




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 & ConditionsContact InfoNotificationsReview & SubmitConfirmation

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”.

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Registration

Terms & Conditions Contact Info Notifications Review & Submit Confirmation

Country of Residence *

First Name * Last Name *

E-mail *

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

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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.



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Registration

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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](#)



- 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.

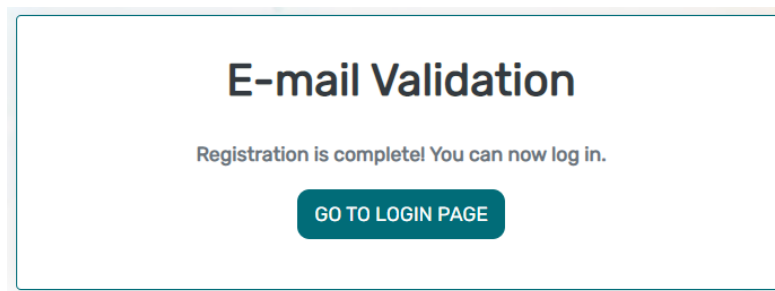
Password

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 ×

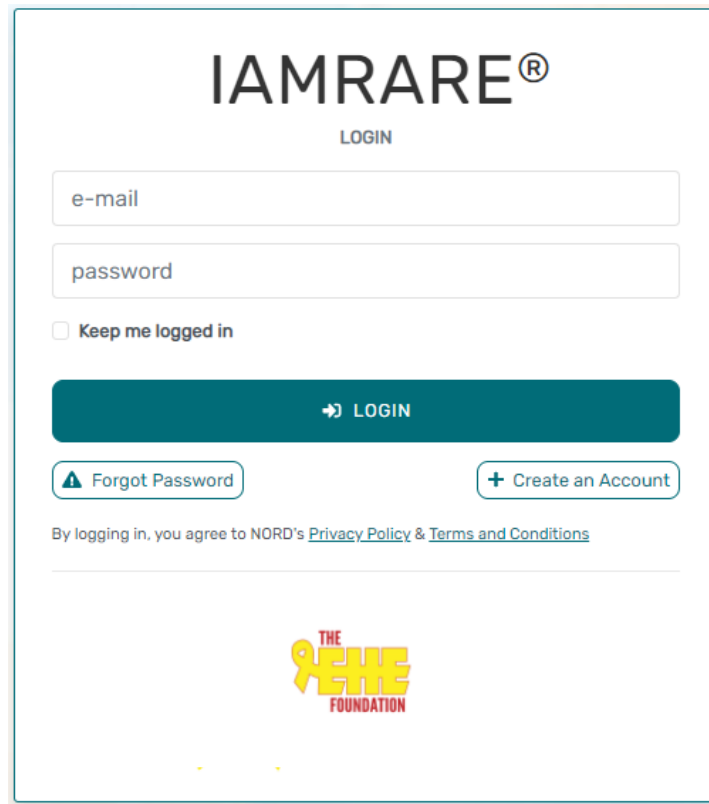
Repeat Password

SUBMIT

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

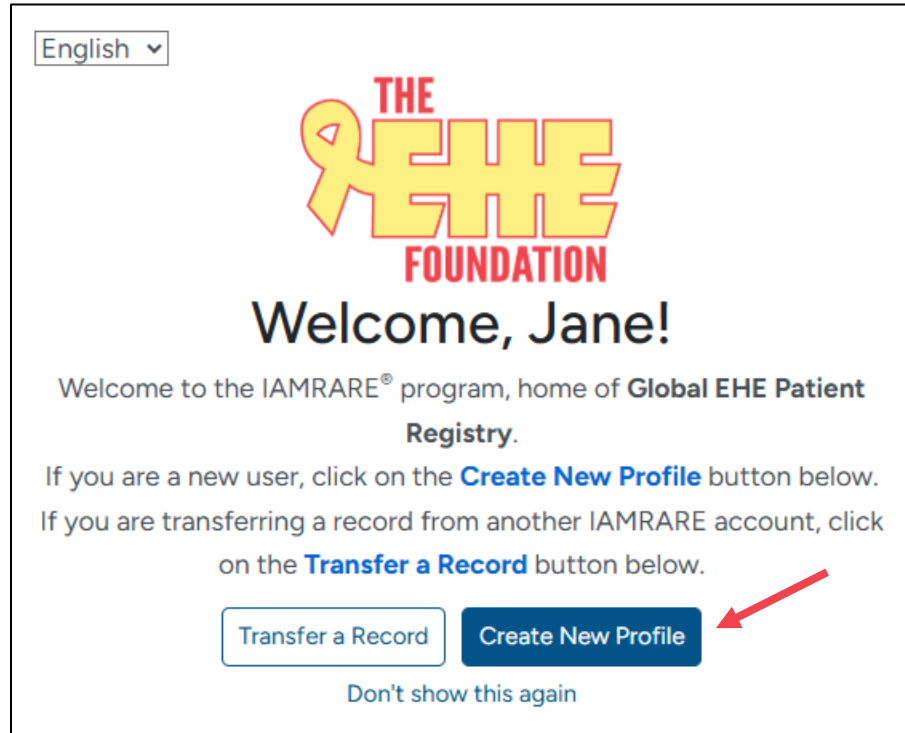


- Step 7: Log in using your new e-mail and password.

