



CureARS 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



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
CureARS

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
CureARS

Registration

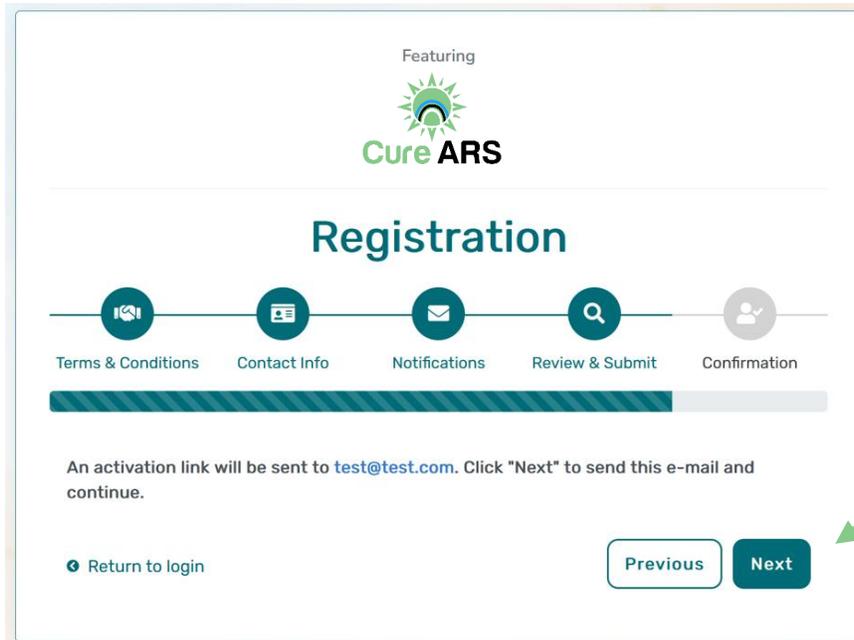
Terms & Conditions Contact Info Notifications Review & Submit Confirmation

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

Yes No

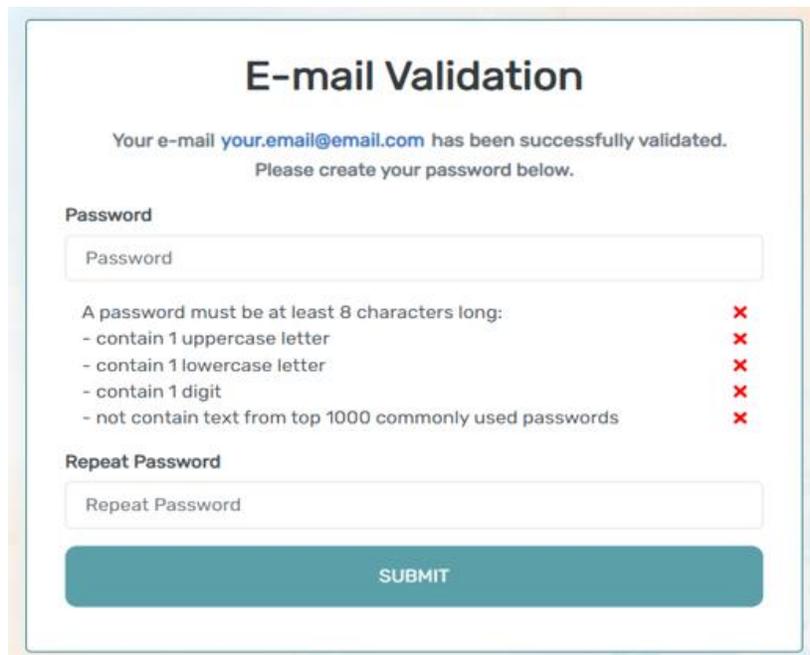
[Return to login](#) [Previous](#) [Next](#)

