



Moebius Syndrome Foundation Research Registry 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”.

The screenshot shows the registration page for the Moebius Syndrome Foundation Research Registry. At the top, it says "Featuring MOEBIUS SYNDROME FOUNDATION" with the logo. Below that is the heading "Registration". A progress bar shows five steps: "Terms & Conditions", "Contact Info", "Notifications", "Review & Submit", and "Confirmation". The "Terms & Conditions" step is currently active, indicated by a blue bar under the progress bar. Below the progress bar, there is a paragraph of text explaining the purpose of the Terms of Use and Privacy Guidelines. This is followed by a section titled "Acknowledgements:" with four checkboxes, each followed by a statement of agreement. At the bottom left, there is a link "Return to login" and at the bottom right, there is a blue button labeled "Next".

Featuring
MOEBIUS
SYNDROME FOUNDATION

Registration

Terms & Conditions Contact Info Notifications Review & Submit Confirmation

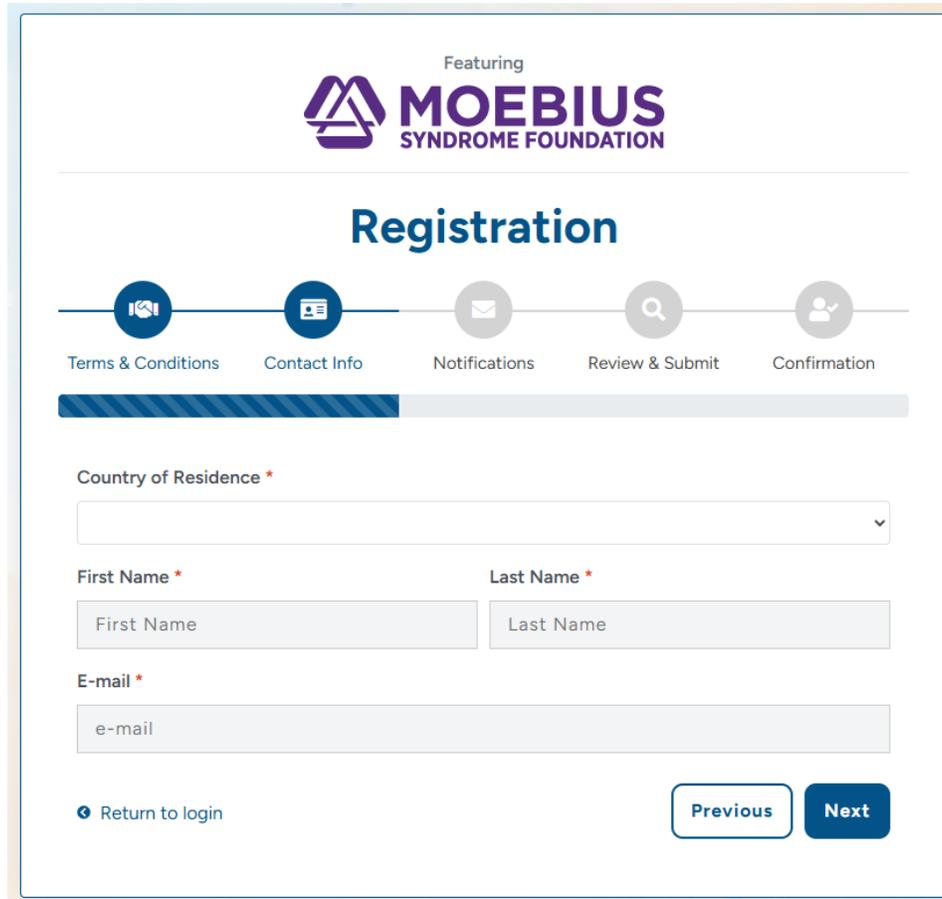
Below are links to the IAMRARE Terms of Use and Privacy Guidelines. The purpose of these documents is to outline your rights and responsibilities when using the platform. These documents include: 1) Standard policies for all studies on this platform, 2) A privacy statement that details how your data 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](#) & [Privacy Policy](#) *

