

CADASIL Community Natural History Study Participant User Guide

This user guide provides step-by-step instructions for registering an account for yourself, as a participant in the CADASIL Community Natural History Study.

The CADASIL Community Natural History Study consists of 7 surveys, each with multiple questions. A test conducted by several CADASIL patients showed that it takes on average, about 30 minutes to complete all 7 surveys.

To reduce the time to complete the surveys, we recommend that you assemble several pieces of information in advance so that you can be prepared to answer a few questions that require detailed responses.

1. The year you were first told you have CADASIL, if ever.
2. The year(s) you experienced CADASIL symptoms, if any.
3. The year and location (hospital/outpatient clinic) where your most recent MRI was done, if any.
4. The year and location (hospital/outpatient clinic) your most recent skin biopsy was done, if any.
5. A list of medications (including vitamins and supplements) you currently take.
6. The report of your genetic blood test results, if you have one. We ask that you upload the report. If you don't have a copy of the report, but can obtain it, then you can upload it at a later date.

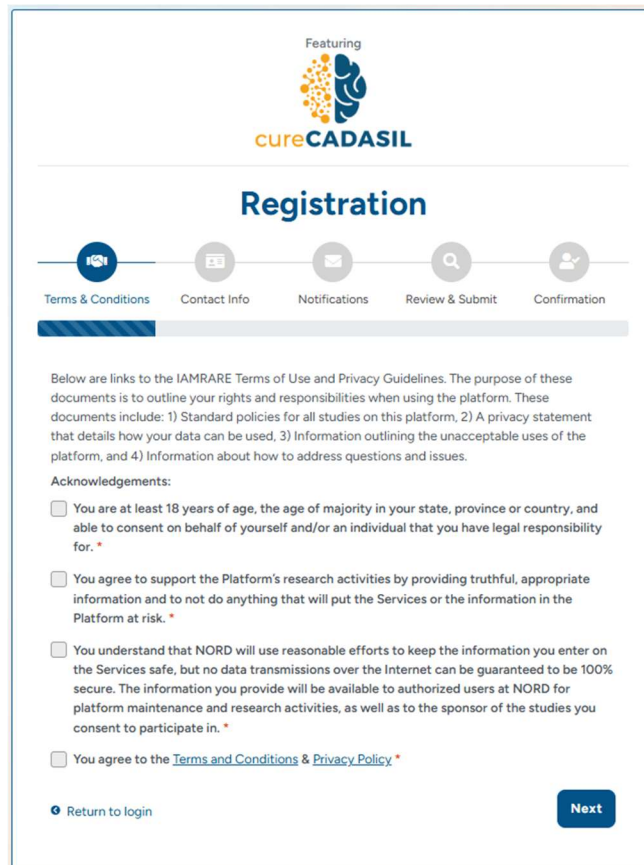
In overview, the detailed steps in this user guide can be summarized as follows:

- Register for an account by entering your contact information. You will receive an email with a link. Click on the link to select a password and activate your account.
- Once activated, log in and select the option to “Create a New Profile” for “Yourself”. Then, complete the consent to participate in the study.
- After consenting, choose specific “opt-ins” to express interest in receiving information about or participating in CADASIL research.
- Proceed to take the surveys. After you submit your responses to a survey, you can review your responses, and you can review reports that show graphs summarizing the responses of all participants who completed the survey.

Please use the following step-by-step instructions to register and take the study surveys:

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 first step of the registration process. At the top, it features the 'Featuring cureCADASIL' logo. Below the logo is a progress bar with five steps: 'Terms & Conditions' (active), 'Contact Info', 'Notifications', 'Review & Submit', and 'Confirmation'. The main content area contains a paragraph explaining the purpose of the Terms of Use and Privacy Guidelines. Below this, there are four checkboxes for acknowledgements, each followed by a detailed statement. At the bottom left is a 'Return to login' link, and at the bottom right is a blue 'Next' button.