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



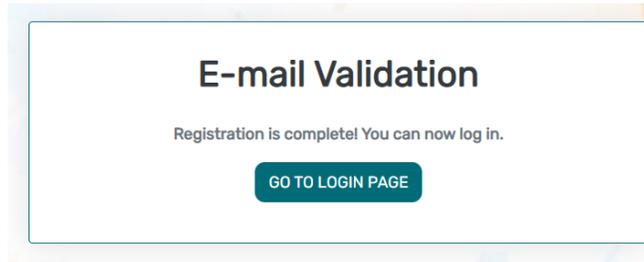
The image shows a registration progress screen for CureARS. At the top, it says "Featuring" above the CureARS logo. The main heading is "Registration". Below this is a progress bar with five steps: "Terms & Conditions", "Contact Info", "Notifications", "Review & Submit", and "Confirmation". The "Review & Submit" step is currently active, indicated by a teal bar under the progress bar. Below the progress bar, there is a message: "An activation link will be sent to test@test.com. Click 'Next' to send this e-mail and continue." At the bottom left, there is a link "Return to login". At the bottom right, there are two buttons: "Previous" and "Next". A green 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”.

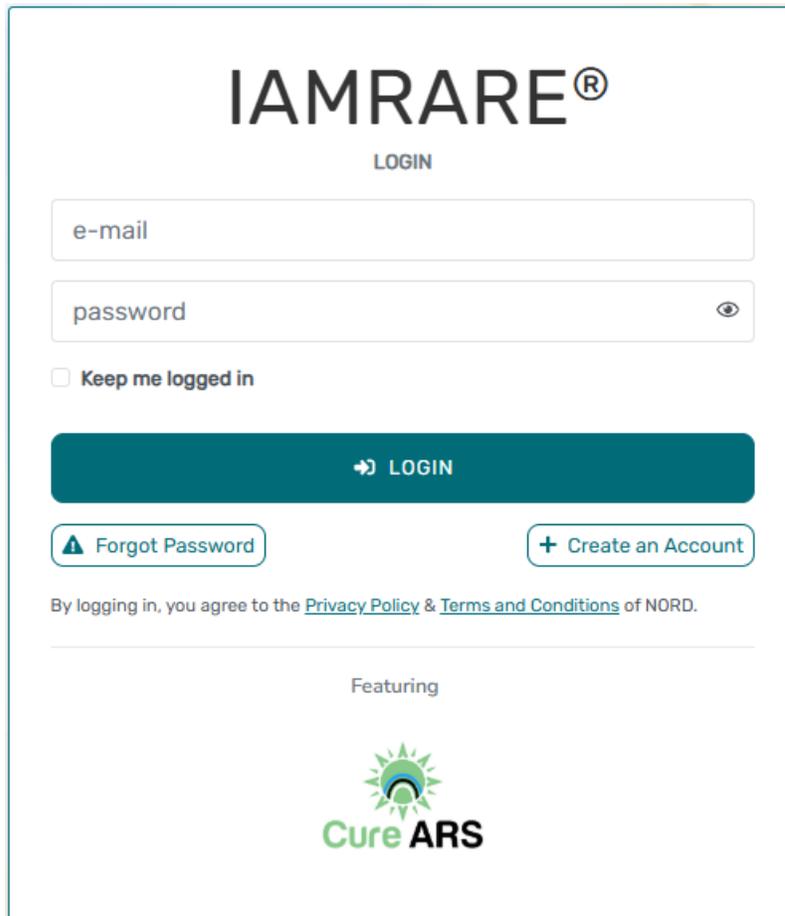


The image shows an "E-mail Validation" screen. The heading is "E-mail Validation". Below the heading, it says "Your e-mail your.email@email.com has been successfully validated. Please create your password below." There are two input fields: "Password" and "Repeat Password". Below the "Password" field, there are four validation rules, each with a red "X" indicating a failure: "A password must be at least 8 characters long:", "- contain 1 uppercase letter", "- contain 1 lowercase letter", "- contain 1 digit", and "- not contain text from top 1000 commonly used passwords". At the bottom, there is a large teal "SUBMIT" button.