[Return to login](#) **Next**

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



Featuring
MOEBIUS
SYNDROME FOUNDATION

Registration

Terms & Conditions Contact Info Notifications Review & Submit Confirmation

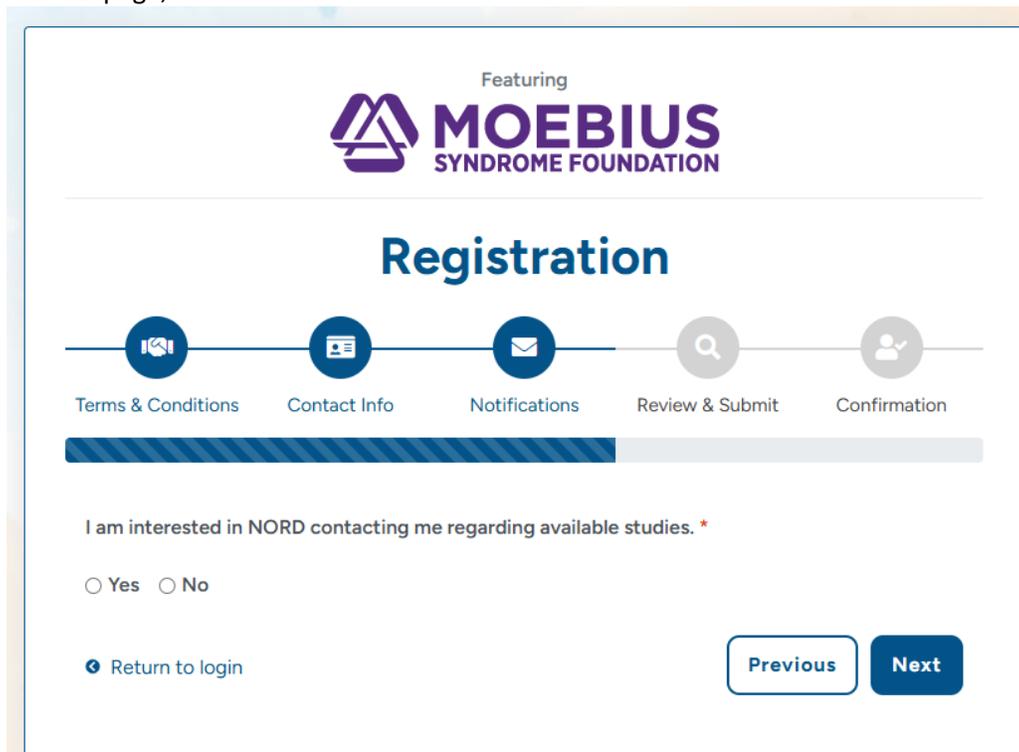
Country of Residence *

First Name * Last Name *

E-mail *

[Return to login](#) [Previous](#) [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”.



Featuring
MOEBIUS
SYNDROME FOUNDATION

Registration

Terms & Conditions Contact Info Notifications Review & Submit Confirmation

I am interested in NORD contacting me regarding available studies. *

Yes No

[Return to login](#) [Previous](#) [Next](#)

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

Featuring
MOEBIUS
SYNDROME FOUNDATION

Registration

Terms & Conditions Contact Info Notifications Review & Submit Confirmation

An activation link will be sent to youremail@email.com. Click "Next" to send this e-mail and continue.

[Return to login](#) [Previous](#) [Next](#)

- 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”.

E-mail Validation

Your e-mail your.email@email.com has been successfully validated.
Please create your password below.

Password

A password must be at least 8 characters long: ✘
- contain 1 uppercase letter ✘
- contain 1 lowercase letter ✘
- contain 1 digit ✘
- not contain text from top 1000 commonly used passwords ✘

Repeat Password

[SUBMIT](#)

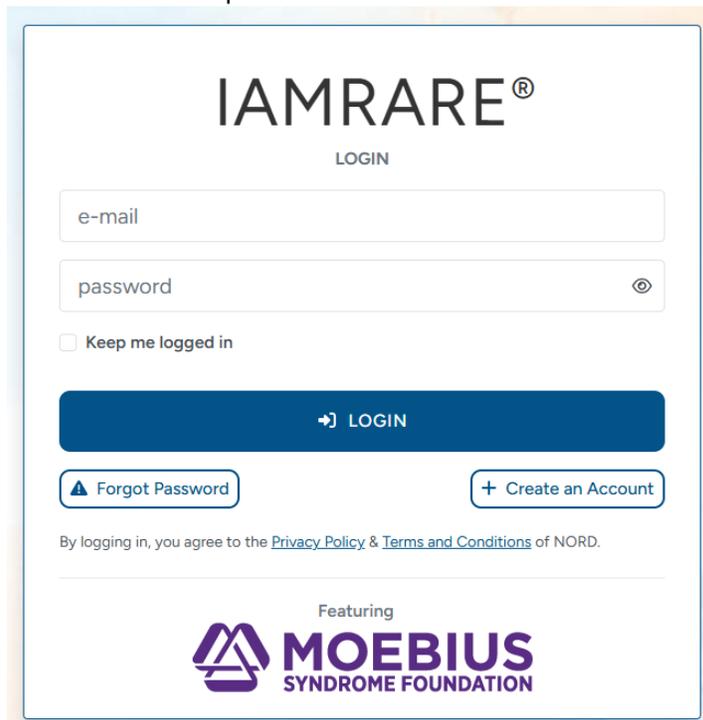
- Step 6: Your validation is now complete. Select “Go to Login Page”.