The login page for IAMRARE®. It features the brand name "IAMRARE®" at the top, followed by the word "LOGIN". There are two input fields: "e-mail" and "password". Below these is a checkbox labeled "Keep me logged in". A large teal button with a right arrow icon and the text "LOGIN" is positioned below the checkbox. At the bottom of the login section, there are two links: "Forgot Password" (with a warning triangle icon) and "Create an Account" (with a plus icon). A line of text below these links states: "By logging in, you agree to NORD's [Privacy Policy](#) & [Terms and Conditions](#)". At the very bottom of the page is the logo for "THE RARE FOUNDATION", which includes a stylized yellow ribbon icon.

Add a Participant

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



English ▾

THE EHE FOUNDATION

Welcome, Jane!

Welcome to the IAMRARE® program, home of **Global EHE Patient Registry**.

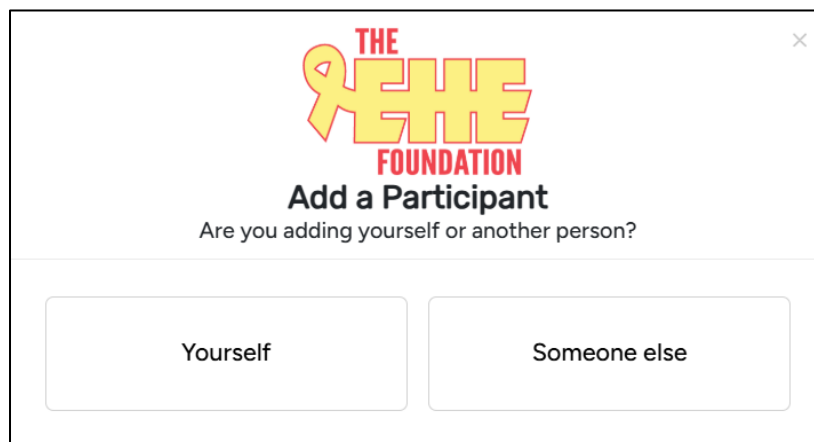
If you are a new user, click on the **Create New Profile** button below.
If you are transferring a record from another IAMRARE account, click on the **Transfer a Record** button below.

[Transfer a Record](#) [Create New Profile](#)

[Don't show this again](#)

A red arrow points to the "Create New Profile" button.

