



EHE Global Patient 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”.

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](#) and [Privacy Policy](#) and have read the [Consumer Health Data Privacy Notice](#). *

[Return to login](#)

Next

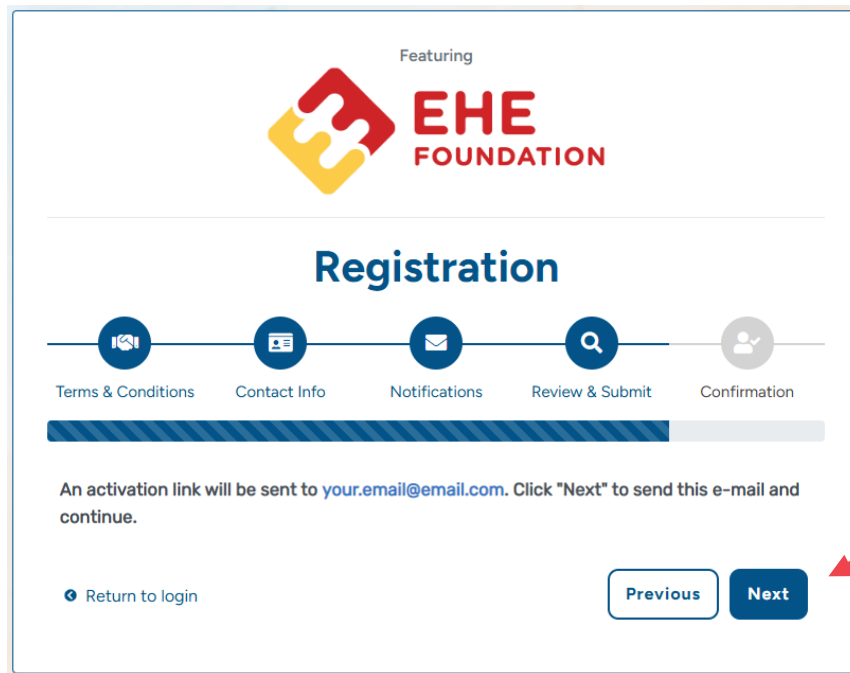
- Step 2: Enter your personal information in the spaces provided. When you are finished with this page, click “Next”.

The screenshot shows the 'Registration' page for the EHE Foundation. At the top, it says 'Featuring' above the EHE Foundation logo, which consists of a yellow and red puzzle piece icon and the text 'EHE FOUNDATION'. Below the logo is a progress bar with five steps: 'Terms & Conditions', 'Contact Info', 'Notifications', 'Review & Submit', and 'Confirmation'. The 'Contact Info' step is currently active, indicated by a blue bar under the first step and a blue circle icon above the 'Contact Info' label. The form fields include: 'Country of Residence *' (a dropdown menu), 'First Name *' (a text input field with 'First Name' as a placeholder), 'Last Name *' (a text input field with 'Last Name' as a placeholder), and 'E-mail *' (a text input field with 'e-mail' as a placeholder). At the bottom left is a link 'Return to login' with a circular arrow icon. At the bottom right are two buttons: 'Previous' (a light blue button) and 'Next' (a dark blue button).

- 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 the EHE Foundation, specifically Step 3. The header and logo are the same as in Step 2. The progress bar shows the 'Notifications' step as the current active step, with a blue bar under the second step and a blue circle icon above the 'Notifications' label. The form field is: 'I am interested in NORD contacting me regarding available studies. *' (a text input field). Below this field are two radio buttons: 'Yes' and 'No'. At the bottom left is a link 'Return to login' with a circular arrow icon. At the bottom right are two buttons: 'Previous' (a light blue button) and 'Next' (a dark blue button).

