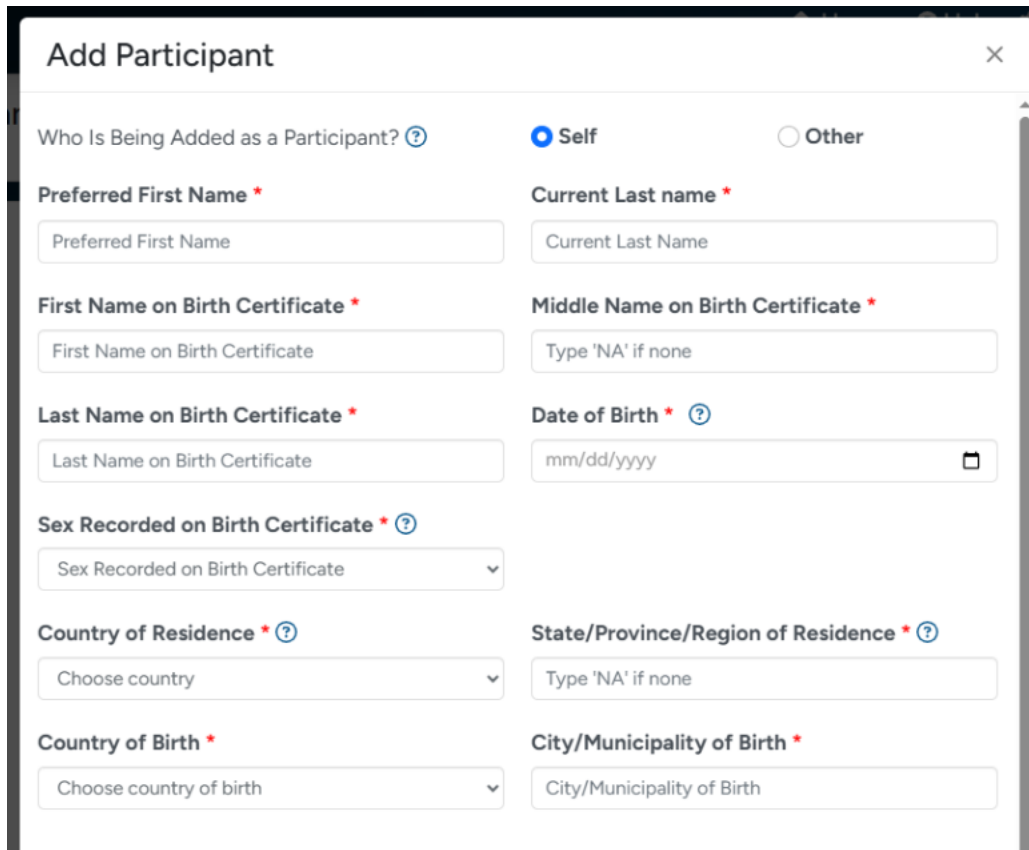
ALLIANCE

Add a Participant

Are you adding yourself or another person?

[Yourself](#) [Someone else](#)

- Step 3: Fill out the Participant's information.



The 'Add Participant' form is a web-based interface for adding a new participant. It features a title bar with a close button (X) and a question mark icon. The form is organized into two columns. The first column contains fields for 'Preferred First Name', 'First Name on Birth Certificate', 'Last Name on Birth Certificate', 'Sex Recorded on Birth Certificate', 'Country of Residence', and 'Country of Birth'. The second column contains fields for 'Current Last name', 'Middle Name on Birth Certificate', 'Date of Birth', 'State/Province/Region of Residence', and 'City/Municipality of Birth'. There are radio buttons for 'Self' and 'Other' at the top. The form includes various input types: text boxes, dropdown menus, and a date picker. Red asterisks indicate required fields. A red arrow points to the 'Yes, complete consent for this participant.' button in the consent dialog.

