

The Mast Cell Diseases Patient and Provider 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 Mast Cell Disease Society. At the top, the logo is displayed with the text 'Featuring The Mast Cell Disease Society'. Below the logo, the word 'Registration' is centered. A progress bar with five icons (Terms & Conditions, Contact Info, Notifications, Review & Submit, Confirmation) is shown, with the first icon highlighted. 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 and their corresponding text. At the bottom left, there is a link 'Return to login' and at the bottom right, a blue button labeled 'Next'.

Featuring
The Mast Cell Disease Society

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](#) 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 screenshot shows the 'Registration' page for The Mast Cell Disease Society, specifically the 'Contact Info' step. The progress bar now highlights the second icon. The form contains a dropdown menu for 'Country of Residence', followed by two text input fields for 'First Name' and 'Last Name', and a text input field for 'E-mail'. At the bottom left, there is a link 'Return to login' and at the bottom right, two buttons labeled 'Previous' and 'Next'.

Featuring
The Mast Cell Disease Society

Registration

Terms & Conditions Contact Info Notifications Review & Submit Confirmation

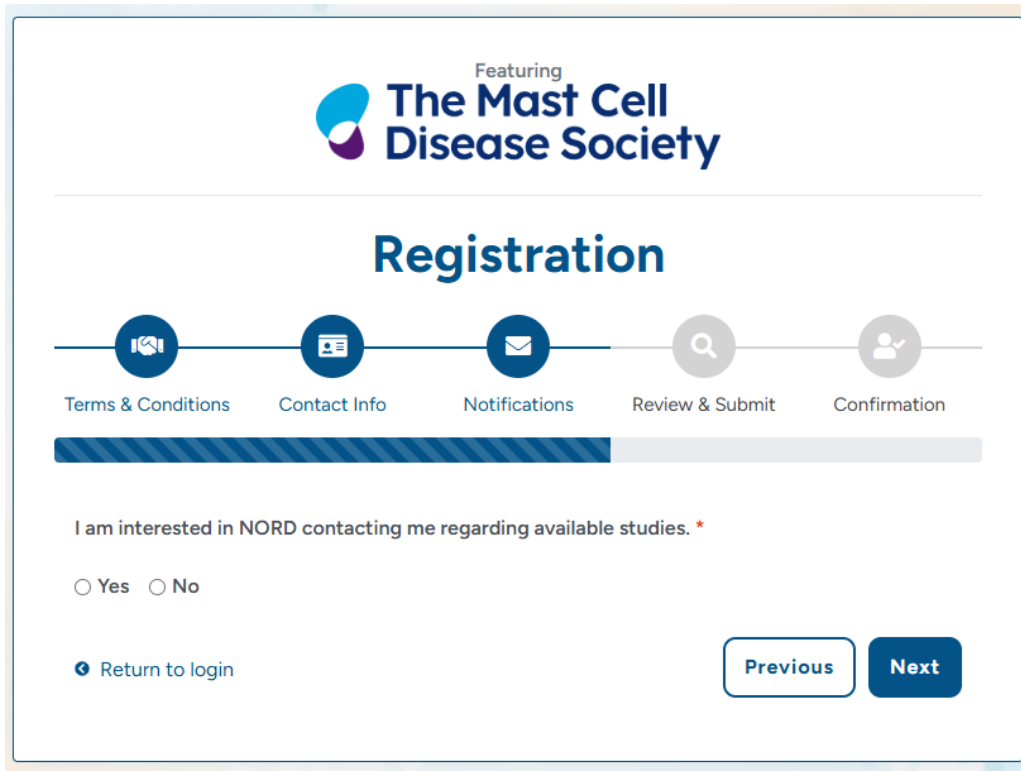
Country of Residence *

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”.



The screenshot shows the 'Registration' page for 'Featuring The Mast Cell Disease Society'. A progress bar at the top indicates the current step is 'Terms & Conditions', followed by 'Contact Info', 'Notifications', 'Review & Submit', and 'Confirmation'. Below the progress bar, the text reads: 'I am interested in NORD contacting me regarding available studies. *'. There are two radio buttons: 'Yes' and 'No'. At the bottom left is a link 'Return to login'. At the bottom right are two buttons: 'Previous' and 'Next'.