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



Featuring



Registration

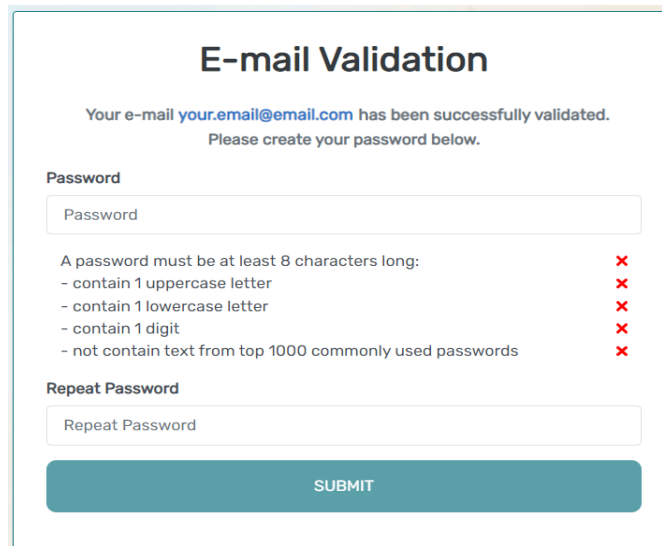
Terms & Conditions Contact Info Notifications Review & Submit Confirmation

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

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



E-mail Validation

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

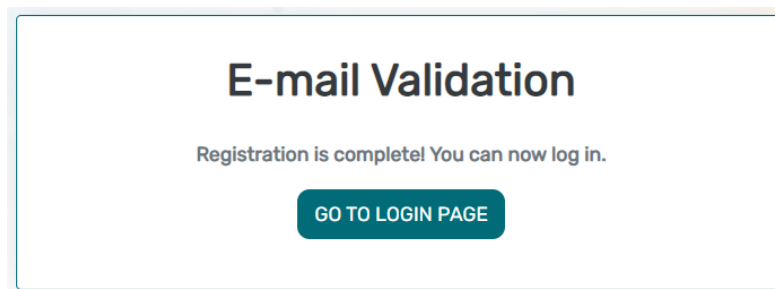
Password

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 ×

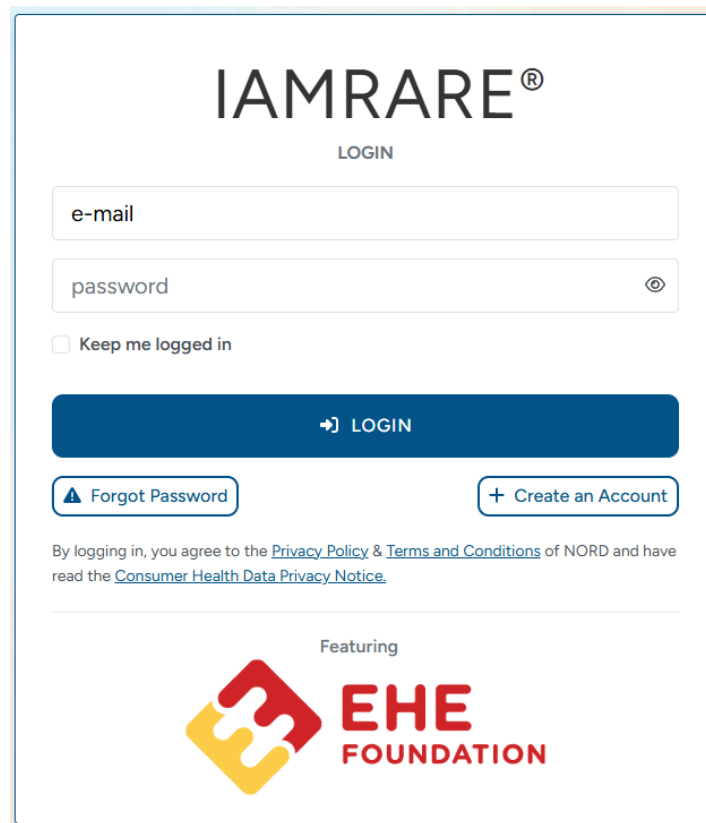
Repeat Password

[SUBMIT](#)

