



## HHT Connect 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”.

A screenshot of the HHT Connect Registration page. At the top, it says "Featuring" above the HHT CONNECT logo. Below the logo is the word "Registration" in a large, bold, teal font. A progress bar below the title shows five steps: "Terms & Conditions", "Contact Info", "Notifications", "Review & Submit", and "Confirmation". The "Terms & Conditions" step is currently active, indicated by a teal bar under the label. 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, each followed by a statement of agreement. The first checkbox is selected. At the bottom left, there is a link "Return to login" and at the bottom right, there is a teal button labeled "Next".

Featuring



HHT C@NNECT

## 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  
HHT C@NNECT

## 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  
HHT C@NNECT

## 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.

Featuring  
HHT CONNECT

## Registration

Terms & Conditions   Contact Info   Notifications   Review & Submit   Confirmation

An activation link will be sent to [test@test.com](mailto:test@test.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](mailto:your.email@email.com) has been successfully validated.  
Please create your password below.

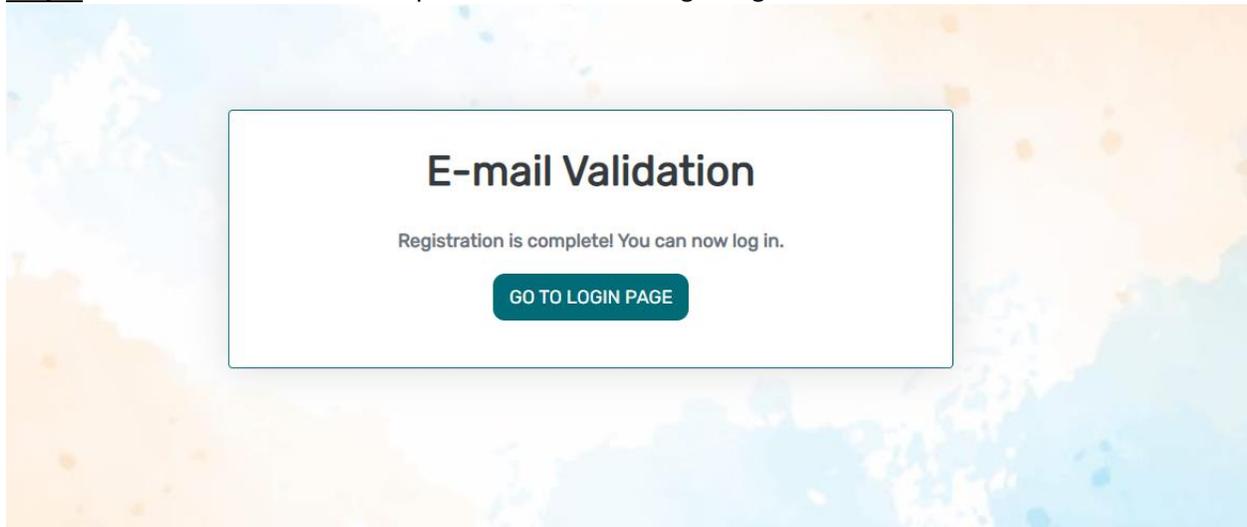
**Password**

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 ✘

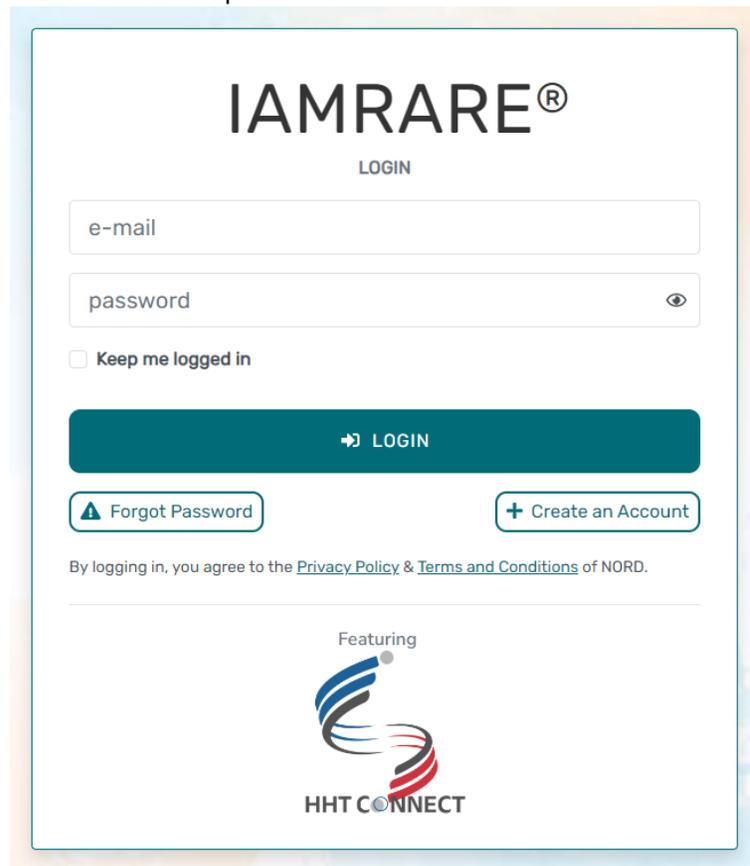
**Repeat Password**

[SUBMIT](#)