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



The screenshot shows the 'Registration' page for 'Featuring The Mast Cell Disease Society'. The progress bar now indicates the current step is 'Review & Submit', with 'Terms & Conditions', 'Contact Info', and 'Notifications' completed. Below the progress bar, the text reads: 'An activation link will be sent to test@email.com. Click "Next" to send this e-mail and continue.' At the bottom left is a link 'Return to login'. At the bottom right are two buttons: 'Previous' and 'Next'. A blue 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”.

E-mail Validation

Your e-mail 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

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

E-mail Validation

Registration is complete! You can now log in.

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

IAMRARE®

LOGIN

☐ Keep me logged in

By logging in, you agree to the [Privacy Policy](#) & [Terms and Conditions](#) of NORD and have read the [Consumer Health Data Privacy Notice](#).

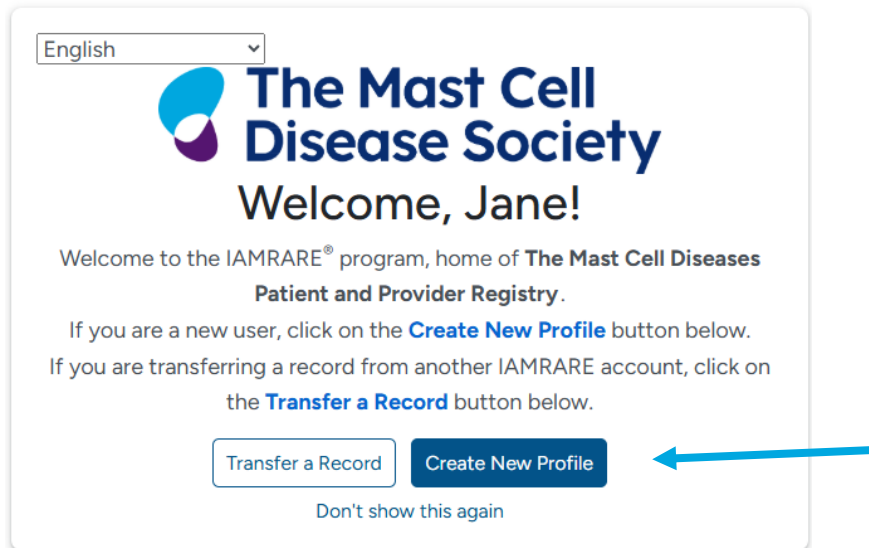
Featuring



**The Mast Cell
Disease Society**

Add a Participant

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



English

The Mast Cell Disease Society

Welcome, Jane!

Welcome to the IAMRARE® program, home of **The Mast Cell Diseases Patient and Provider Registry**.

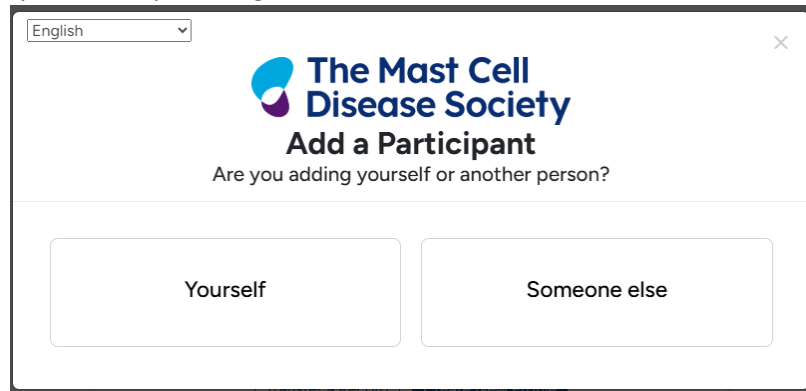
If you are a new user, click on the [Create New Profile](#) button below.