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

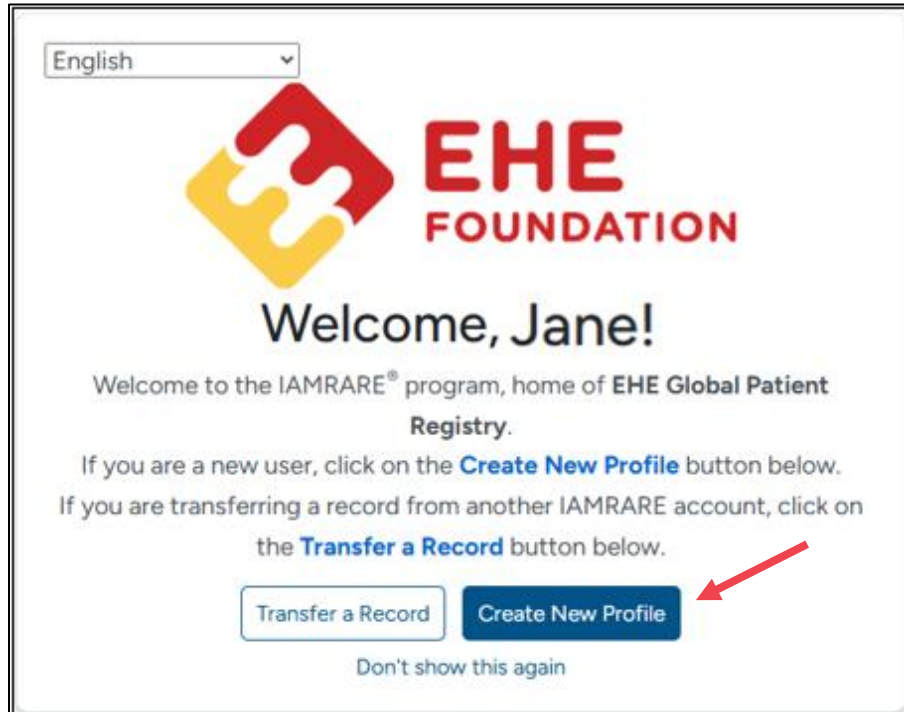


- Step 7: Log in using your new e-mail and password.

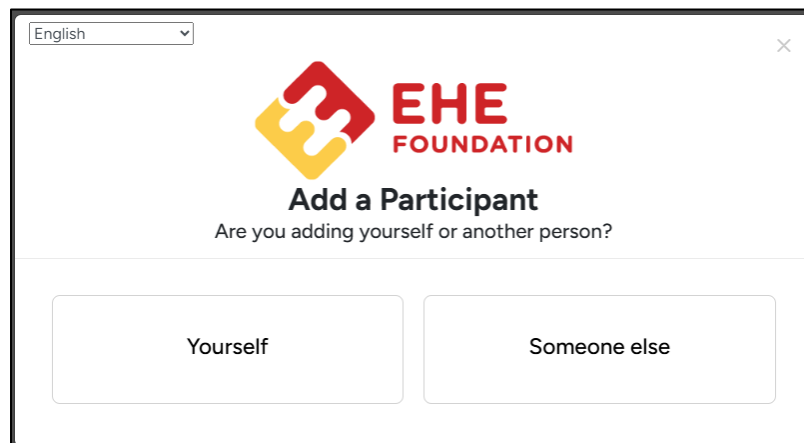
The login page for IAMRARE. At the top is the "IAMRARE®" logo and the word "LOGIN". Below are input fields for "e-mail" and "password" (with a toggle icon). A checkbox labeled "Keep me logged in" is present. A large blue "LOGIN" button is in the center. Below it are links for "Forgot Password" and "Create an Account". A disclaimer states: "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 bottom, it says "Featuring" above the "EHE FOUNDATION" logo, which consists of a red and yellow puzzle piece icon and the text "EHE FOUNDATION".