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

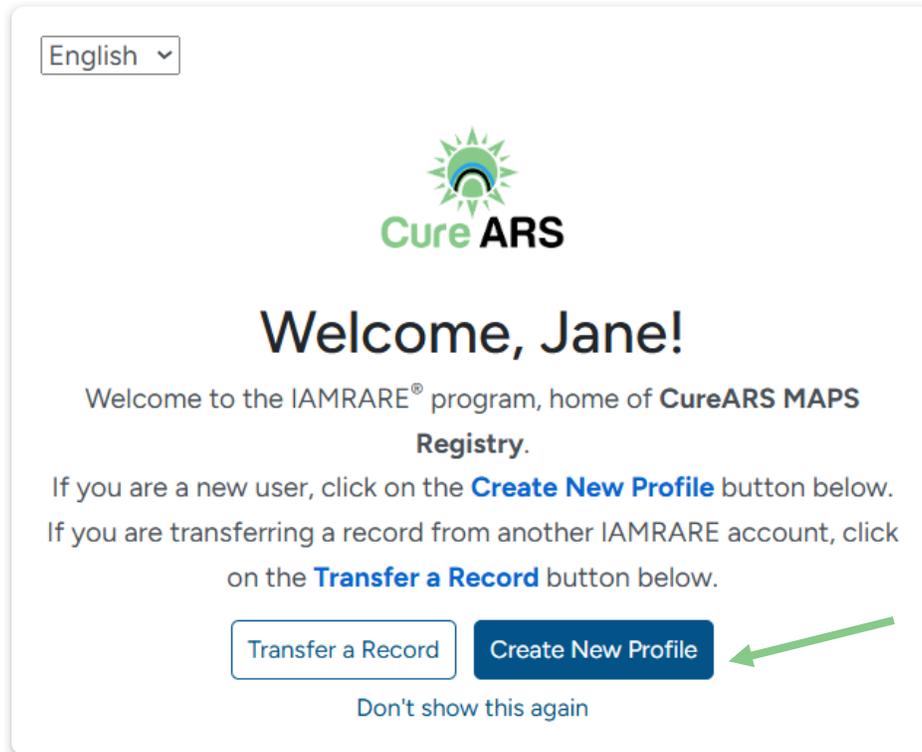


- Step 7: Log in using your new e-mail and password.

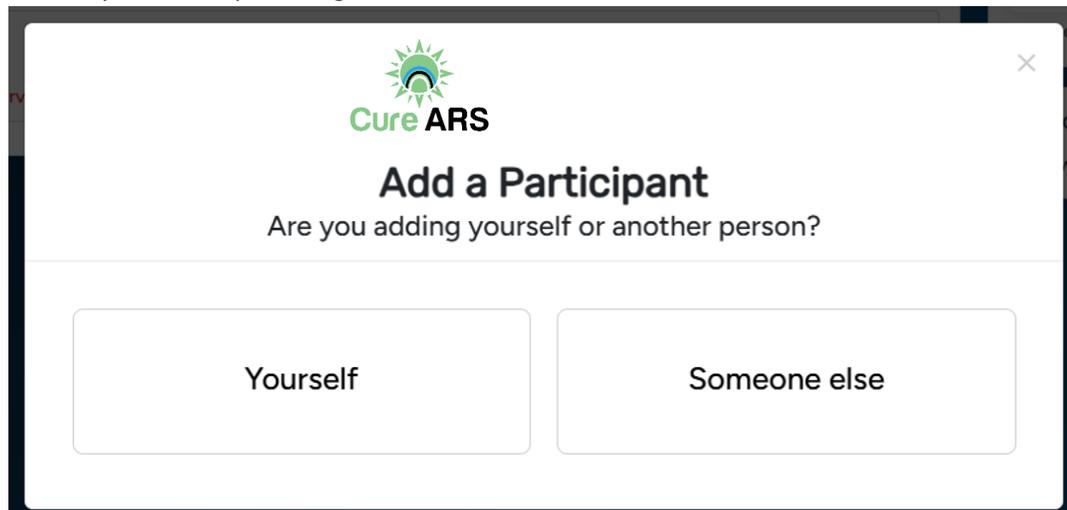


Add a Participant

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



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



- 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 *

What Is Your Relationship to ? * ?