Featuring
cureCADASIL

Registration

Terms & Conditions Contact Info Notifications Review & Submit Confirmation

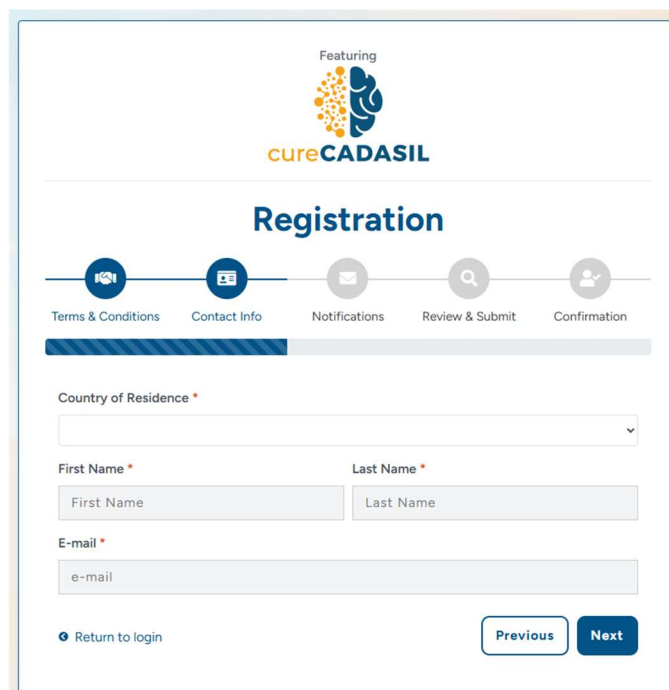
Below are links to the IAMRARE Terms of Use and Privacy Guidelines. The purpose of these documents is to outline your rights and responsibilities when using the platform. These documents include: 1) Standard policies for all studies on this platform, 2) A privacy statement that details how your data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



The screenshot shows the second step of the registration process. It features the same 'Featuring cureCADASIL' logo and progress bar as the first step. The 'Contact Info' step is now active. The form contains three input fields: 'Country of Residence' (a dropdown menu), 'First Name' (a text box), and 'Last Name' (a text box). Below these is an 'E-mail' input field. At the bottom left is a 'Return to login' link, and at the bottom right are 'Previous' and 'Next' buttons.

Featuring
cureCADASIL

Registration

Terms & Conditions Contact Info Notifications Review & Submit Confirmation

Country of Residence *

First Name * Last Name *

E-mail *

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

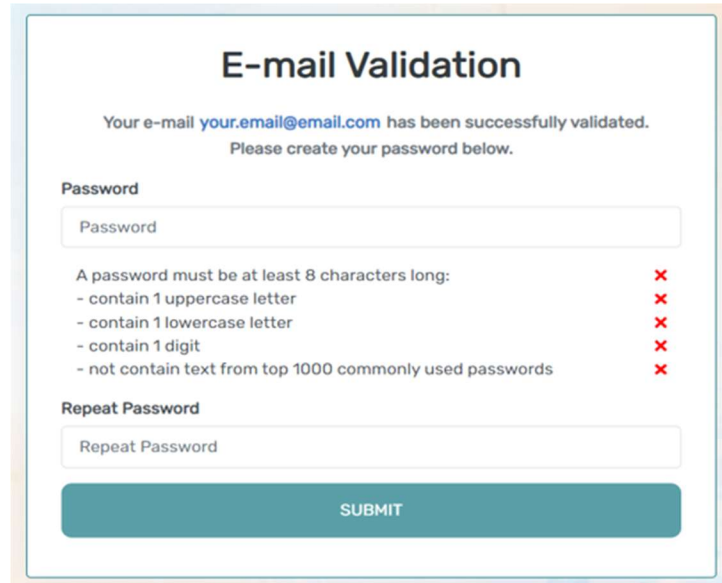
- Step 3: Select whether you are interested in being contacted by NORD regarding available studies. When you are finished with this page, click “Next”.

The screenshot shows the 'Registration' page for cureCADASIL. At the top, it says 'Featuring' above the cureCADASIL logo. Below the logo, the word 'Registration' is centered. A progress bar with five steps is shown: 'Terms & Conditions', 'Contact Info', 'Notifications', 'Review & Submit', and 'Confirmation'. The 'Notifications' step is currently active, indicated by a blue bar under the progress bar. Below the progress bar, there is a text input field with the placeholder text 'I am interested in NORD contacting me regarding available studies. *'. Below this field are two radio buttons: 'Yes' and 'No'. At the bottom left, there is a link 'Return to login'. At the bottom right, there 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 cureCADASIL, now at Step 4. The progress bar shows that the 'Review & Submit' step is now active. Below the progress bar, there is a text input field with the placeholder text 'An activation link will be sent to youremail@email.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'. An orange 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 [your.email@email.com](#) has been successfully validated.
Please create your password below.