Add a Participant

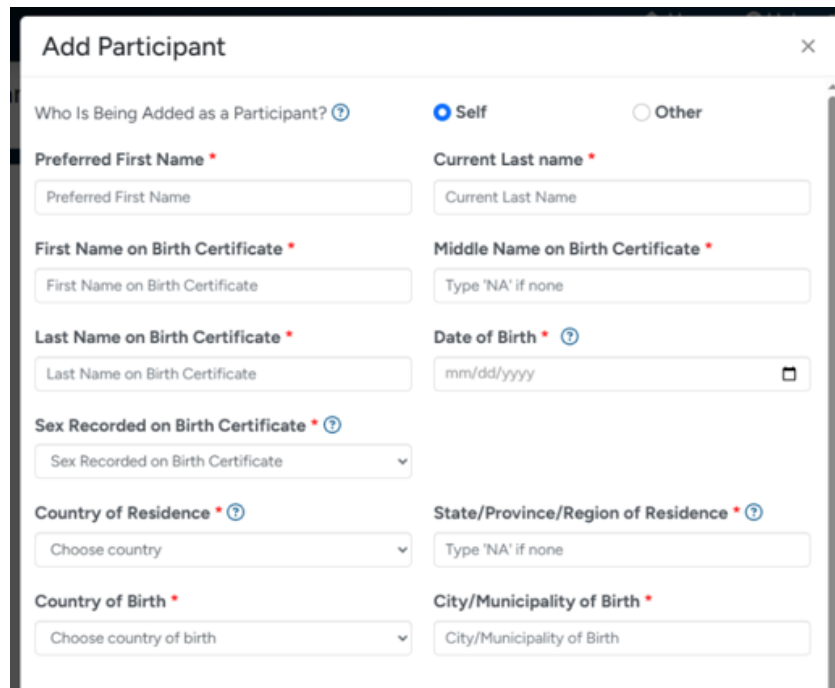
- Step 1: To start, click Create New Profile.



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



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



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 and includes the following fields:

- Who Is Being Added as a Participant?**: Radio buttons for 'Self' (selected) and 'Other'.
- Preferred First Name ***: Text input field.
- Current Last name ***: Text input field.
- First Name on Birth Certificate ***: Text input field.
- Middle Name on Birth Certificate ***: Text input field with a placeholder 'Type 'NA' if none'.
- Last Name on Birth Certificate ***: Text input field.
- Date of Birth ***: Date picker with a placeholder 'mm/dd/yyyy' and a calendar icon.
- Sex Recorded on Birth Certificate ***: Dropdown menu with a question mark icon.
- Country of Residence ***: Dropdown menu with a question mark icon.
- State/Province/Region of Residence ***: Text input field with a placeholder 'Type 'NA' if none' and a question mark icon.
- Country of Birth ***: Dropdown menu.
- City/Municipality of Birth ***: Text input field.

Consent to the Study

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



The EHE Foundation consent screen features the organization's logo (a stylized red and yellow puzzle piece) and the text 'EHE FOUNDATION'. Below the logo, the text reads: 'Thank you for registering your first participant! Would you like to consent to participate in EHE Global 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.

- Step 2: Scroll down and read through the consent form thoroughly. Once you finish reading, click the “Next” button.

Jane Smith

Consent to EHE Global Patient Registry

×

Consent Overview

Those eligible to participate in our study include:

Participant: An individual diagnosed with Epithelioid Hemangioendothelioma (EHE) 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 from EHE, defined as a spouse, parent, sibling, offspring, close relative, close friend, guardian and/or significant other of the individual who had EHE 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

Jane Smith

Consent to EHE Global Patient Registry

×

Adult Consent

Consent to Participate in The EHE Global Patient Registry and to Allow Your Data to be Shared for Future Research

Title: EHE Global Patient Registry: A Natural History Study of Epithelioid Hemangioendothelioma

Principal Investigator: Denise Robinson

Phone: 1-877-460-4240, Ext 704

Email: Registry@FightEHE.org

Sponsor: The EHE Foundation

Key Information

You are being invited to take part in a global patient registry, which is a research study for people diagnosed with Epithelioid Hemangioendothelioma (EHE). The study is called the EHE Global Patient Registry, and also is referred to as the “Registry” in this form. This form contains information that will help you decide whether to join the study.