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

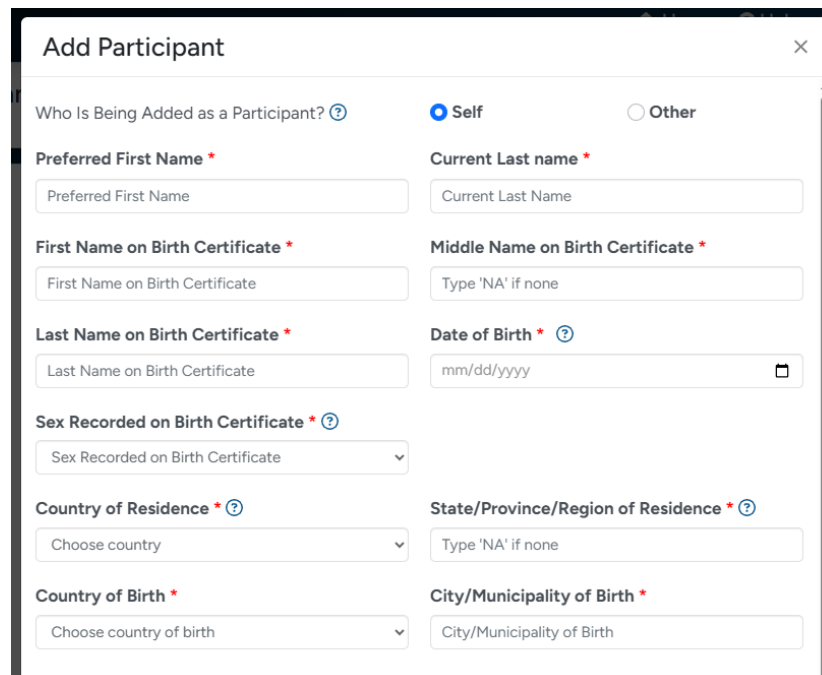
The Mast Cell Disease Society

Add a Participant

Are you adding yourself or another person?

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

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



Add Participant

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

Preferred First Name *

Current Last name *

First Name on Birth Certificate *

Middle Name on Birth Certificate *

Last Name on Birth Certificate *

Date of Birth * [?](#) 

Sex Recorded on Birth Certificate * [?](#)

Country of Residence * [?](#)

State/Province/Region of Residence * [?](#)

Country of Birth *

City/Municipality of Birth *

Consent to the Study

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



The Mast Cell Disease Society

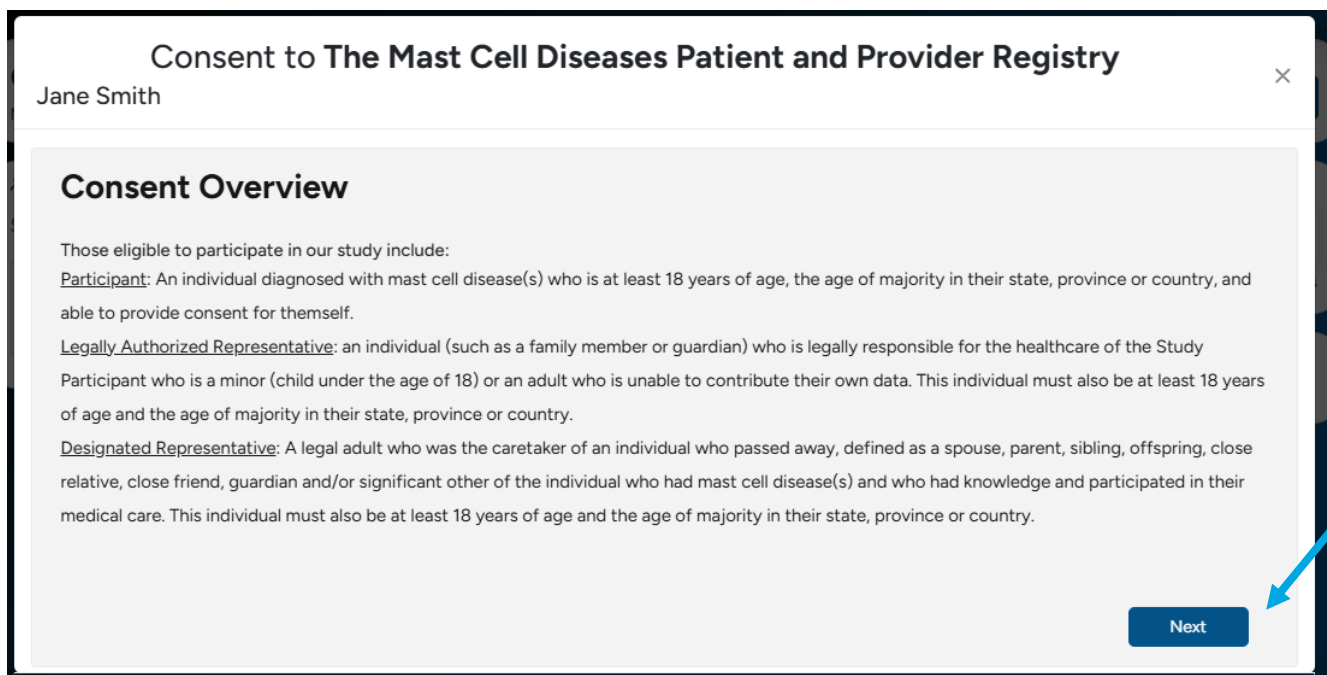
Thank you for registering your first participant!