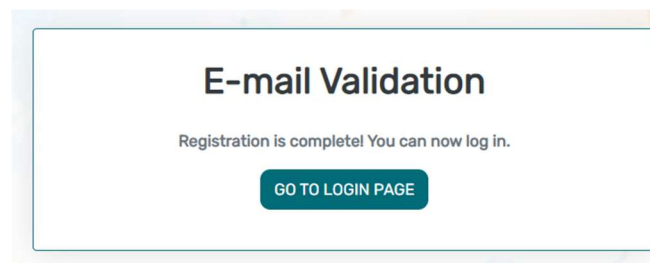
Password

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”.

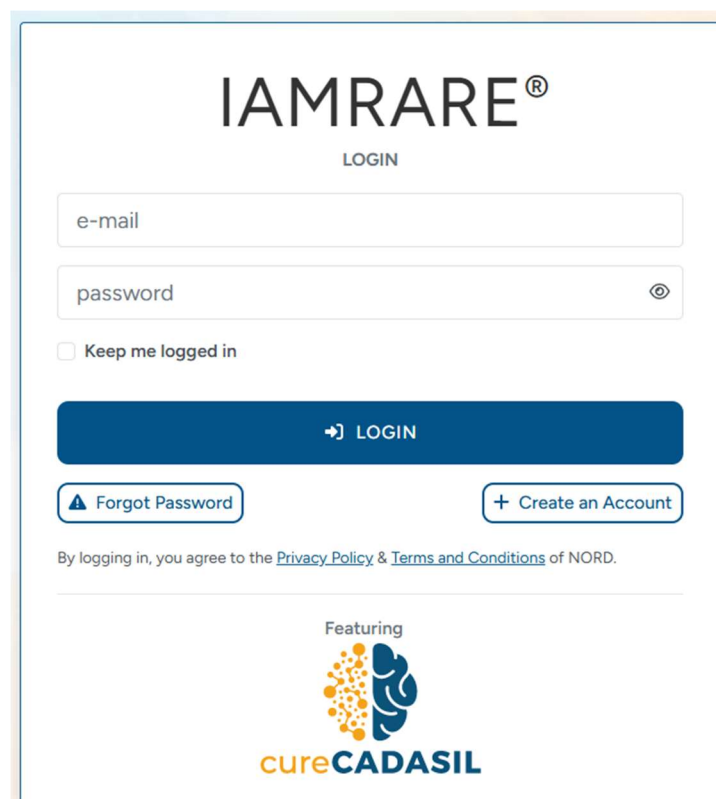


E-mail Validation

Registration is complete! You can now log in.

GO TO LOGIN PAGE

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



IAMRARE®

LOGIN


☐ Keep me logged in

LOGIN

[Forgot Password](#) [+ Create an Account](#)

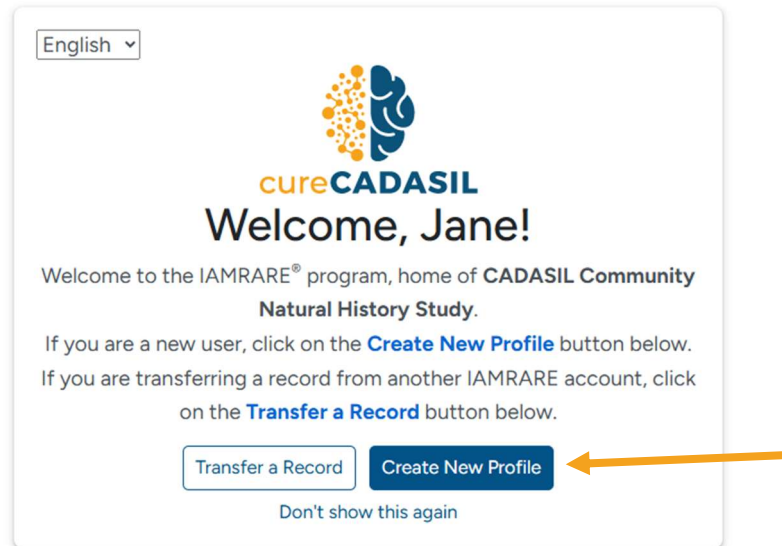
By logging in, you agree to the [Privacy Policy](#) & [Terms and Conditions](#) of NORD.