For the purpose of enrolling in this registry, a legal adult is defined as a person who is at least 18 years of age, the age of majority in their state, province or country, and able to consent for themselves. Throughout this form and in the Registry the terms “Study Participant” and “You” refer to the person of legal age diagnosed with EHE and whose information will be collected in the Registry. “Sponsor” or “We” refers to The EHE Foundation, the organization who has initiated this research study. The EHE Foundation is a non-profit organization with the mission to seek treatments and a cure for EHE.

Things you should know:

- The purpose of the study is to collect and store basic demographic and medical information about people who have been diagnosed with EHE.
- If you choose to take part, you will be asked to fill out questionnaires about you, including personal information, your medical history, your EHE diagnosis and presentation, and any treatments you have had. You can take as much time as you need to complete questions in the Registry.

Previous

Next

- Step 3: Once you click “Next” and 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 EHE Global 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.

You will be asked to acknowledge that you:

- Have read the consent form and have no further questions about the Registry and your participation;
- Wish to provide personal data to the Registry for the purposes of the Study;
- Allow for your data to be used for future research, and
- 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 EHE Global 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 EHE Global 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 information to the EHE Global Patient Registry for the purposes described above under Study Aims.

Previous Next

- Step 4: Once you click “Next” and reach the Thank You page, click “Continue to Opt-Ins”.

Jane Smith

Consent to EHE Global 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 5: 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 EHE Global Patient Registry

Select Opt-Ins for this study

- ☐ Interest in hearing about other studies from The EHE Foundation
- ☐ Interest in hearing about relevant clinical trials
- ☐ Interest in donating specimens or DNA (biobanking) for future research
- ☐ Interest in learning more about The EHE Foundation

Save and Review

- Step 6: 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® dashboard. At the top, there's a navigation bar with 'Home', 'Help', 'Settings', and a user profile 'Hi, Jane!'. Below the navigation bar, a greeting 'Good Afternoon, Jane!' is displayed along with 'Member since Mar 28, 2025'. On the right, there's a '+ Add Participant' button. The main section is titled 'Participants' and includes instructions: 'Select a participant to view their studies. Click on the "Add Participant" button above to add a participant.' Below this, there's a list of participants. The first participant is 'Jane Smith', with a date '5-May-2000' and a status '1 pending surveys'. A red arrow points to the 'Add Participant' button.

- Step 2: Click on the appropriate study.

The screenshot shows the 'Enrolled Studies' section for Jane Smith. At the top, there's a 'Back to the participant list' link. Below it, there's a dropdown menu for 'Jane Smith' and a 'Search Studies' button. The main section is titled 'Enrolled Studies' and includes 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.' Below this, there's a list of studies. The first study is 'EHE Global Patient Registry', with a date '5-May-2000' and a status '1 pending surveys'. A red arrow points to the 'EHE Global Patient Registry' study.

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

The screenshot shows the 'EHE Global Patient Registry' study details. At the top, there's a 'Back to the study list' link. Below it, there's a dropdown menu for 'Jane Smith' and a 'Search Studies' button. The main section is titled 'EHE Global Patient Registry' and includes a 'Surveys' section with a status '1 pending'. Below this, there's a list of surveys. The first survey is 'Getting Started and Demographics', with a date '5-May-2000' and a status 'Not Started'. A red arrow points to the 'Take Survey' button.