Would you like to consent to participate in The Mast Cell Diseases Patient and Provider Registry?

Not right now Yes, complete consent for this participant.

A blue arrow points to the "Yes, complete consent for this participant." button.

- 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 The Mast Cell Diseases Patient and Provider Registry

Jane Smith

Consent Overview

Those eligible to participate in our study include:

Participant: An individual diagnosed with mast cell disease(s) 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.

Designated Representative: A legal adult who was the caretaker of an individual who passed away, defined as a spouse, parent, sibling, offspring, close relative, close friend, guardian and/or significant other of the individual who had mast cell disease(s) 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

A blue arrow points to the "Next" button.

Consent to The Mast Cell Diseases Patient and Provider Registry

Jane Smith



Adult Consent

Consent to Participate in The Mast Cell Diseases Patient and Provider Registry and to Allow Your Data to be Shared for Future Research

Title: The Mast Cell Diseases Patient and Provider Registry

Principal Investigator: Shonna Snyder, PhD, Sr. Research Scientist

Phone: (317) 735-6626

E-mail: registry@tmsforacure.org

Sponsor: Sponsor Name

Key Information

You are invited to take part in a research study for people with mast cell disease(s). This form will help you decide if you want to

Previous

Next

Consent to The Mast Cell Diseases Patient and Provider 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.

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 Mast Cell Diseases Patient and Provider 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.

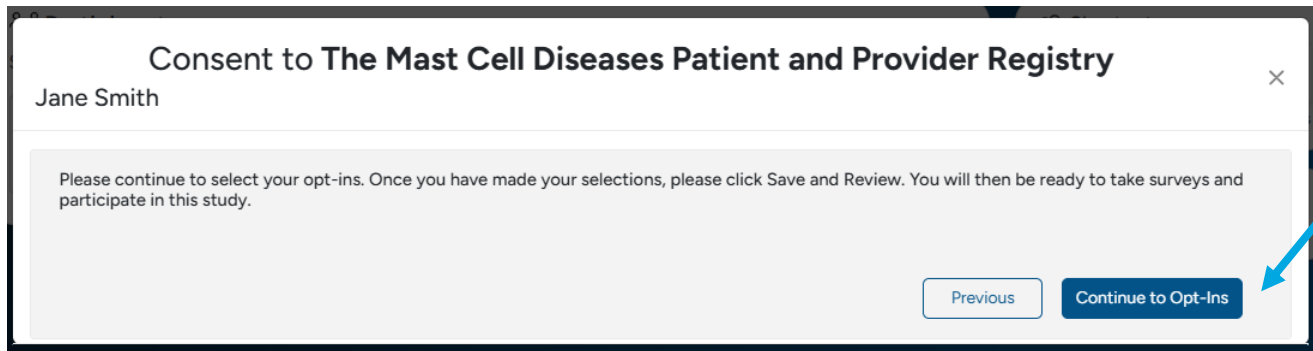
☐

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 Mast Cell Diseases Patient and Provider Registry have been answered to my satisfaction, and I understand the