Profile Image
 OR
No image selected

Consent to the Study

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



Thank you for registering your first participant!
Would you like to consent to participate in **CureARS MAPS Registry?**



- 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 CureARS MAPS Registry

Consent Overview

Those eligible to participate in our study include:

Participant: An individual diagnosed with a mitochondrial aminoacyl-tRNA synthetase (Mt-ARS) Disorder 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 a mitochondrial aminoacyl-tRNA synthetase (Mt-ARS) Disorder 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 a mitochondrial aminoacyl-tRNA synthetase (Mt-ARS) Disorder, defined as a spouse, parent, sibling, offspring, close relative, close friend, guardian and/or significant other of the individual who had Rare Disease 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.

Please tell us about the Participant you would like to enroll in this study. *

They are a minor or an adult who is unable to contribute their own data. I am currently their caregiver.

They were a patient with a mitochondrial aminoacyl-tRNA synthetase (Mt-ARS) Disorder. I participated in their medical care.

Next

Jane Smith

Consent to CureARS MAPS Registry

Consent for a Person with a Legally Authorized Representative (Caregiver)

Consent to Participate in the CureARS MAPS Registry and to Allow Data to be Shared for Future Research

Title: CureARS MAPS Registry

Co-Principal Investigator: Desiree Magee, Co-Founder of CureARS

Co-Principal Investigator: Ashley Rowland, Co-Founder of CureARS

Sponsor: CureARS

25422 Trabuco Road

Suite 105-237

Lake Forest, CA 92630

Phone: (949) 546-9443

Study Staff Email: registry@carears.org

Sponsor Study Number: Mt-ARS-MAPS-REG01

Key Information

You are invited to take part in a research study for individuals with a mitochondrial aminoacyl-tRNA synthetase (Mt-ARS) Disorder on behalf of the person in your care who is not able or no longer able to provide their own consent. Your role is called Legally Authorized Representative (LAR). We hope that this form will help you decide whether or not to participate, but you can also call or e-

Previous **Next**

Jane Smith

Consent to CureARS MAPS Registry

Authorization

The following statements are intended to:

- Make sure that you have had the time and opportunity to consider whether you and the Study Participant 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:

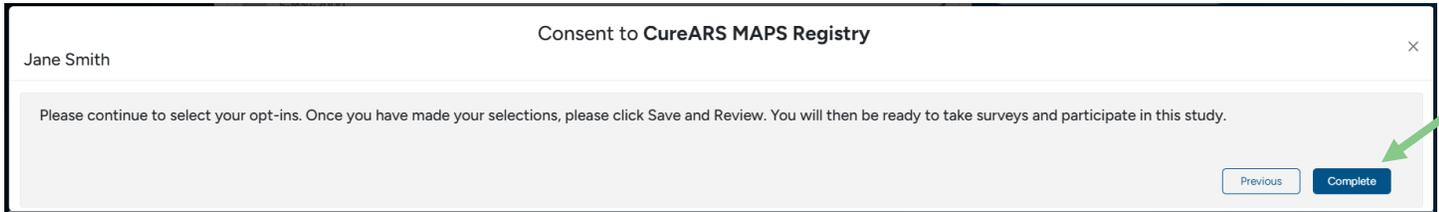
- That you have read the consent form and have no further questions about the registry and the Study Participant's participation;
- That you wish to provide the Study Participant's personal data to the registry for the purposes of the Study;
- That you allow for this data to be used for future research;
- That you have explained the study to the Study Participant to the extent they are able to understand; 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 all of the following statements, you are giving your consent to participate in the CureARS MAPS Registry on behalf of the Study Participant. After signing, a copy of the consent form will be e-mailed 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 the Study Participant's personal and medical data to be shared for the purpose of research. All my questions about the CureARS MAPS Registry have been answered to my satisfaction, and I understand the purpose of the registry and the risks of participation.