Featuring


cureCADASIL

Add a Participant

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



English ▾

cureCADASIL

Welcome, Jane!

Welcome to the IAMRARE® program, home of **CADASIL Community Natural History Study**.

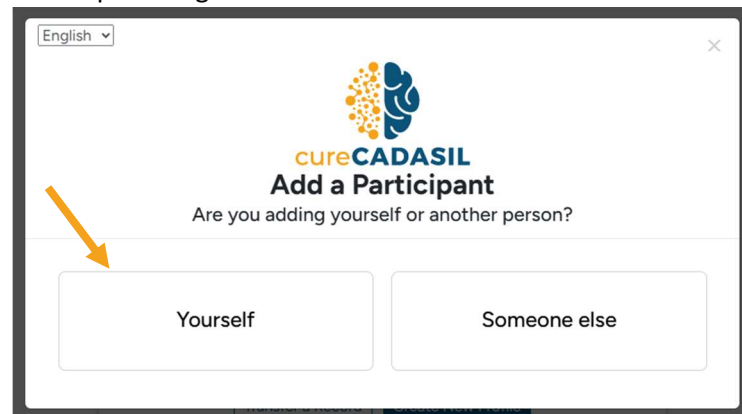
If you are a new user, click on the **Create New Profile** button below.

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 ▾

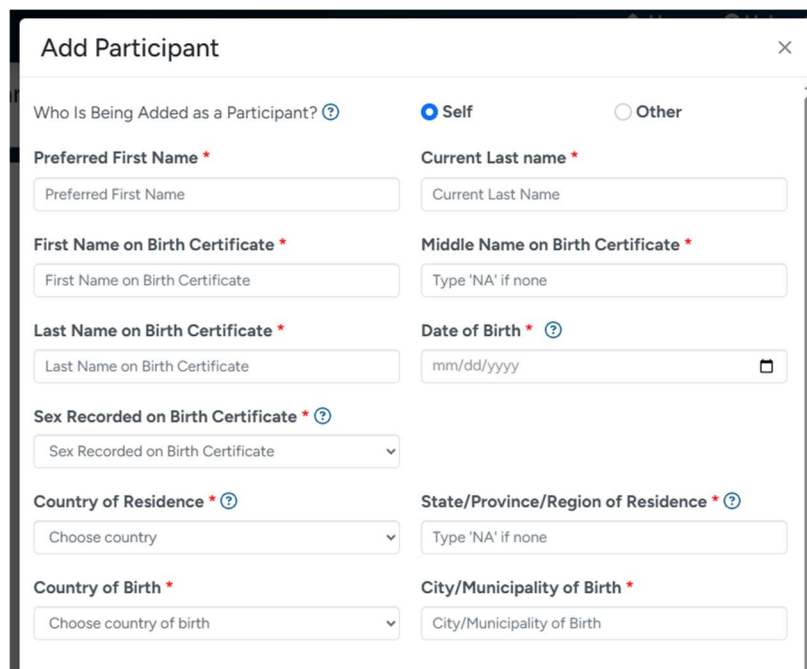
cureCADASIL

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 *

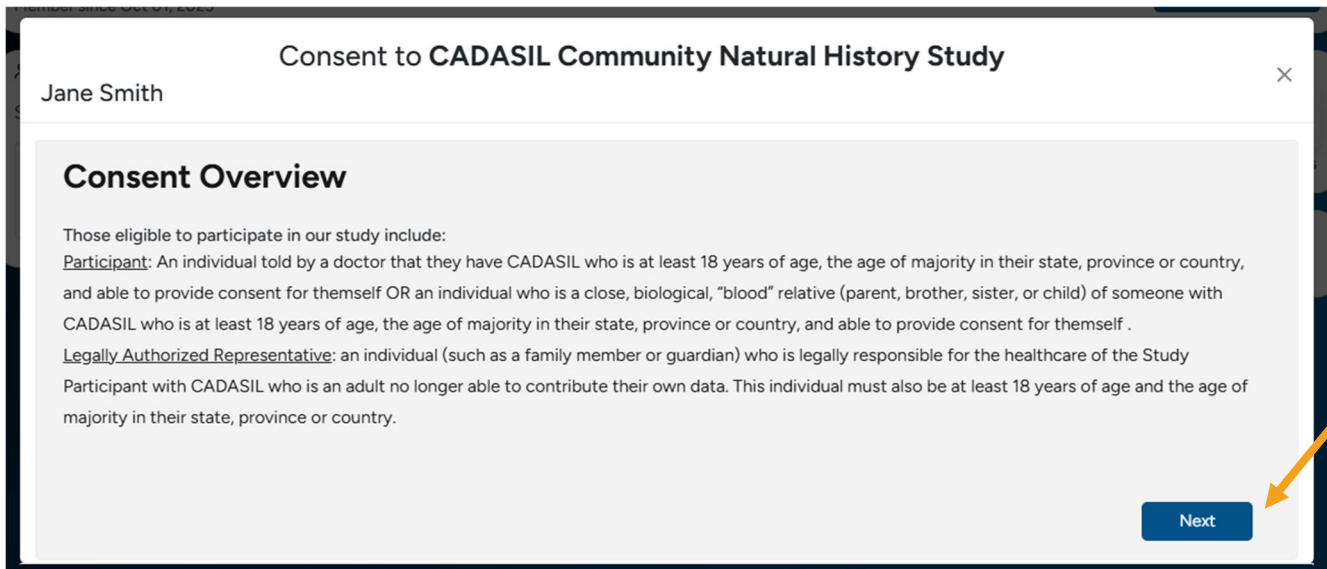
Consent to the Study

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



A white rectangular dialog box with a dark blue border. At the top center is the logo for 'cureCADASIL', which consists of a stylized brain with orange dots on the left and a blue brain silhouette on the right. Below the logo, the text reads: 'Thank you for registering your first participant!' followed by 'Would you like to consent to participate in **CADASIL Community Natural History Study?**'. At the bottom, there are two buttons: 'Not right now' (white with a blue border) and 'Yes, complete consent for this participant.' (solid blue). An orange arrow points to the blue button. A close button (X) is in the top right corner.

- 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.”



A white rectangular form with a dark blue border. The title at the top is 'Consent to **CADASIL Community Natural History Study**'. Below the title, the name 'Jane Smith' is displayed. The main section is titled 'Consent Overview' and contains the following text: 'Those eligible to participate in our study include: Participant: An individual told by a doctor that they have CADASIL 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 OR an individual who is a close, biological, “blood” relative (parent, brother, sister, or child) of someone with CADASIL 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 CADASIL who is an adult no longer able 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.' At the bottom right, there is a blue button labeled 'Next'. An orange arrow points to the 'Next' button. A close button (X) is in the top right corner.

Consent to CADASIL Community Natural History Study