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



THE EHE FOUNDATION

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 *

Preferred First Name

Current Last name *

Current Last Name

First Name on Birth Certificate *

First Name on Birth Certificate

Middle Name on Birth Certificate *

Type 'NA' if none

Last Name on Birth Certificate *

Last Name on Birth Certificate

Date of Birth * ?

mm/dd/yyyy

Sex Recorded on Birth Certificate * ?

Country of Residence * ?

State/Province/Region of Residence * ?

State/Province/Region

Country of Birth *

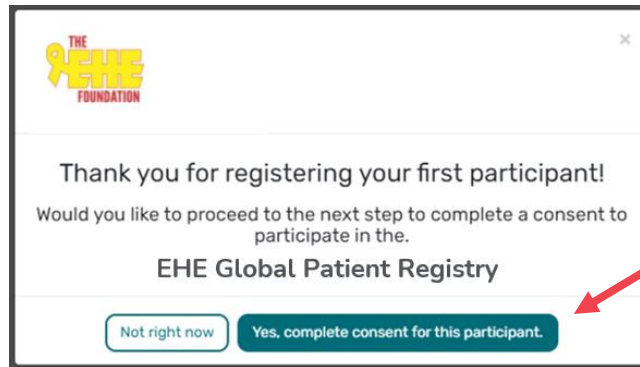
City/Municipality of Birth *

City/Municipality of Birth

What Is Your Relationship to ? * ?

Consent to the Study

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



THE EHE FOUNDATION

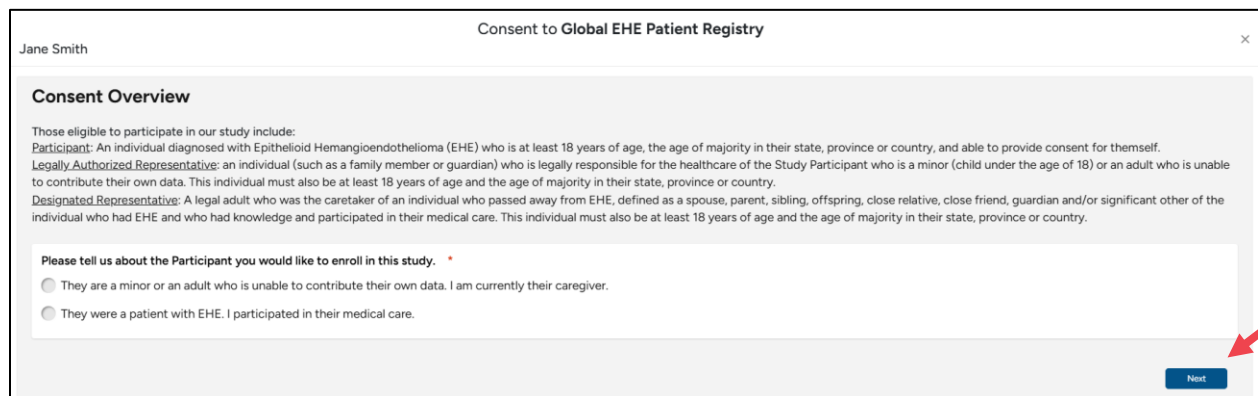
Thank you for registering your first participant!

Would you like to proceed to the next step to complete a consent to participate in the.

EHE Global Patient Registry

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 Global EHE 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.