Previous **Next**

- Step 3: Once you click “Next” and reach the Thank You page, click “Complete”.



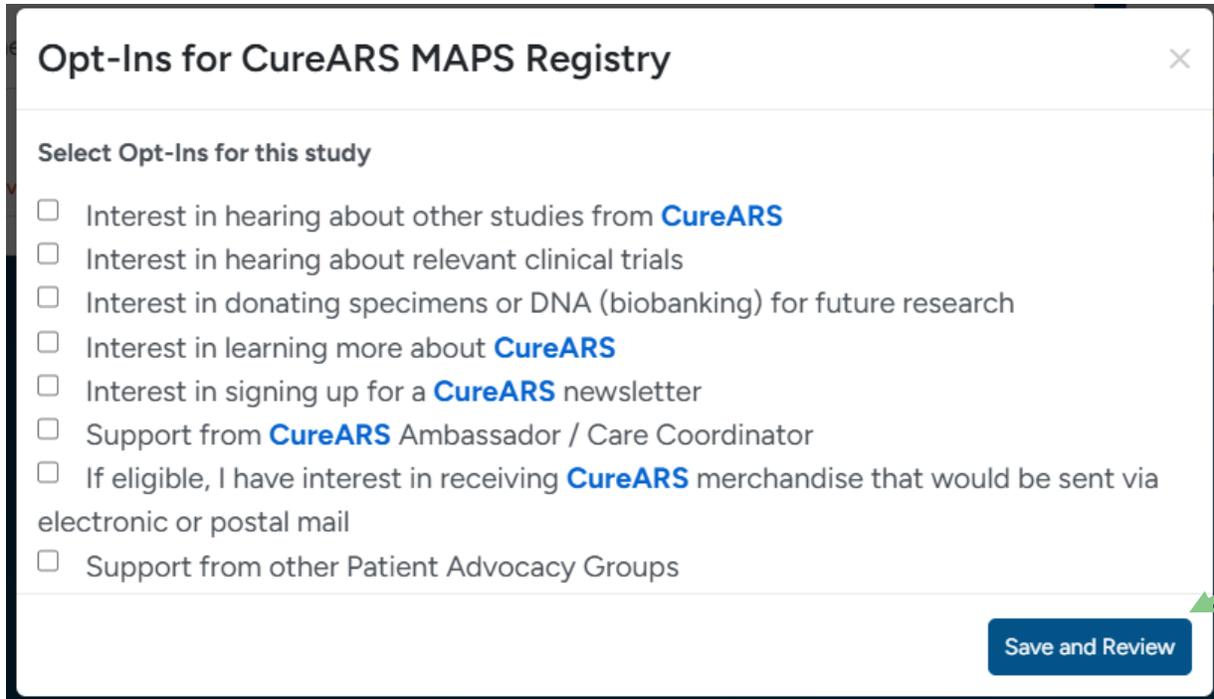
Consent to **CureARS MAPS Registry**

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 Complete

- Step 4: Once you click “Complete” 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 **CureARS MAPS Registry**

Select Opt-Ins for this study

- Interest in hearing about other studies from **CureARS**
- Interest in hearing about relevant clinical trials
- Interest in donating specimens or DNA (biobanking) for future research
- Interest in learning more about **CureARS**
- Interest in signing up for a **CureARS** newsletter
- Support from **CureARS** Ambassador / Care Coordinator
- If eligible, I have interest in receiving **CureARS** merchandise that would be sent via electronic or postal mail
- Support from other Patient Advocacy Groups

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 on your Participant.