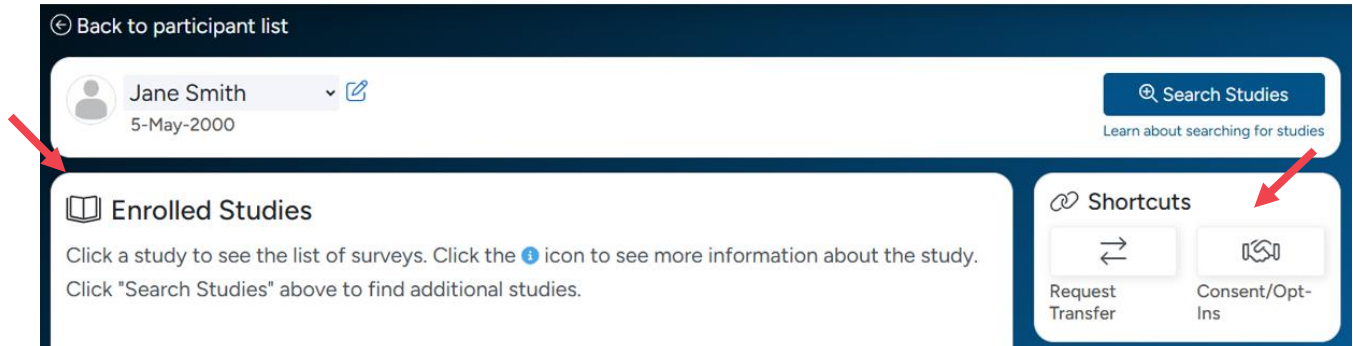
View Responses and Reports

- 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.

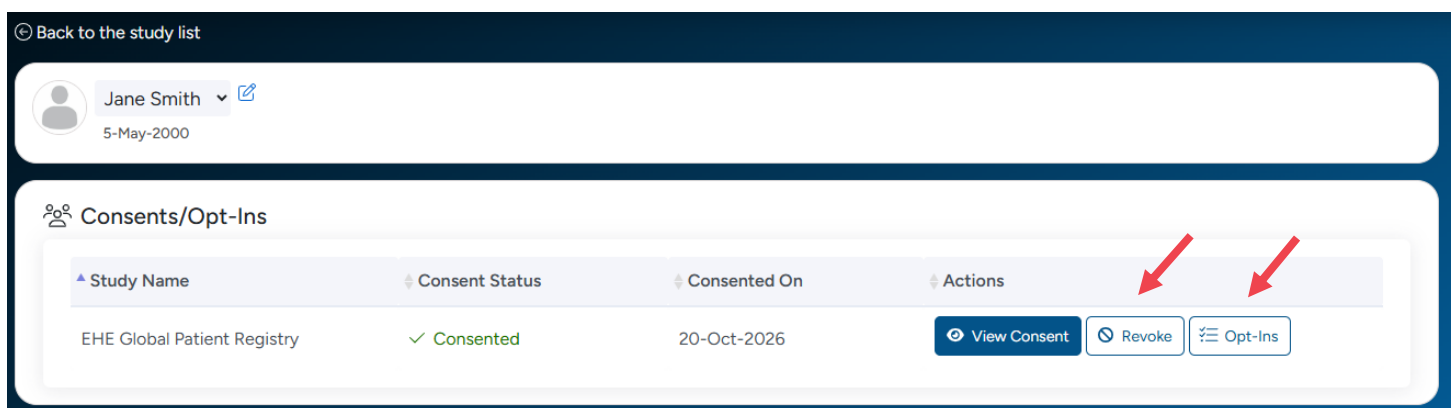


View Consent and Opt-Ins

- 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”.