E-mail Validation

Registration is complete! You can now log in.

[GO TO LOGIN PAGE](#)

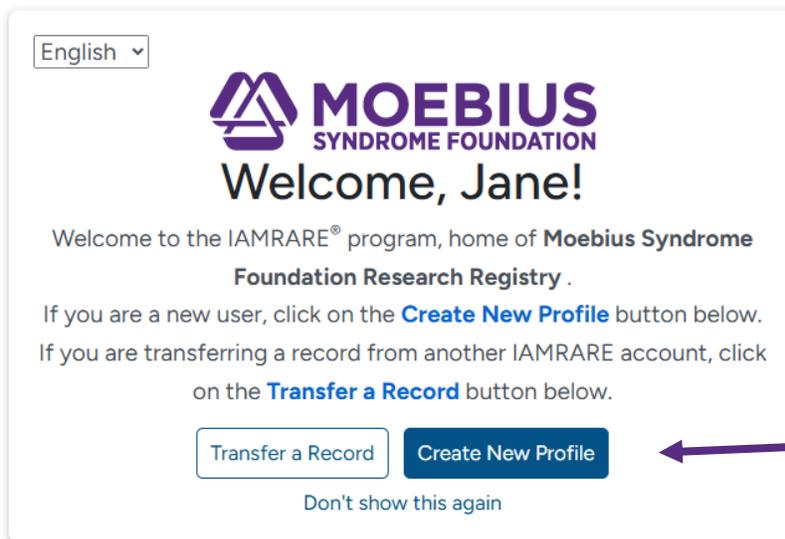
- Step 7: Log in using your new e-mail and password.



The image shows the IAMRARE LOGIN page. At the top, it says "IAMRARE®" and "LOGIN". Below that are two input fields: "e-mail" and "password" (with an eye icon for visibility). There is a checkbox for "Keep me logged in". A large blue button with a right arrow and "LOGIN" is centered. Below the button are two smaller buttons: "Forgot Password" (with a warning icon) and "+ Create an Account". At the bottom, it says "By logging in, you agree to the [Privacy Policy](#) & [Terms and Conditions](#) of NORD." Below a horizontal line, it says "Featuring" and shows the "MOEBIUS SYNDROME FOUNDATION" logo.

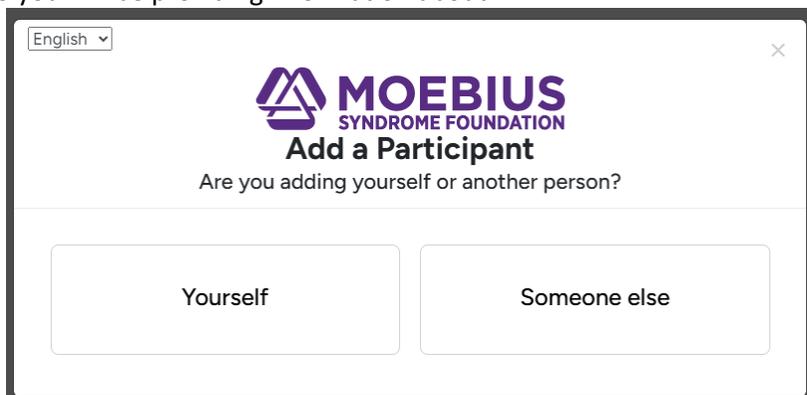
Add a Participant

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



The image shows a welcome screen for a user named Jane. At the top left, there is a language dropdown menu set to "English". The Moebius Syndrome Foundation logo is centered, followed by "Welcome, Jane!". Below that, it says "Welcome to the IAMRARE® program, home of Moebius Syndrome Foundation Research Registry." It then provides instructions: "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." At the bottom, there are two buttons: "Transfer a Record" and "Create New Profile". A purple arrow points to the "Create New Profile" button. Below the buttons is a link that says "Don't show this again".