The screenshot shows the IAMRARE user interface. At the top, there is a navigation bar with 'Home', 'Help', 'Settings', and a user profile 'Hi, Jane!'. Below the navigation bar, a greeting 'Good Morning, Jane!' is displayed along with 'Member since May 16, 2025' and an '+ Add Participant' button. The main content area is divided into two sections. On the left, under the heading 'Participants', there is a list of participants. The first entry is 'Jane Smith' with a date '5-May-2000' and a notification '1 pending surveys'. A green arrow points to the right arrow icon on the right side of this entry. On the right, there are two shortcut buttons: 'Request Transfer' and 'Consent/Opt-Ins'. Below these is a 'Notifications (0)' section with the text 'No new notifications.'

- Step 2: Click on the appropriate study.

The screenshot shows the 'Enrolled Studies' page for Jane Smith. At the top, there is a 'Back to participant list' link and a dropdown menu for 'Jane Smith' with the date '5-May-2000' and a 'Search Studies' button. The main content area is titled 'Enrolled Studies' and contains a list of studies. The first study is 'CureARS MAPS Registry' with a language filter 'English', a status 'Consented', and a notification '1 pending surveys'. A green arrow points to this study card. On the right, there are two shortcut buttons: 'Request Transfer' and 'Consent/Opt-Ins'. Below these is a 'Notifications (0)' section with the text 'No new notifications.'

- Step 3: Click "Take Survey" for an available survey.

The screenshot shows the details for the 'CureARS MAPS Registry' study. At the top, there is a 'Back to study list' link and a dropdown menu for 'Jane Smith' with the date '5-May-2000'. The study title 'CureARS MAPS Registry' is displayed, followed by 'Surveys' and a notification '1 pending'. Below this, there are three tabs: 'All (1)', 'Complete (0)', and 'Pending (1)'. The main content area shows a progress indicator '0% Getting Started' with the text 'Not Started' in red. A green arrow points to the 'Take Survey' button on the right side of the progress indicator.

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.

The screenshot shows the user interface for the CureARS MAPS Registry. At the top, the user's name 'Jane Smith' and birth date '5-May-2000' are displayed. Below this, the survey status is shown as '7 pending'. A filter bar indicates 'All (9)' surveys, with 'Complete (2)' and 'Pending (7)' options. Two survey cards are visible: 'Getting Started' (Completed on 16-May-2025) and 'CRID Survey' (Last Completed on 16-May-2025). Each card has a 'View Responses' button with a '1' notification and a 'Reports' button. The 'CRID Survey' card also has a 'Retake Survey' button. Green arrows point to the 'View Responses' and 'Retake Survey' buttons.

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.

The screenshot shows the 'Enrolled Studies' page. At the top, there is a 'Back to participant list' link and the user's name 'Jane Smith' with birth date '5-May-2000'. A 'Search Studies' button is located in the top right. The main content area has a heading 'Enrolled Studies' with a green arrow pointing to it. Below the heading is a brief instruction: '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.' To the right, there is a 'Shortcuts' section with two buttons: 'Request Transfer' and 'Consent/Opt-Ins', with a green arrow pointing to the latter.

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

The screenshot shows the 'Consents/Opt-Ins' page. At the top, there is a 'Back to study list' link and the user's name 'Jane Smith' with birth date '5-May-2000'. The main content area has a heading 'Consents/Opt-Ins' and a table with the following data:

Study Name	Consent Status	Consented On	Actions
CureARS MAPS Registry	✓ Consented	16-May-2025	View Consent Revoke Opt-Ins

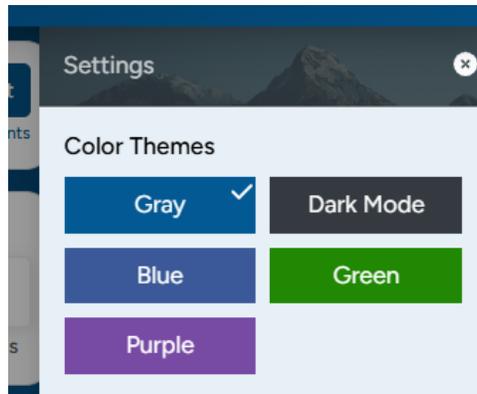
Green arrows point to the 'Revoke' and 'Opt-Ins' buttons in the Actions column.