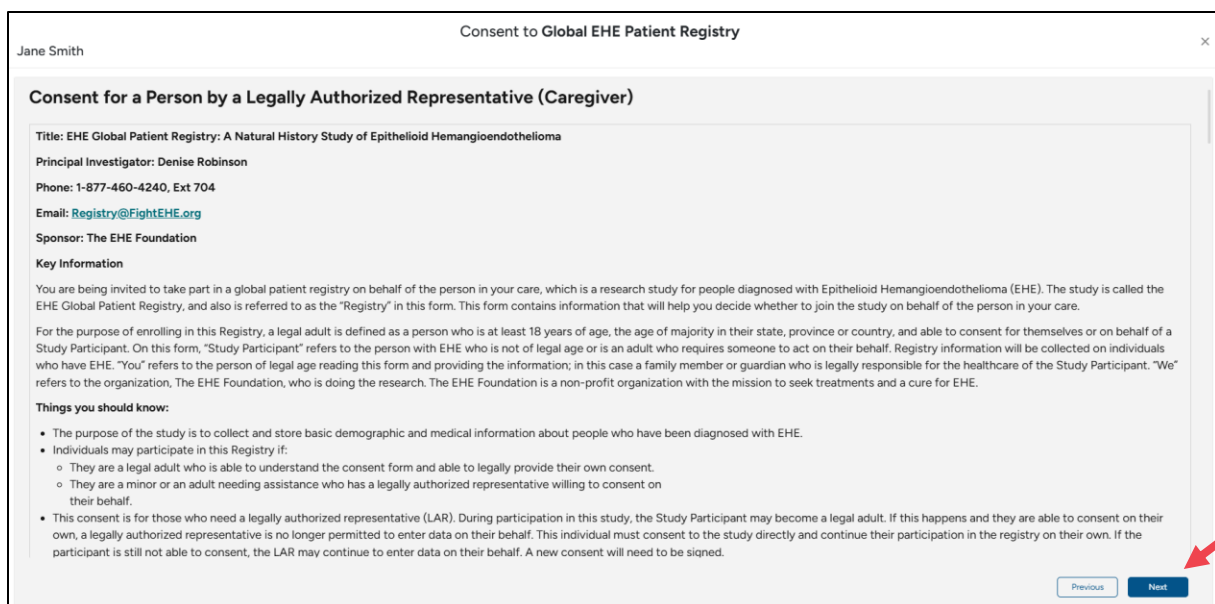
Designated Representative: A legal adult who was the caretaker of an individual who passed away from EHE, defined as a spouse, parent, sibling, offspring, close relative, close friend, guardian and/or significant other of the individual who had EHE and who had knowledge and participated in their medical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

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 EHE. I participated in their medical care.

A red arrow points to the "Next" button.



Jane Smith

Consent to Global EHE Patient Registry

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

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 on behalf of the person in your care, 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 on behalf of the person in your care.

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 or on behalf of a Study Participant. On this form, "Study Participant" refers to the person with EHE who is not of legal age or is an adult who requires someone to act on their behalf. Registry information will be collected on individuals who have EHE. "You" refers to the person of legal age reading this form and providing the information; in this case a family member or guardian who is legally responsible for the healthcare of the Study Participant. "We" refers to the organization, The EHE Foundation, who is doing the research. 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.
- Individuals may participate in this Registry if:
 - They are a legal adult who is able to understand the consent form and able to legally provide their own consent.
 - They are a minor or an adult needing assistance who has a legally authorized representative willing to consent on their behalf.
- This consent is for those who need a legally authorized representative (LAR). During participation in this study, the Study Participant may become a legal adult. If this happens and they are able to consent on their own, a legally authorized representative is no longer permitted to enter data on their behalf. This individual must consent to the study directly and continue their participation in the registry on their own. If the participant is still not able to consent, the LAR may continue to enter data on their behalf. A new consent will need to be signed.

A red arrow points to the "Next" button.

- 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.”

Consent to Global EHE Patient Registry

Jane Smith

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 The EHE Global Patient 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 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 the Study Participant's information to the EHE Global Patient Registry for the purposes described above under Study Aims.

☒ I wish to provide the Study Participant's information to the EHE Global Patient Registry for future research within recognized ethical standards for scientific research, as described under How We Use The Data.