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



The image shows a dialog box titled "Add a Participant" from the Moebius Syndrome Foundation. It has a language dropdown menu set to "English" and a close button (X) in the top right corner. The text asks "Are you adding yourself or another person?". Below the text are two buttons: "Yourself" and "Someone else".

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

Consent to the Study

- Step 1: Click on "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.”

Consent to Moebius Syndrome Foundation Research Registry

Jane Smith

Consent Overview

Those eligible to participate in our study include:

Participant: An individual diagnosed with Moebius syndrome 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 with Moebius syndrome 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.

Designated Representative: A legal adult who was the caretaker of an individual who passed away from Moebius syndrome, defined as a spouse, parent, sibling, offspring, close relative, close friend, guardian and/or significant other of the individual who had Moebius syndrome and who had knowledge and participated in their medical care. This individual must also be at least 18 years of age and the age of majority in their state, province or country.

[Next](#)

Consent to Moebius Syndrome Foundation Research Registry

Jane Smith

Adult Consent

Consent to Participate in the Moebius Syndrome Foundation Research Registry and to Allow Your Data to be Shared for Future Research

Title: Moebius Syndrome Foundation Research Registry

Principal Investigator: Bryn Webb, MD

Scientific Advisory Board Moebius Syndrome Foundation

Phone: 1 (844) 663-2487 ext 706, or 1 (844) MOEBIUS ext 706

E-mail: Research@moebiussyndrome.org

Sponsor: Moebius Syndrome Foundation

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

Consent to Moebius Syndrome Foundation Research Registry

Jane Smith

Authorization

The following statements are intended to:

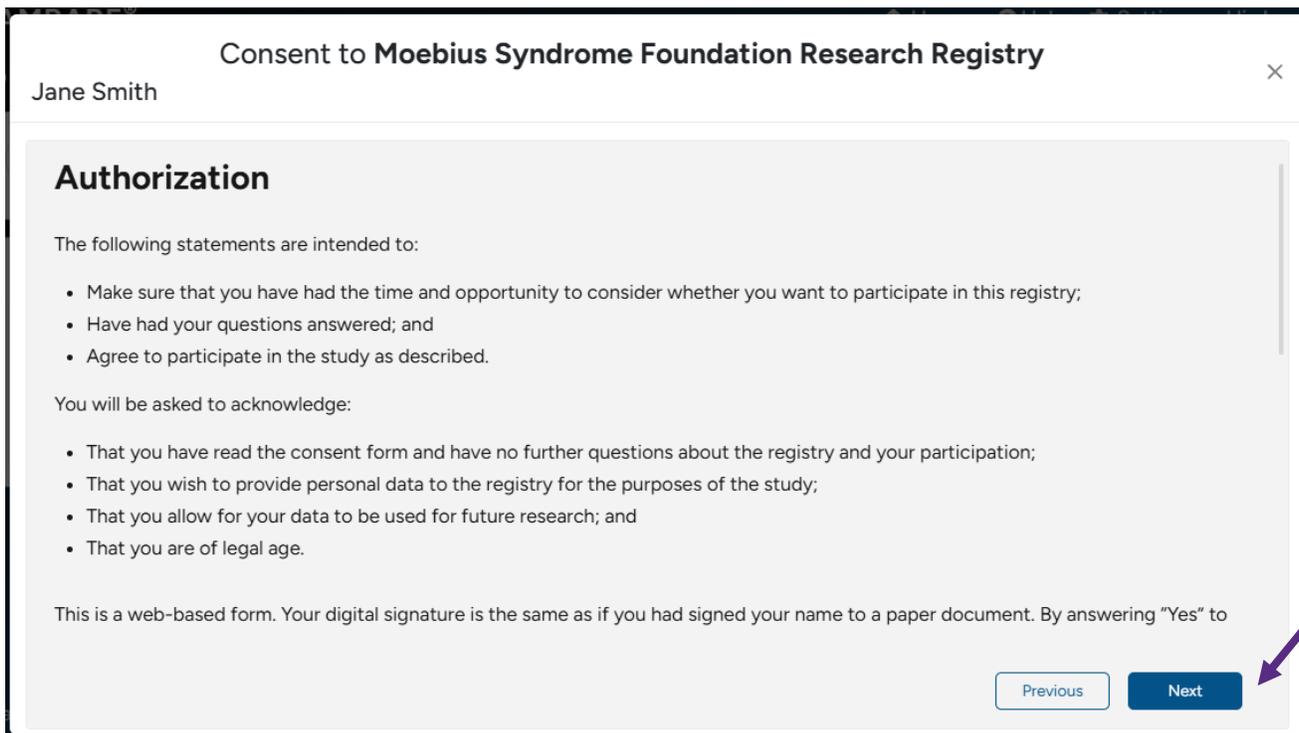
- Make sure that you have had the time and opportunity to consider whether you want to participate in this registry;
- Have had your questions answered; and
- Agree to participate in the study as described.