Dark Mode Settings

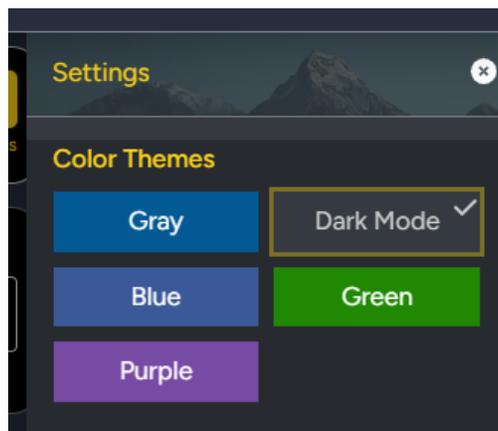
- Step 1: You can view the platform in Dark Mode. First, click Settings.



- Step 2: Select Dark Mode.



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

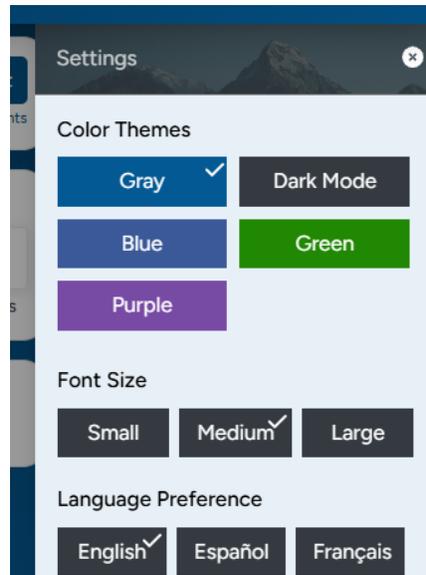


Display Settings

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



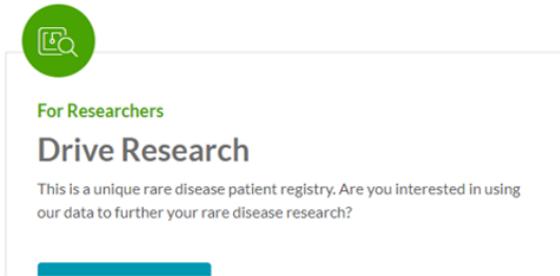
- Step 2: Select a color theme, a font size, or language preference.



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

Microsite Visibility

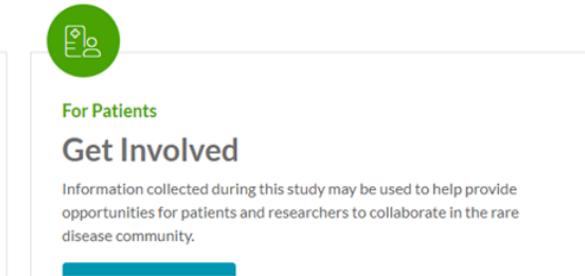
- Step 1: You can change how you view the microsite curears-maps-registry.iamrare.org using an Accessibility menu. Click the icon of a person at the bottom of the screen. You are able to change the settings such as the contrast, text sizing, and text spacing.