Previous

Next

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



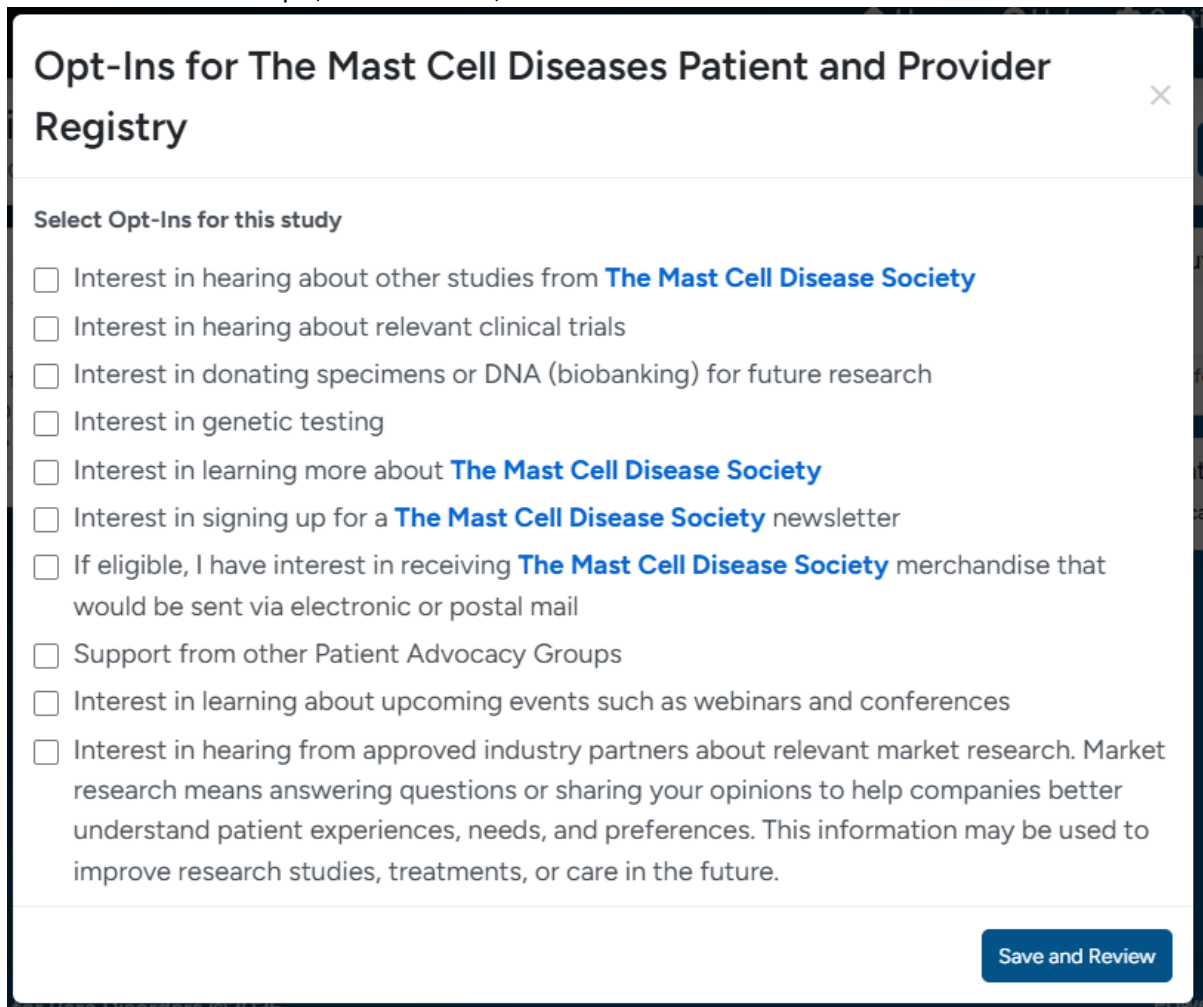
Consent to **The Mast Cell Diseases Patient and Provider Registry**

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 **The Mast Cell Diseases Patient and Provider Registry**