Jane Smith



Adult Consent

Consent to Participate in the CADASIL Community Natural History Study and to Allow Your Data to be Shared for Future Research

Title: CADASIL Community Natural History Study

Principal Investigator: Vinita Bahl

E-mail: info@curecadasil.org

Sponsor: cureCADASIL

Address: P.O. Box 390023; Edina, MN 55439

Key Information

You are invited to take part in this research study to benefit individuals with CADASIL. Those eligible to participate must be at least 18 years of age, able to understand survey questions and this consent document. You must have a diagnosis of CADASIL (Cerebral Autosomal Dominant Arteriopathy with Subcortical Infarcts and Leukoencephalopathy) or a mother, father, brother, sister, son, or daughter with CADASIL. We hope that this form will help you decide whether or not to participate, but you can also call or e-mail the

Previous

Next



Consent to CADASIL Community Natural History Study

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 all of the following statements, you are giving your consent to participate in the CADASIL Community Natural History Study 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.

Previous

Next



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

- 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.

The screenshot shows the user profile for Jane Smith (5-May-2000) at the top. Below is the 'CADASIL Community Natural History Study' section. It displays 'Surveys' with a '4 pending' status. There are two survey entries: 'Getting Started' and 'Demographics', both marked as 'Completed on 1-Oct-2025'. For each survey, there are buttons for 'View Responses' (with a circled '1') and 'Reports'. Orange arrows point from the survey names to their respective 'View Responses' 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 for Jane Smith. At the top, there is a 'Back to participant list' link and a 'Search Studies' button. Below the participant information, there is a section for 'Enrolled Studies' with instructions: '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'. Orange arrows point to the 'Enrolled Studies' section and the 'Consent/Opt-Ins' shortcut button.