You will be asked to acknowledge:

- That you have read the consent form and have no further questions about the registry and your participation;
- That you wish to provide personal data to the registry for the purposes of the study;
- That you allow for your data to be used for future research; and
- That you are of legal age.

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

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



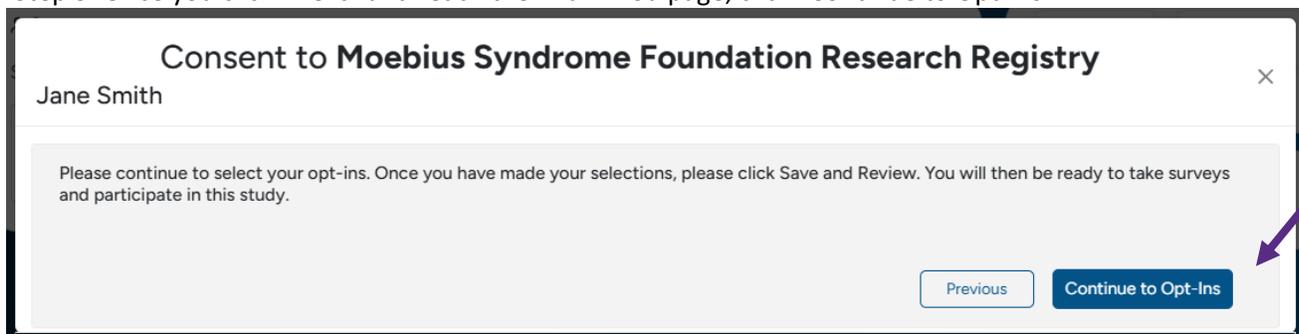
- Step 3: Once you click "Next" and reach the Thank You page, click "Continue to Opt-Ins".

Consent to Moebius Syndrome Foundation Research Registry

Jane Smith

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](#)



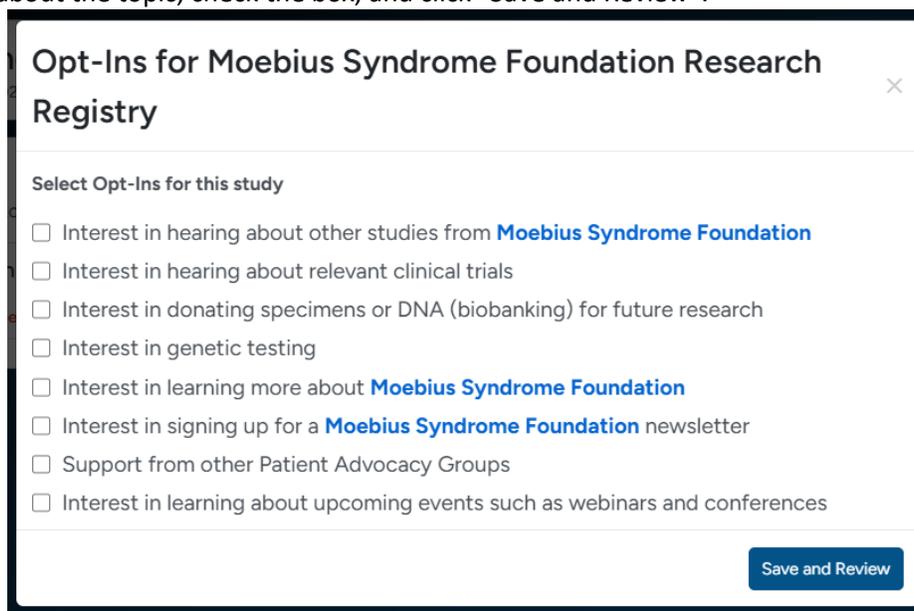
- Step 4: Once you click "Continue to Opt-Ins" read through the opt-ins thoroughly. If you would like to receive information about the topic, check the box, and click "Save and Review".