For Researchers

Drive Research

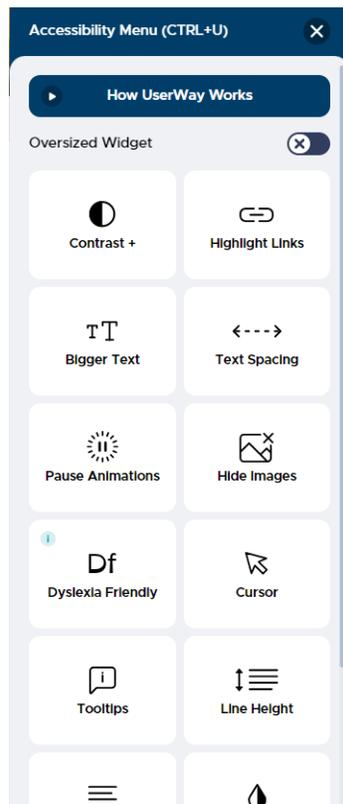
This is a unique rare disease patient registry. Are you interested in using our data to further your rare disease research?



For Patients

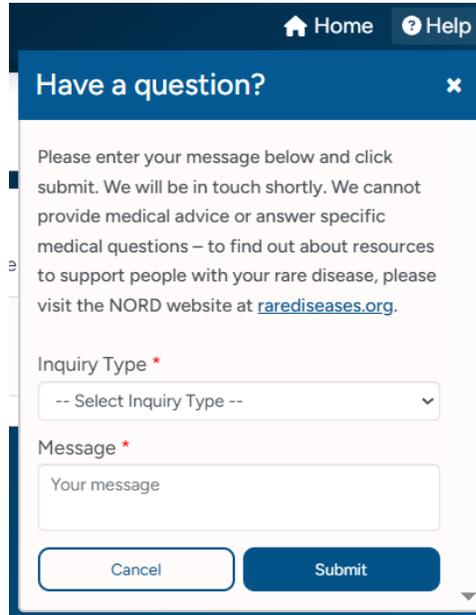
Get Involved

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



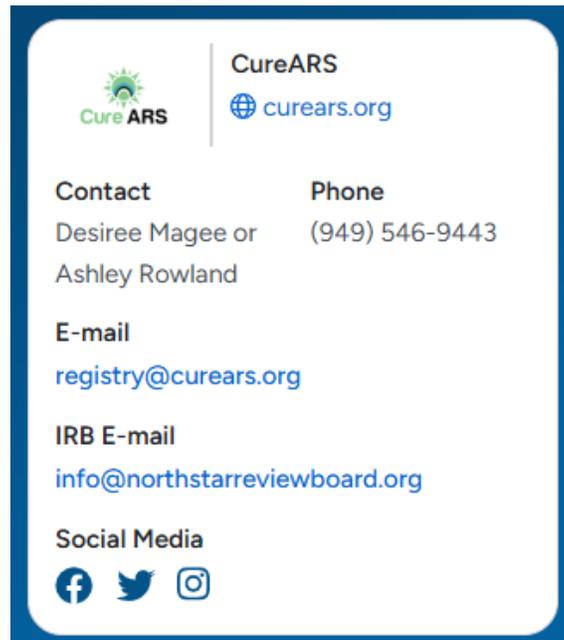
Need Assistance?

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



The screenshot shows a mobile application interface with a dark blue header containing a home icon and a 'Help' button with a question mark icon. Below the header is a white modal window titled 'Have a question?' with a close button (X) in the top right corner. 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 for 'Inquiry Type' with the placeholder text '-- Select Inquiry Type --'. Underneath is a text input field for '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 screenshot shows a contact information card for CureARS. The card has a white background with a blue border. At the top left is the CureARS logo, which consists of a green sun-like icon and the text 'CureARS'. To the right of the logo is the text 'CureARS' and the website address 'curears.org' with a globe icon. Below this, the card is organized into sections: 'Contact' with the names 'Desiree Magee or Ashley Rowland', 'Phone' with the number '(949) 546-9443', 'E-mail' with the address 'registry@curears.org', 'IRB E-mail' with the address 'info@northstarreviewboard.org', and 'Social Media' with icons for Facebook, Twitter, and Instagram.