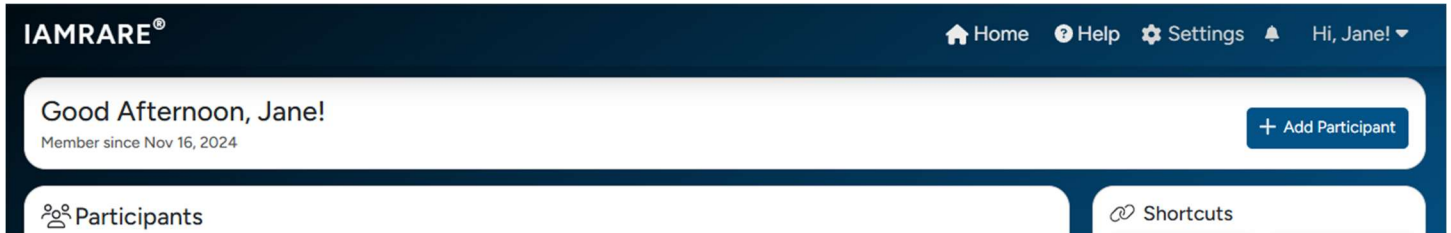
- Step 2: You may revoke your consent at any time by clicking “Revoke”. You may also edit your Opt-Ins by clicking “Opt-Ins”.

The screenshot shows the 'Consents/Opt-Ins' page for Jane Smith. It features a table with the following columns: 'Study Name', 'Consent Status', 'Consented On', and 'Actions'. The table contains one row for the 'CADASIL Community Natural History Study' with a 'Consented' status and a date of '1-Oct-2025'. In the 'Actions' column, there are three buttons: 'View Consent', 'Revoke', and 'Opt-Ins'. Orange arrows point to the 'Revoke' and 'Opt-Ins' buttons.

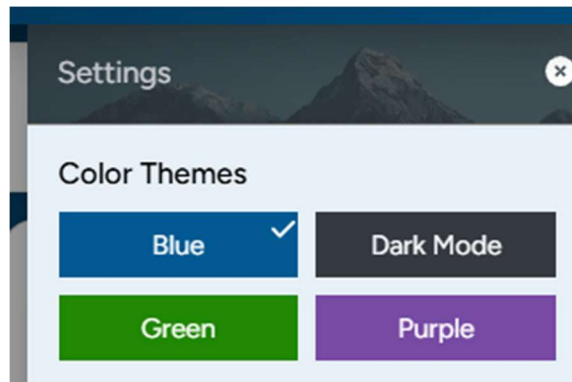
Study Name	Consent Status	Consented On	Actions
CADASIL Community Natural History Study	✓ Consented	1-Oct-2025	View Consent Revoke Opt-Ins

Dark Mode Settings

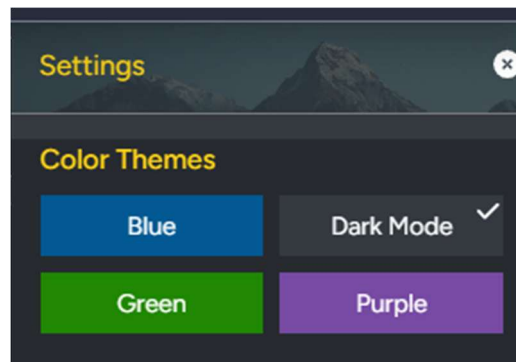
- Step 1: You can view the platform in Dark Mode. First, click Settings.



- Step 2: Select Dark Mode.