Add Participant [X]

Who Is Being Added as a Participant? [?] ☒ Self ☐ Other

Preferred First Name * [Preferred First Name]

Current Last name * [Current Last Name]

First Name on Birth Certificate * [First Name on Birth Certificate]

Middle Name on Birth Certificate * [Type 'NA' if none]

Last Name on Birth Certificate * [Last Name on Birth Certificate]

Date of Birth * [?] [mm/dd/yyyy] [📅]

Sex Recorded on Birth Certificate * [?] [Sex Recorded on Birth Certificate] [v]

Country of Residence * [?] [Choose country] [v]

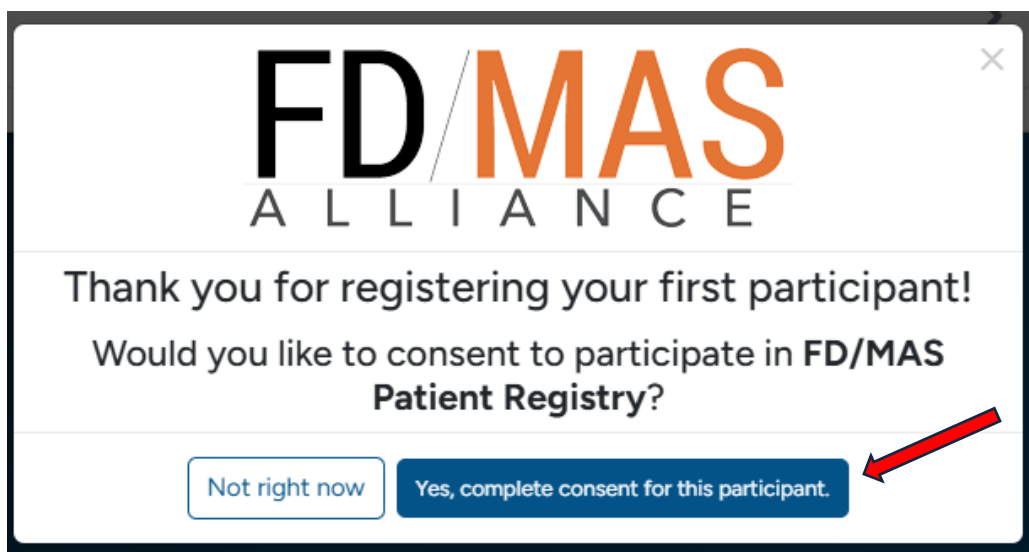
State/Province/Region of Residence * [?] [Type 'NA' if none]

Country of Birth * [Choose country of birth] [v]

City/Municipality of Birth * [City/Municipality of Birth]

Consent to the Study

- Step 1: Click on “Yes, complete consent for this participant.”



The 'Consent to the Study' dialog is a modal window with a dark blue border. It features the 'FD/MAS ALLIANCE' logo at the top. The main text reads: 'Thank you for registering your first participant! Would you like to consent to participate in FD/MAS Patient Registry?'. At the bottom, there are two buttons: 'Not right now' and 'Yes, complete consent for this participant.'. A red arrow points to the 'Yes, complete consent for this participant.' button.

FD/MAS
ALLIANCE

Thank you for registering your first participant!
Would you like to consent to participate in FD/MAS Patient Registry?

[Not right now] [Yes, complete consent for this participant.]

- Step 2: Scroll down and read through the consent form thoroughly. Once you finish each page, click the “Next” button. Once you reach the Authorization form, read through the statements thoroughly. If you are comfortable consenting to participate in the study, please read each statement and authorize your consent. After checking the boxes, click “Next.”

Jane Smith

Consent to FD/MAS Patient Registry

Consent Overview

Those eligible to participate in our study include:

Participant: An individual diagnosed with fibrous dysplasia and/or McCune-Albright Syndrome (FD/MAS), who is at least 18 years of age, the age of majority in their state, province or country, and able to provide consent for themselves.
Legally Authorized Representative: An individual (such as a family member or guardian) who is legally responsible for the healthcare of the Study Participant who is a minor (child under the age of 18) or an adult who is unable to contribute their own data. This individual must also be at least 18 years of age and the age of majority in their state, province or country.