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

Consent to Global EHE Patient 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 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 Global EHE 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

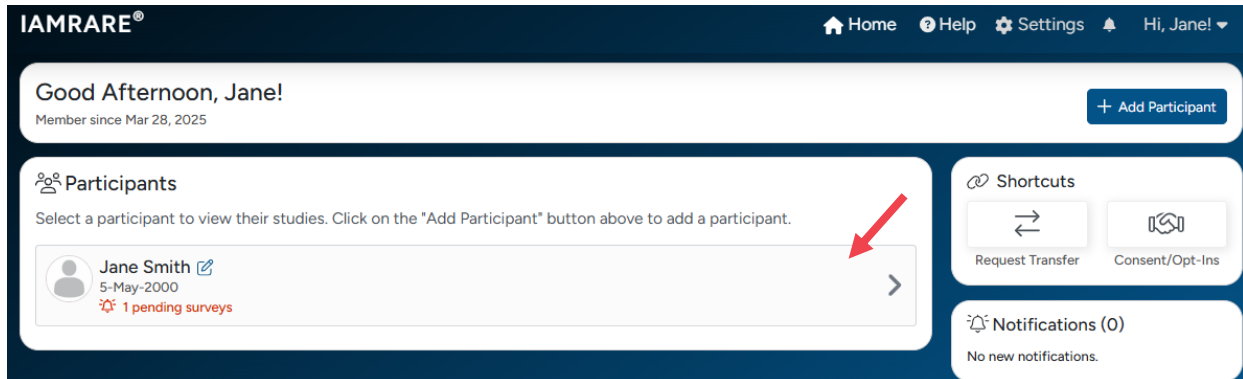
☐ Interest in learning more about **The EHE Foundation**

[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.



IAMRARE® Home Help Settings Hi, Jane!

Good Afternoon, Jane!
Member since Mar 28, 2025

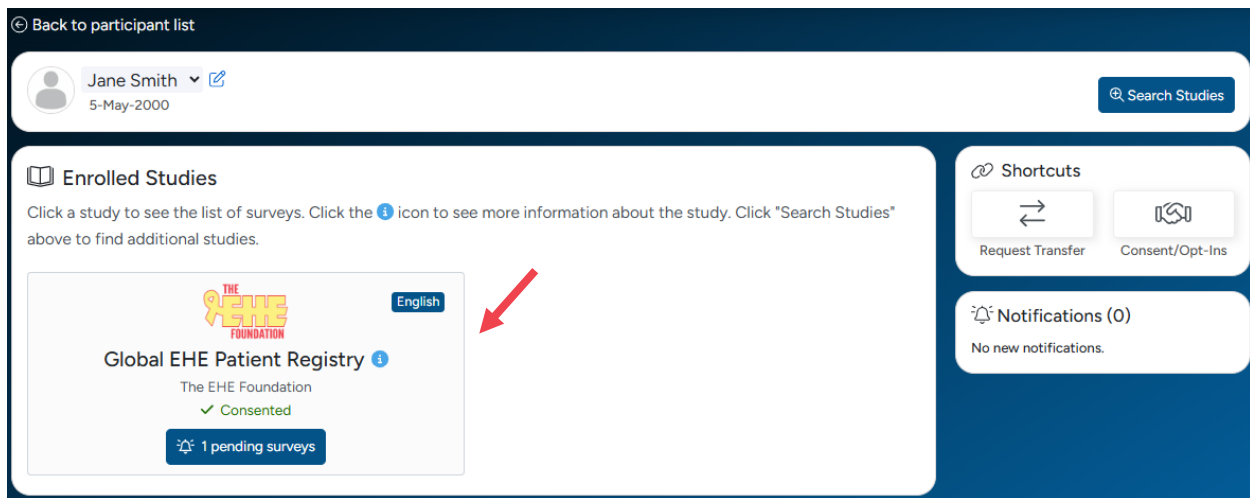
Participants
Select a participant to view their studies. Click on the "Add Participant" button above to add a participant.

Jane Smith
5-May-2000
1 pending surveys

Shortcuts
Request Transfer Consent/Opt-Ins

Notifications (0)
No new notifications.