Select Opt-Ins for this study

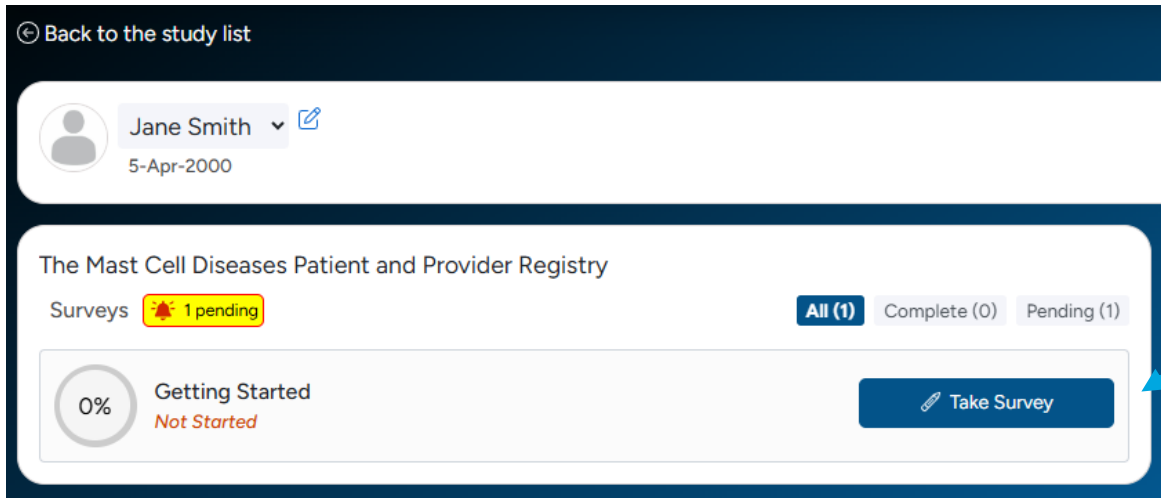
- ☐ Interest in hearing about other studies from **The Mast Cell Disease Society**
- ☐ Interest in hearing about relevant clinical trials
- ☐ Interest in donating specimens or DNA (biobanking) for future research
- ☐ Interest in genetic testing
- ☐ Interest in learning more about **The Mast Cell Disease Society**
- ☐ Interest in signing up for a **The Mast Cell Disease Society** newsletter
- ☐ If eligible, I have interest in receiving **The Mast Cell Disease Society** 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
- ☐ Interest in hearing from approved industry partners about relevant market research. Market research means answering questions or sharing your opinions to help companies better understand patient experiences, needs, and preferences. This information may be used to improve research studies, treatments, or care in the future.

[Save and Review](#)

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

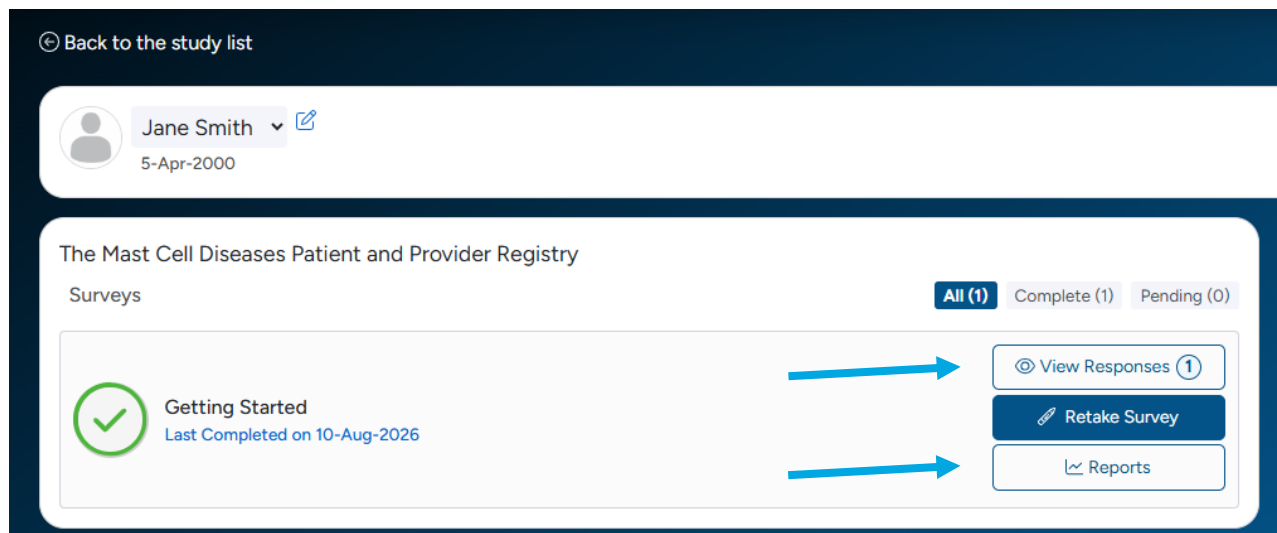
Taking Surveys

- 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.