Next

Jane Smith

Consent to FD/MAS Patient Registry

Adult Consent

Consent to Participate in the FD/MAS Patient Registry and to Allow Your Data to be Shared for Future Research

Title: FD/MAS Patient Registry
Principal Investigator: Carmel Shemmesh-Rafalowsky
Phone: 603-325-2489
Email: pi.registry@fibrousdysplasia.org, registry@fibrousdysplasia.org
Sponsor: FD/MAS Alliance

Key Information

You are invited to take part in a research study for individuals with fibrous dysplasia and/or McCune-Albright Syndrome (FD/MAS). We hope that this form will help you decide whether or not to participate, but you can also call or e-mail the study staff at the contacts above if you have any other questions.

Things you should know:

We are doing this research to better understand the impact FD/MAS has on the lives of patients and their families. Through this research, we aim to:

- Answer outstanding questions about FD/MAS
- Identify which issues, or aspects of FD/MAS, most concern patients and impact their quality of life to guide future research
- Determine common barriers to care and quantify them, if possible
- Notify patients about FD/MAS clinical trials that they may qualify to participate in

Previous

Next

Jane Smith

Consent to FD/MAS Patient Registry

Authorization

The following statements are intended to:

- Make sure that you have had the time and opportunity to consider whether you want to participate in this registry;
- Have had your questions answered; and
- Agree to participate in the study as described.

This is a web-based form. Your digital signature is the same as if you had signed your name to a paper document. By answering "Yes" to all of the following statements, you are giving your consent to participate in the FD/MAS Patient Registry. After signing, a copy of the consent form will be emailed to you. If you cannot comfortably answer "Yes" to these statements, please do not check the consent boxes in the following section.

☐ I have read this Consent and Authorization Form to provide my personal and medical data to be shared for the purpose of research. All my questions about the FD/MAS Patient Registry have been answered to my satisfaction, and I understand the purpose of the registry and the risks of participation.

☐ I wish to provide my research data to the FD/MAS Patient Registry for the purposes described above under Study Aims.

☐ I wish to provide my research data to the FD/MAS Patient Registry for future research within recognized ethical standards for scientific research, as described under How We Use Your Data.

☐ I acknowledge that I am at least 18 years of age, the age of majority in my state, province or country, and able to provide consent for myself.

[Previous](#) [Next](#)



- Step 3: Once you click "Next" and reach the Thank You page, click "Continue to Opt-Ins".

Jane Smith

Consent to FD/MAS Patient Registry

Please continue to select your opt-ins. Once you have made your selections, please click Save and Review. You will then be ready to take surveys and participate in this study.

[Previous](#) [Continue to Opt-Ins](#)



- Step 4: Once you click "Continue to Opt-Ins" read through the opt-ins thoroughly. If you would like to receive information about the topic, check the box, and click "Save and Review".

Opt-Ins for FD/MAS Patient Registry

Select Opt-Ins for this study

- ☐ Interest in hearing about other studies from **Fibrous Dysplasia Foundation dba FD/MAS Alliance**
- ☐ Interest in hearing about relevant clinical trials
- ☐ Interest in donating specimens or DNA (biobanking) for future research
- ☐ Interest in genetic testing
- ☐ Interest in learning more about **Fibrous Dysplasia Foundation dba FD/MAS Alliance**
- ☐ Interest in signing up for a **Fibrous Dysplasia Foundation dba FD/MAS Alliance** newsletter
- ☐ Support from **Fibrous Dysplasia Foundation dba FD/MAS Alliance** Ambassador / Care Coordinator
- ☐ If eligible, I have interest in receiving **Fibrous Dysplasia Foundation dba FD/MAS Alliance** merchandise that would be sent via electronic or postal mail
- ☐ Support from other Patient Advocacy Groups
- ☐ Interest in learning about upcoming events such as webinars and conferences

[Save and Review](#)



- Step 5: Once you've reviewed your consent, click "Close". You will then have access to start taking surveys.