Opt-Ins for Moebius Syndrome Foundation Research Registry

Select Opt-Ins for this study

- Interest in hearing about other studies from [Moebius Syndrome Foundation](#)
- 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 [Moebius Syndrome Foundation](#)
- Interest in signing up for a [Moebius Syndrome Foundation](#) newsletter
- Support from other Patient Advocacy Groups
- Interest in learning about upcoming events such as webinars and conferences

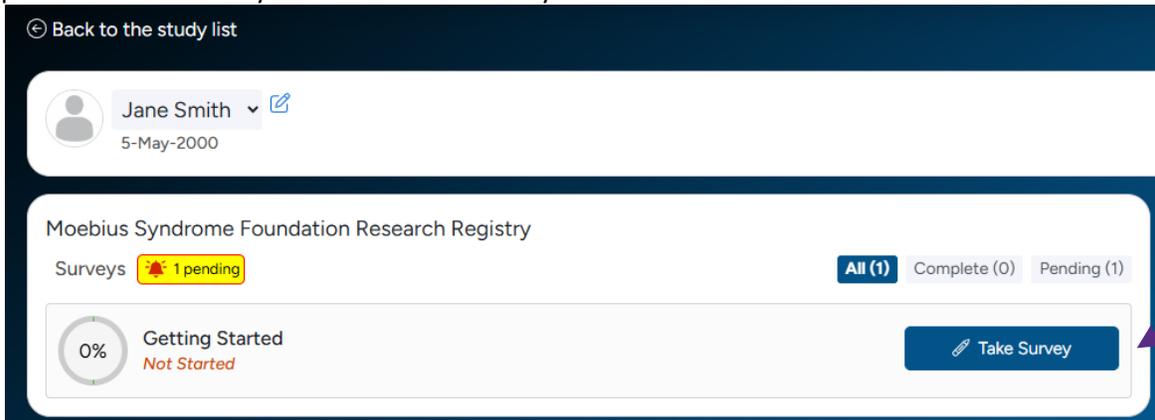
[Save and Review](#)