Back to participant list

Jane Smith 5-May-2000

Search Studies

Learn about searching for studies

Enrolled Studies

Click a study to see the list of surveys. Click the **i** icon to see more information about the study. Click "Search Studies" above to find additional studies.

Shortcuts

Request Transfer

Consent/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”.

Back to the study list

Jane Smith 5-Apr-2000

Consents/Opt-Ins

Study Name	Consent Status	Consented On	Actions
The Mast Cell Diseases Patient and Provider Registry	✓ Consented	24-Jul-2026	View Consent Revoke Opt-Ins

Dark Mode Settings

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

IAMRARE®

Home Help Settings Hi, Jane!

Back to the participant list

Jane Smith 5-Apr-2000

Search Studies

- Step 2: Select Dark Mode.

Settings

Color Themes

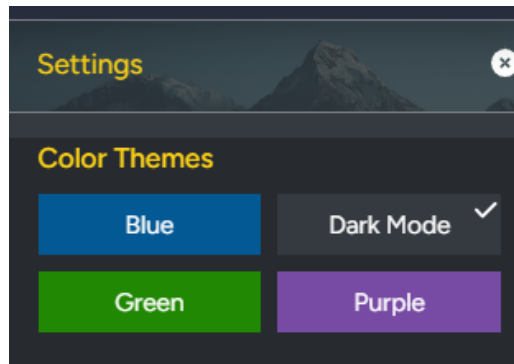
Blue ✓

Dark Mode

Green

Purple

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

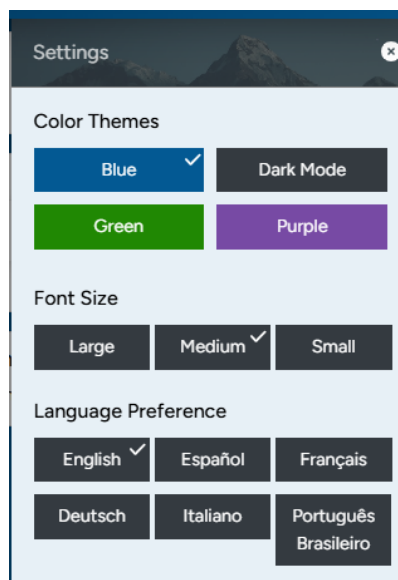


Display Settings

- 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 (MCDregistry.iamrare.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.



For Researchers

Drive Research

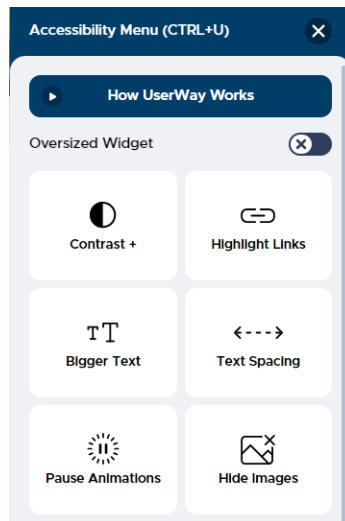
This is a unique rare disease patient registry. Are you interested in using our data to further your rare disease research?



For Patients

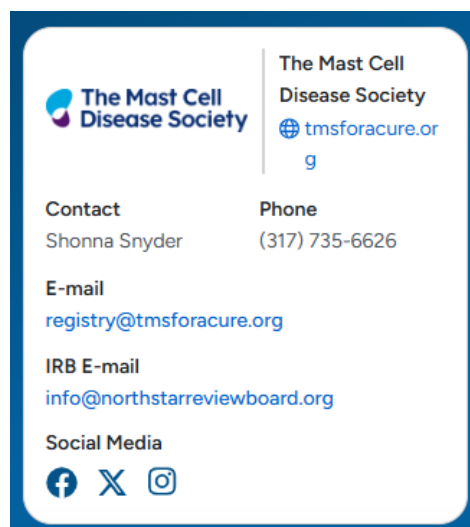
Get Involved

Information collected during this study may be used to help provide opportunities for patients and researchers to collaborate in the rare disease community.



Need Assistance?

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



Home
Help

Have a question?

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.

Inquiry Type *

-- Select Inquiry Type --

Message *

Your message

Cancel Submit