Taking Surveys

- Step 1: Click "Take Survey" for an available survey.

← Back to the study list

Jane Smith 5-May-2000

FD/MAS Patient Registry

Surveys 15 pending

All (15) Complete (0) Pending (15)

0% Getting Started
Not Started

Take Survey

View Responses and Reports

- Step 1: Once you have submitted a survey, you are able to view your responses to that survey as well as the graphs for any questions that are programmed to show graphs. Click "View Responses" to see your completed survey. Click "Reports" to see any available graphs.

Jane Smith 5-May-2000

FD/MAS Patient Registry

Surveys 13 pending

All (15) Complete (2) Pending (13)

Getting Started
Last Completed on 25-Oct-2024

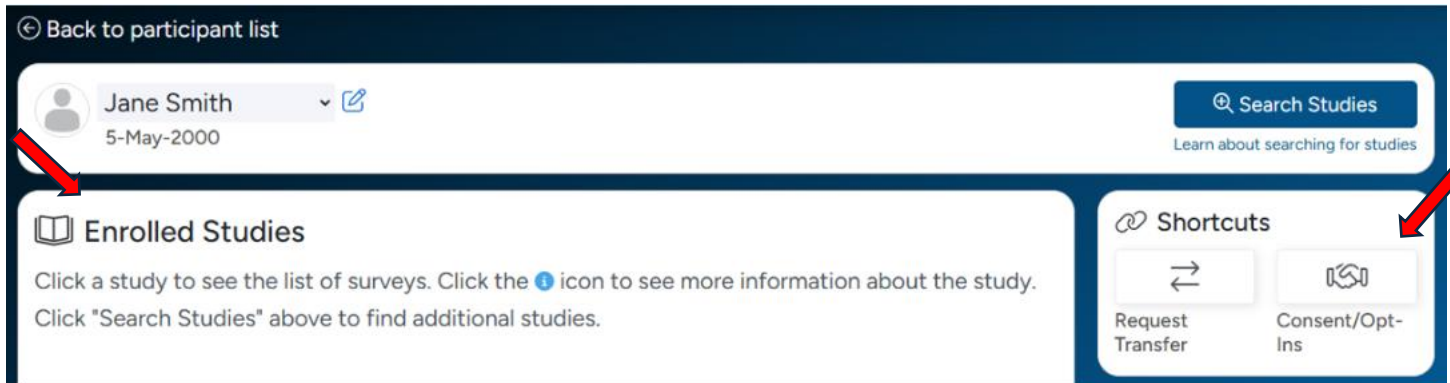
View Responses 1
Retake Survey
Reports

Basic Information About the Participant
Completed on 25-Oct-2024