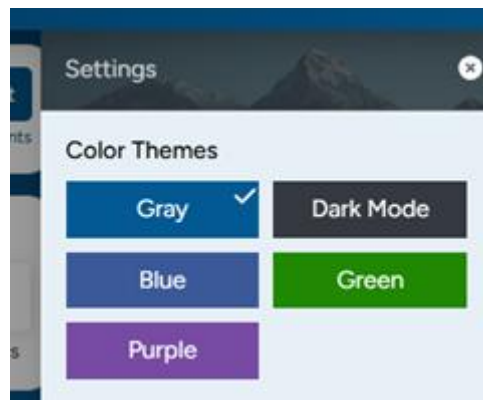


Dark Mode Settings

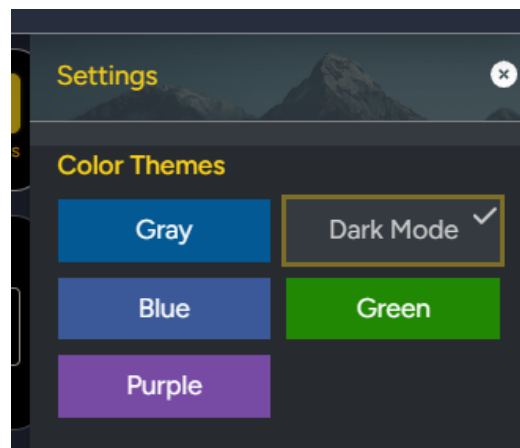
- Step 1: You can view the platform in Dark Mode. First, click Settings.



- Step 2: Select Dark Mode.



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

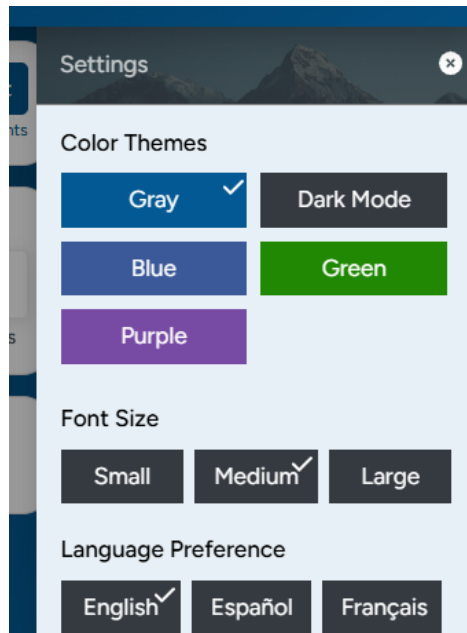


Display Settings

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



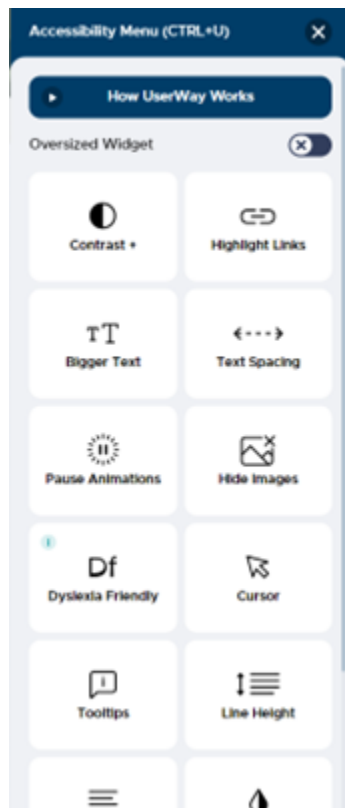
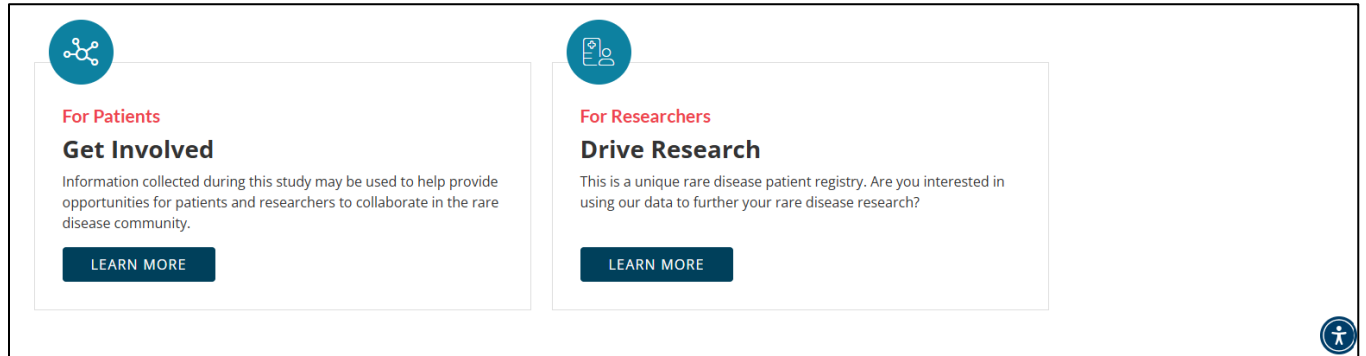
- Step 2: Select a color theme, a font size, or language preference.