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

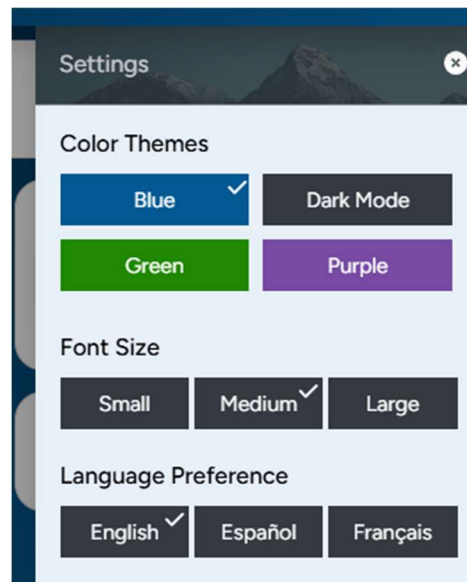


Display Settings

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



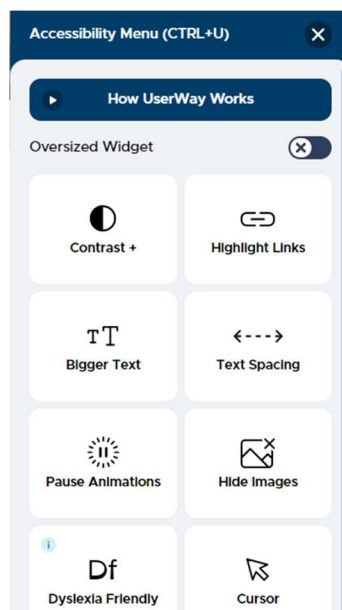
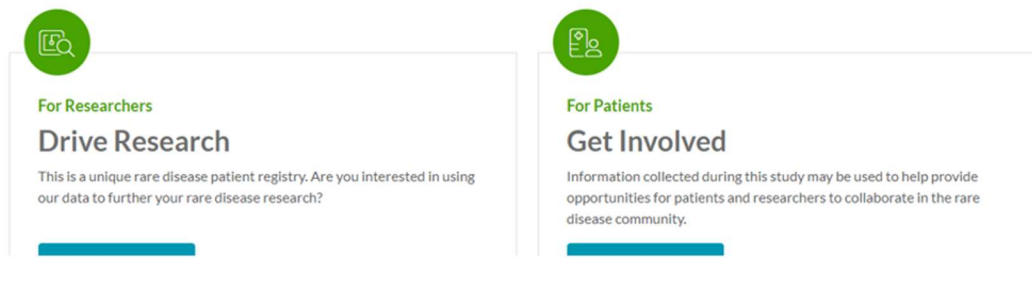
- Step 2: Select a color theme, a font size, or language preference.



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

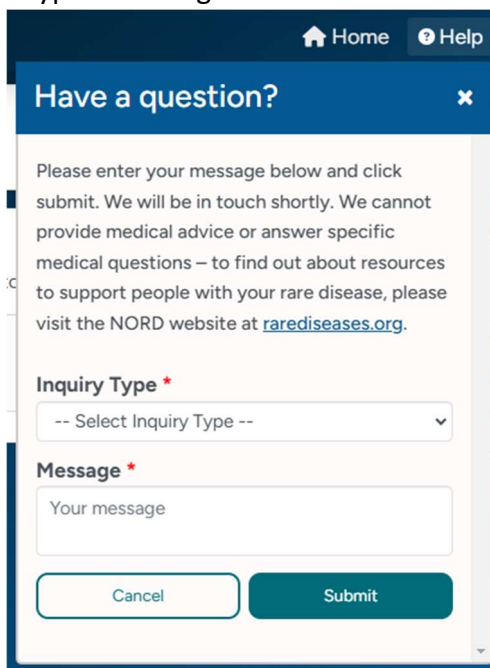
Microsite Visibility

- 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 mobile application interface with a dark blue header containing 'Home' and 'Help' icons. Below the header is a white modal box titled 'Have a question?' with a close button (X). The modal contains 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 text is a dropdown menu labeled 'Inquiry Type *' with the placeholder text '-- Select Inquiry Type --'. Underneath the dropdown 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 screenshot shows a contact information page for cureCADASIL. At the top left is the cureCADASIL logo, which consists of a stylized brain made of orange dots and the text 'cureCADASIL'. To the right of the logo is the text 'cureCADASIL' and 'cureCADASIL.org' with a globe icon. Below this is the heading 'Contact' followed by 'Vinita Bahl'. Underneath is the heading 'E-mail' followed by the email address 'info@curecadasil.org'. Below that is the heading 'IRB E-mail' followed by the email address 'info@northstarreviewboard.org'. At the bottom is the heading 'Social Media' followed by icons for Facebook, Twitter, and Instagram.