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

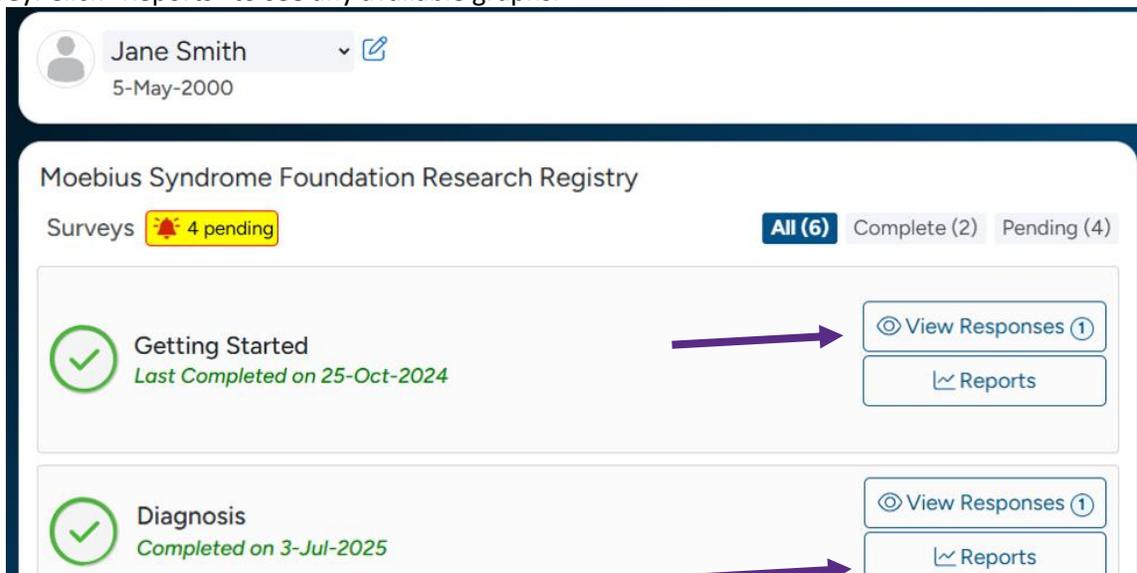
Taking Surveys

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



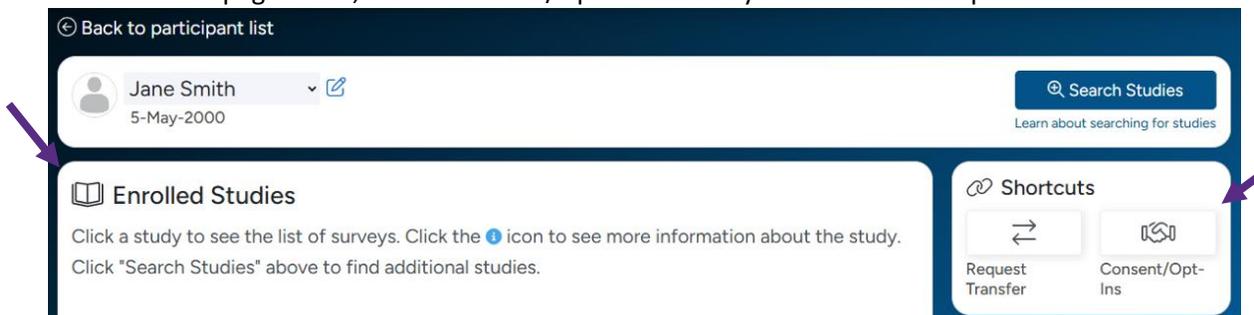
View Responses and Reports

- 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.



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

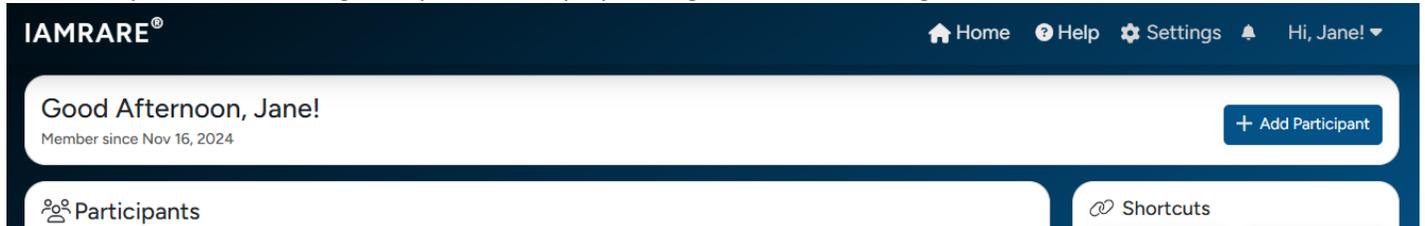
- Step 1: You can view the platform in Dark Mode. First, click Settings.

- Step 2: Select Dark Mode.

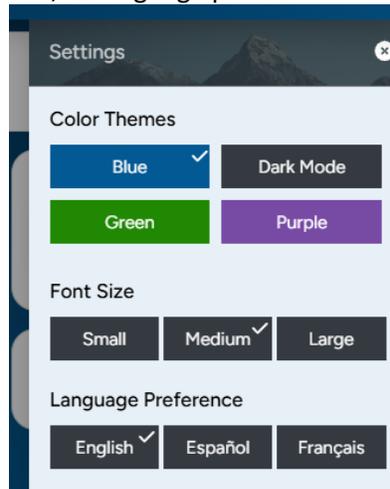
- Step 3: Exit the Settings menu, and your selection will be saved.

Display Settings

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



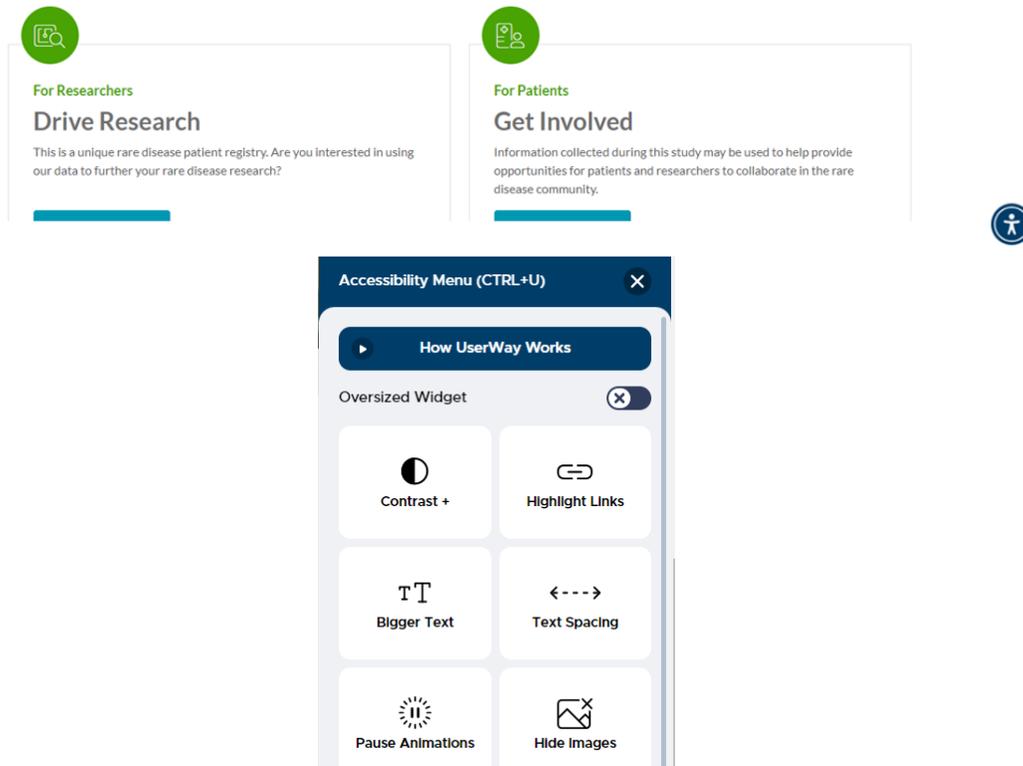
- Step 2: Select a color theme, a font size, or language preference.