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

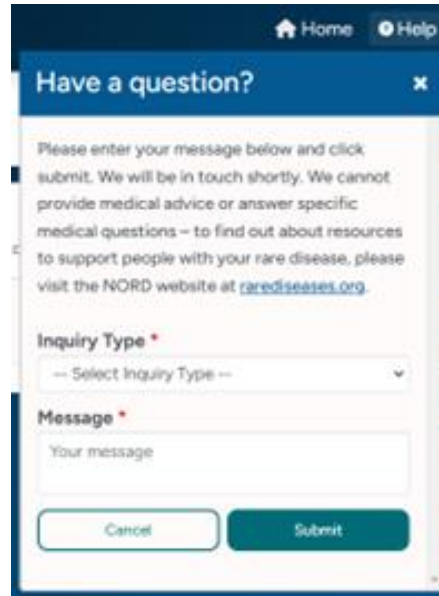
Microsite Visibility

- Step 1: You can change how you view the microsite (eheregistry.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.



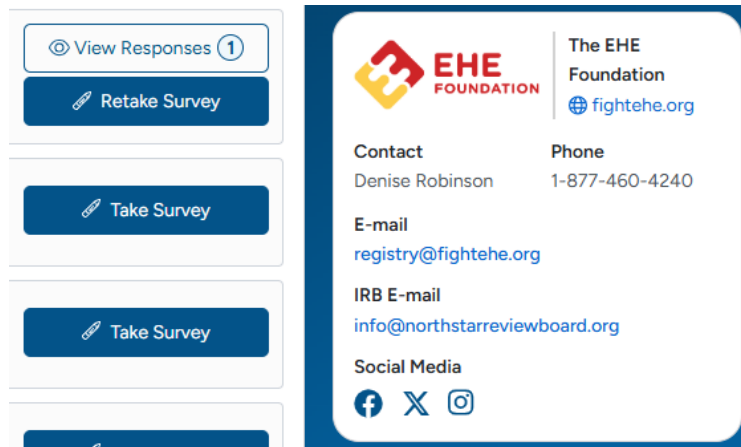
Need Assistance?

- 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 app interface with a dark blue header containing 'Home' and 'Help' icons. Below the header is a white box titled 'Have a question?' with a close button (X). Inside the box, there 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 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 form 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 mobile app interface with a white background and a blue header. On the left side, there is a vertical list of buttons: 'View Responses 1', 'Retake Survey', 'Take Survey', 'Take Survey', and 'Take Survey'. On the right side, there is a blue box with white text and icons. The box contains the EHE Foundation logo, the text 'The EHE Foundation', the website 'fightehe.org', and contact information: 'Contact Denise Robinson', 'Phone 1-877-460-4240', 'E-mail registry@fightehe.org', 'IRB E-mail info@northstarreviewboard.org', and 'Social Media' with icons for Facebook, X, and Instagram.