- Step 2: Click on the appropriate study.



Back to participant list

Jane Smith
5-May-2000

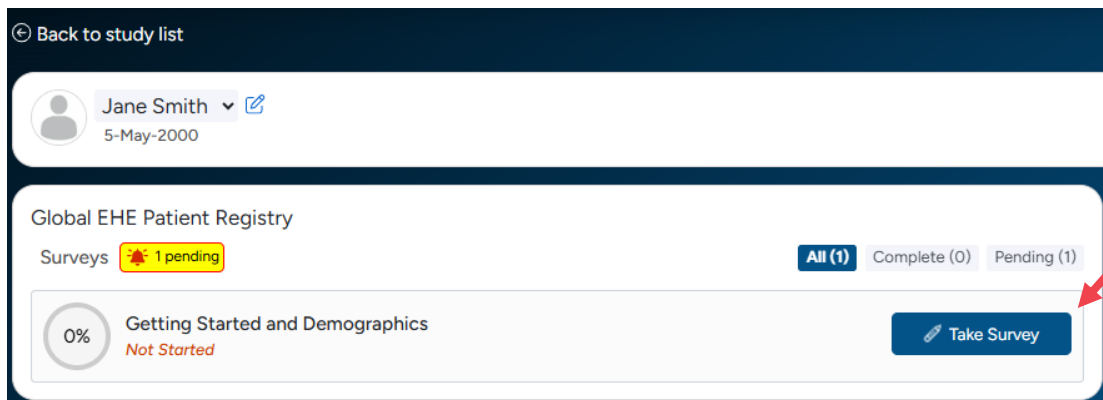
Enrolled Studies
Click a study to see the list of surveys. Click the **i** icon to see more information about the study. Click "Search Studies" above to find additional studies.

Global EHE Patient Registry
The EHE Foundation
Consented
1 pending surveys

Shortcuts
Request Transfer Consent/Opt-Ins

Notifications (0)
No new notifications.

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



Back to study list

Jane Smith
5-May-2000

Global EHE Patient Registry

Surveys 1 pending

All (1) Complete (0) Pending (1)

0% Getting Started and Demographics
Not Started

Take 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 'Jane Smith' with a dropdown arrow and an edit icon, and the date '5-May-2000'. Below this is the title 'Global EHE Patient Registry'. A 'Surveys' section shows a status of '9 pending' with a clock icon. To the right, there are filters: 'All (10)' (selected), 'Complete (1)', and 'Pending (9)'. A survey card for 'Getting Started and Demographics' is shown, marked as 'Completed on 28-Mar-2025' with a green checkmark icon. To the right of the card are two buttons: 'View Responses 1' and 'Reports'. Two red arrows point to these 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. Below the user profile, there is a 'Search Studies' button and a link to 'Learn about searching for studies'. The main content area has a heading 'Enrolled Studies' with a book icon, followed by instructions: 'Click a study to see the list of surveys. Click the ⓘ 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'. A red arrow points to the 'Consent/Opt-Ins' 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”.

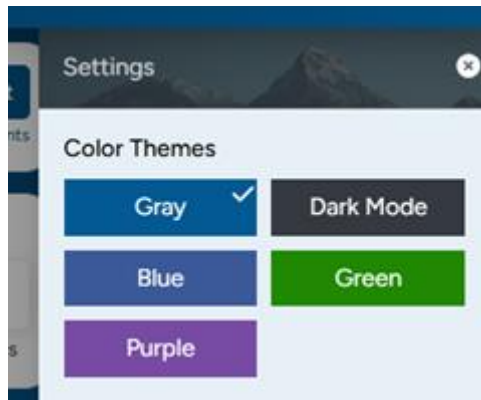
The screenshot shows the 'Consents/Opt-Ins' page for Jane Smith. At the top, there is a 'Back to study list' link. Below the user profile, there is a heading 'Consents/Opt-Ins' with a group of people icon. Below this is a table with the following columns: 'Study Name', 'Consent Status', 'Consented On', and 'Actions'. The table has one row for 'Global EHE Patient Registry' with a status of 'Consented' (green checkmark) and a date of '28-Mar-2025'. In the 'Actions' column, there are three buttons: 'View Consent', 'Revoke', and 'Opt-Ins'. Two red arrows point to the 'Revoke' and 'Opt-Ins' buttons.