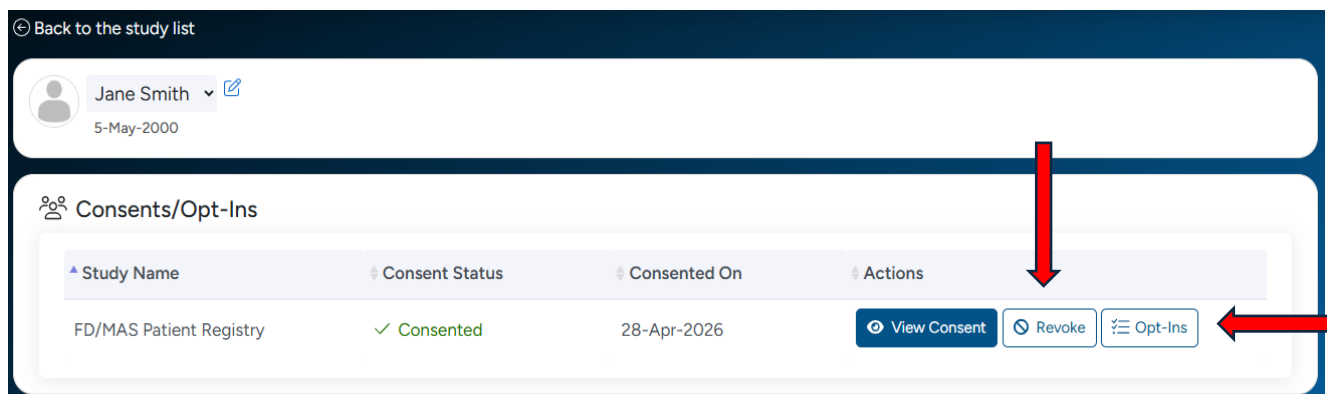
View Responses 1
Reports

View Consent and Opt-Ins

- Step 1: Once you have consented to the study, you are able to view your consent at any time. Navigate to the Enrolled Studies page. Then, click “Consents/Opt-Ins” to see your consent and opt-ins.



- Step 2: You may revoke your consent at any time by clicking “Revoke”. You may also edit your Opt-Ins by clicking “Opt-Ins”.

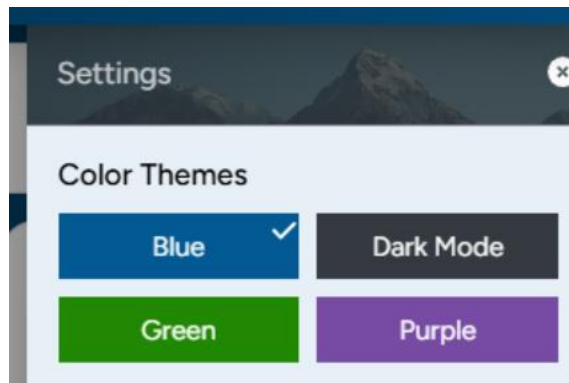


Dark Mode Settings

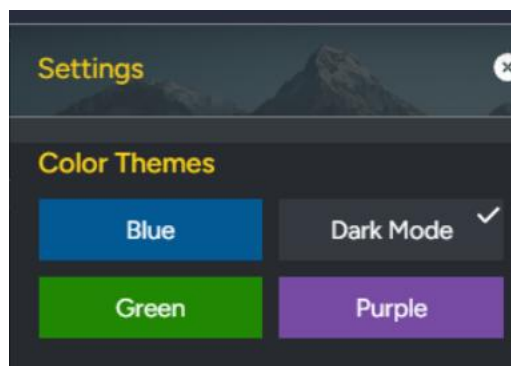
- Step 1: You can view the platform in Dark Mode. First, click Settings.



- Step 2: Select Dark Mode



- Step 3: Exit the Settings menu, and your selection will be saved.

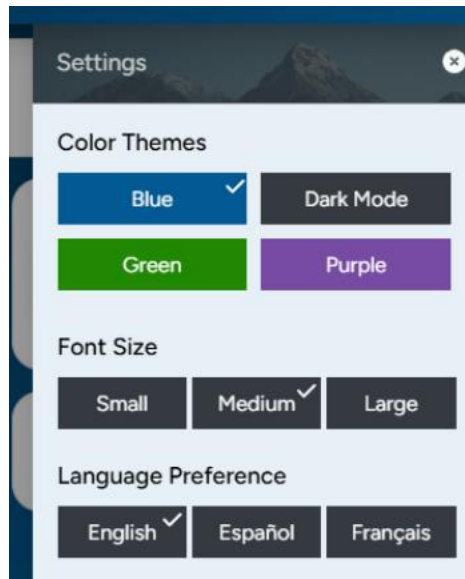


Display Settings

- Step 1: You can change the platform display settings. First, click Settings.