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

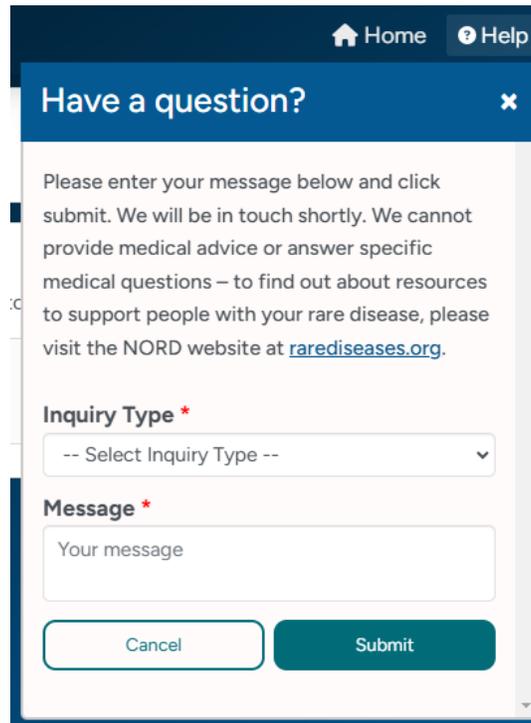
Microsite Visibility

- Step 1: You can change how you view the microsite [insert URL] 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.



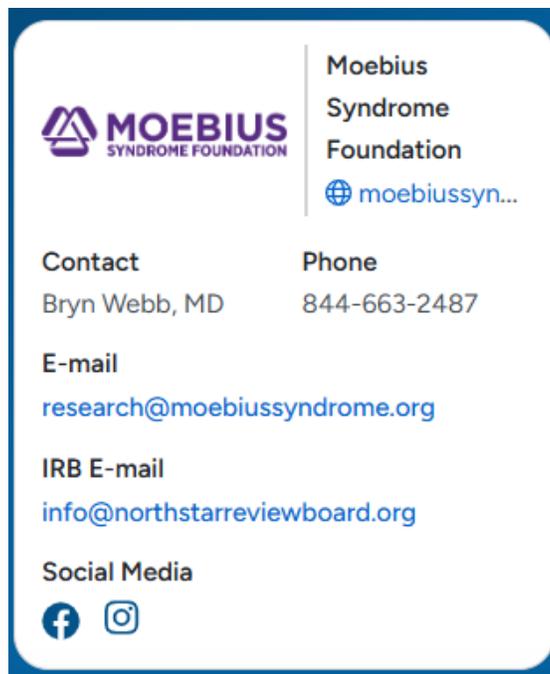
Need Assistance?

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



The screenshot shows a web interface with a dark blue header containing 'Home' and 'Help' links. Below the header is a modal window titled 'Have a question?' with a close button (X). The modal contains the following 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 text is a dropdown menu labeled 'Inquiry Type *' with the option '-- Select Inquiry Type --'. Underneath is a text input field labeled 'Message *' with the placeholder text 'Your message'. At the bottom of the modal 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.



The contact information card features the Moebius Syndrome Foundation logo on the left, which consists of a stylized 'M' and the text 'MOEBIUS SYNDROME FOUNDATION'. To the right of the logo, the text reads 'Moebius Syndrome Foundation' followed by a globe icon and the text 'moebiusyn...'. Below this, the contact details are organized into sections: 'Contact' with 'Bryn Webb, MD', 'Phone' with '844-663-2487', 'E-mail' with 'research@moebiusyndrome.org', and 'IRB E-mail' with 'info@northstarreviewboard.org'. At the bottom, the 'Social Media' section includes icons for Facebook and Instagram.