Dark Mode Settings

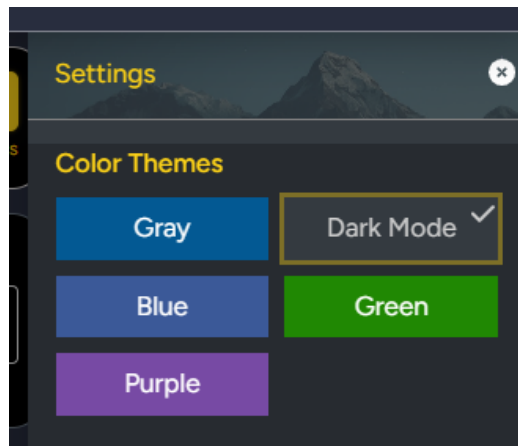
- Step 1: You can view the platform in Dark Mode. First, click Settings.



- Step 2: Select Dark Mode.



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

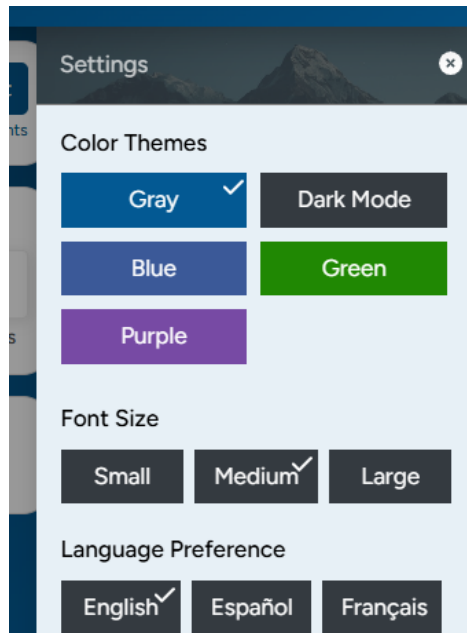


Display Settings

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



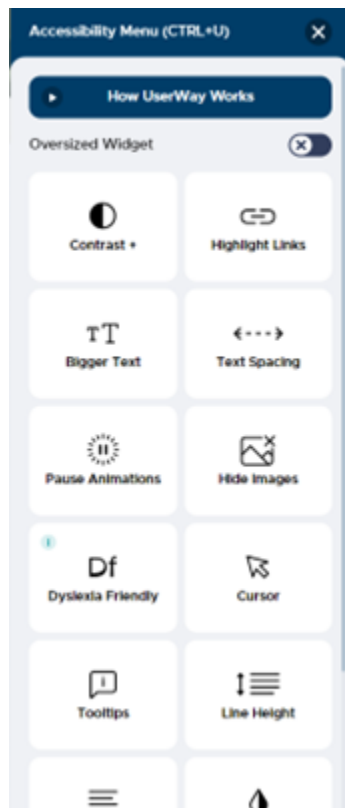
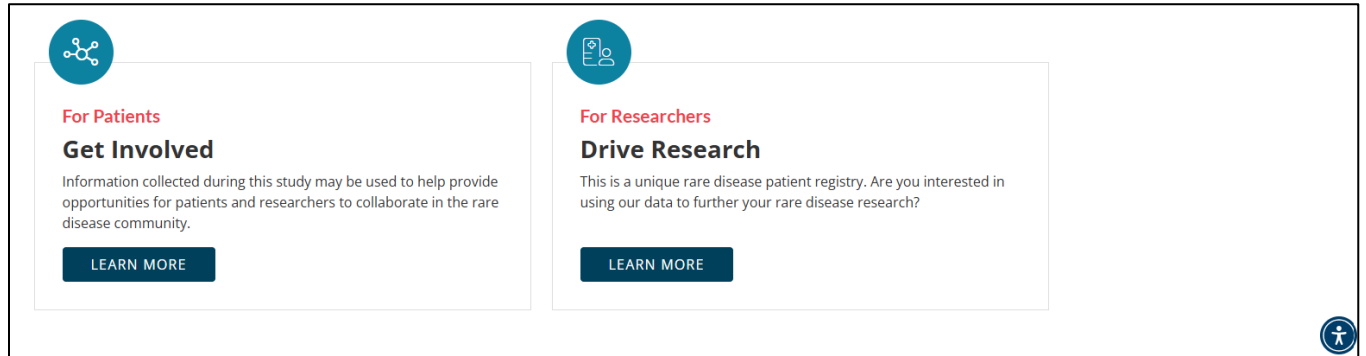
- Step 2: Select a color theme, a font size, or language preference.