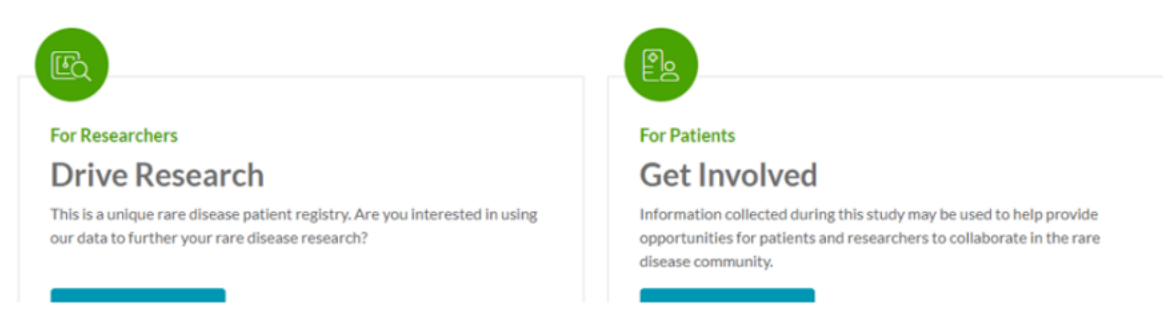
- Step 2: Select a color theme, a font size, or language preference.

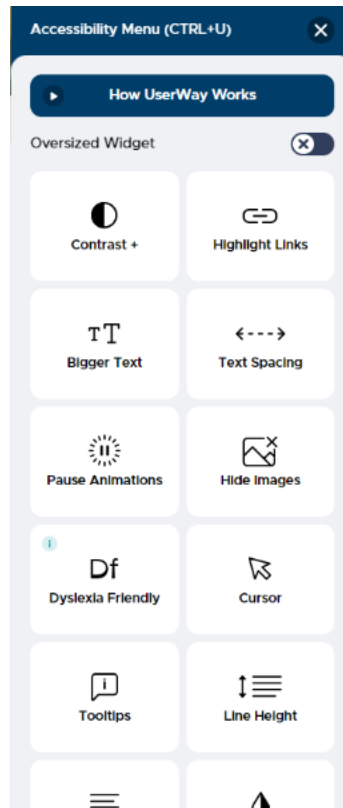


- Step 3: Exit the Settings menu, and your selection will be saved.

Microsite Visibility

- Step 1: You can change how you view the microsite (fdmasregistry.org) using an Accessibility menu. Click the icon of a person at the bottom of the screen. You are able to change the settings such as the contrast, text sizing, and text spacing.





Need Assistance?

- Step 1: If you need help while using the platform, click Help.
- Step 2: Select an Inquiry Type and type a message.

 A screenshot of a "Have a question?" form. The form has a dark blue header with a home icon and "Home" text, and a question mark icon and "Help" text. The main title "Have a question?" is in white on a dark blue background, with a close button (X) in the top right. Below the title is a paragraph of text: "Please enter your message below and click submit. We will be in touch shortly. We cannot provide medical advice or answer specific medical questions – to find out about resources to support people with your rare disease, please visit the NORD website at rarediseases.org." Below this is a section titled "Inquiry Type *" with a dropdown menu showing "-- Select Inquiry Type --". Below that is a section titled "Message *" with a text input field containing "Your message". At the bottom are two buttons: "Cancel" and "Submit".

- Step 3: Click Submit.

- You may also contact the study sponsor directly by using the contact information shown on your dashboard or the study website.

Take Survey

Take Survey

Take Survey

FD**MAS**
ALLIANCE

Fibrous Dysplasia
Foundation dba
FD/MAS Alliance

Contact
FD/MAS Alliance

E-mail
registry@fibrousdysplasia.org

IRB E-mail
irb@northstarreviewboard.org

Social Media
 