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

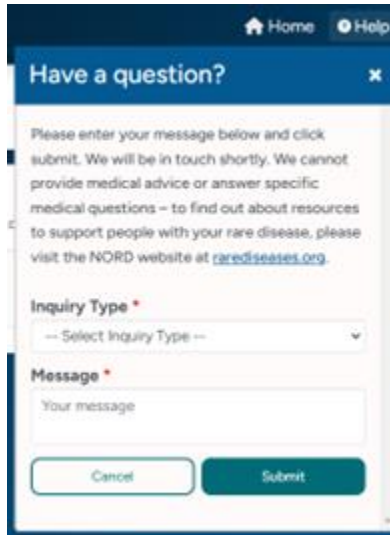
Microsite Visibility

- 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.



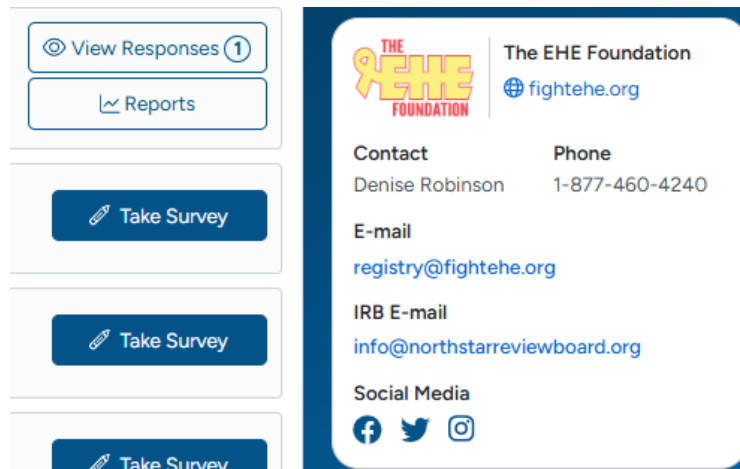
Need Assistance?

- 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 blue header bar containing 'Home' and 'Help' icons. Below the header is a modal titled 'Have a question?' with a close button (X). The modal contains a text area for a message, a dropdown menu for 'Inquiry Type' (currently showing '-- Select Inquiry Type --'), and a 'Submit' button. A 'Cancel' button is also visible at the bottom left of the modal.

- 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 dashboard on the left with three buttons: 'View Responses 1', 'Reports', and 'Take Survey'. To the right is a contact card for 'The EHE Foundation' with the website 'fightehe.org'. The card lists contact information for Denise Robinson, including a phone number (1-877-460-4240), an email address (registry@fightehe.org), and an IRB E-mail address (info@northstarreviewboard.org). It also includes social media icons for Facebook, Twitter, and Instagram.