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

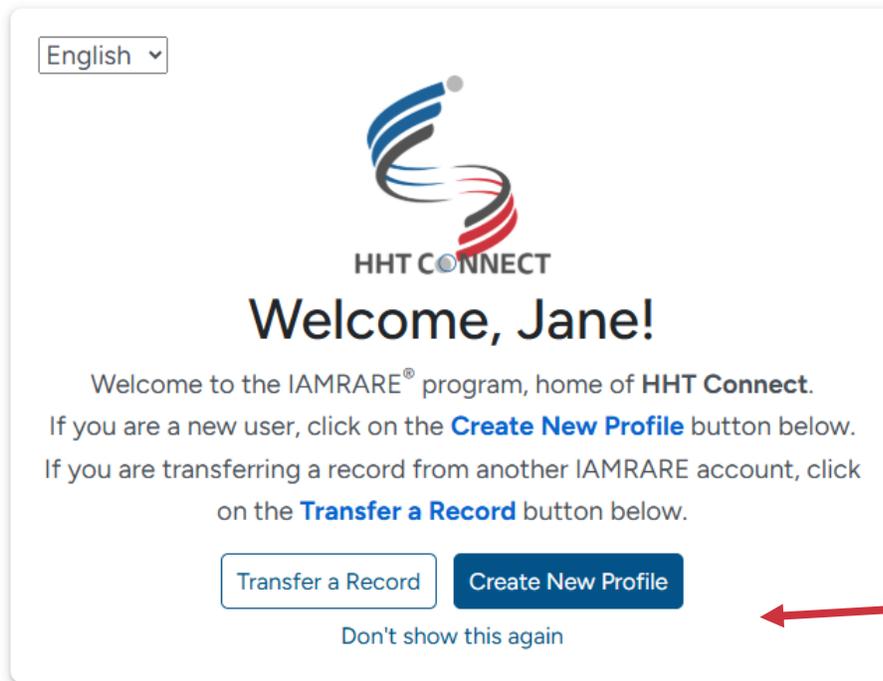


- **Step 7:** Log in using your new e-mail and password.

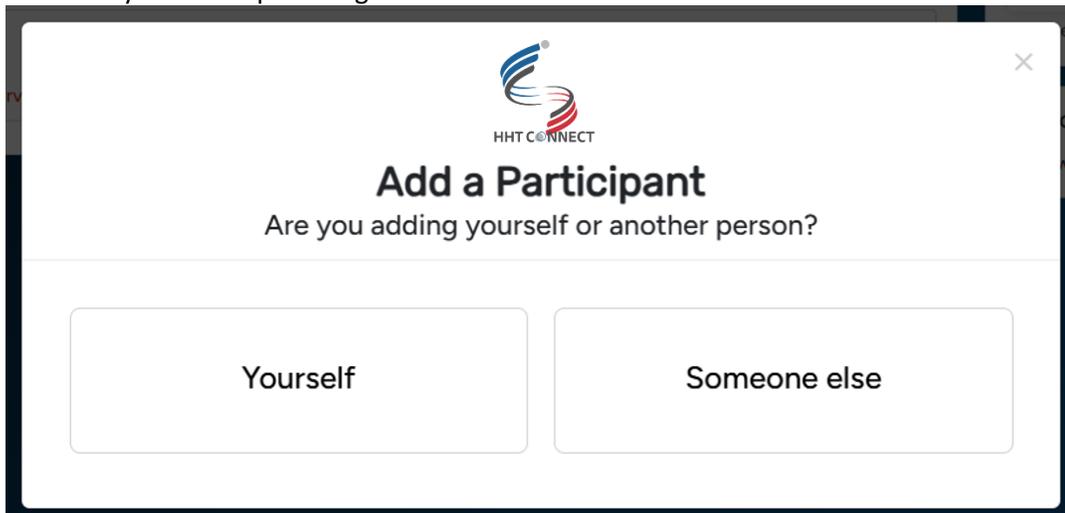


## Add a Participant

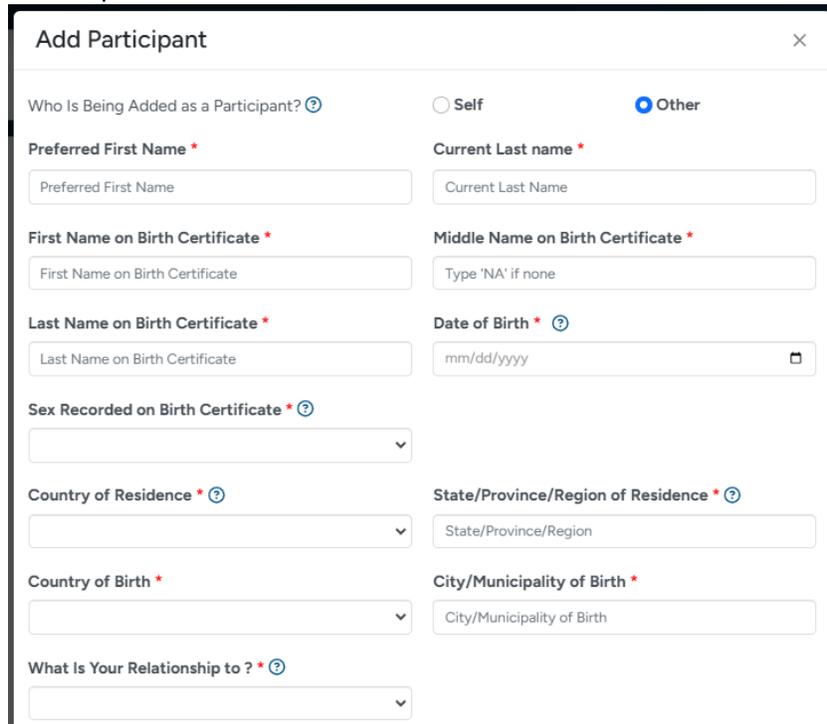
- **Step 1:** To start, click Create New Profile.



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



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

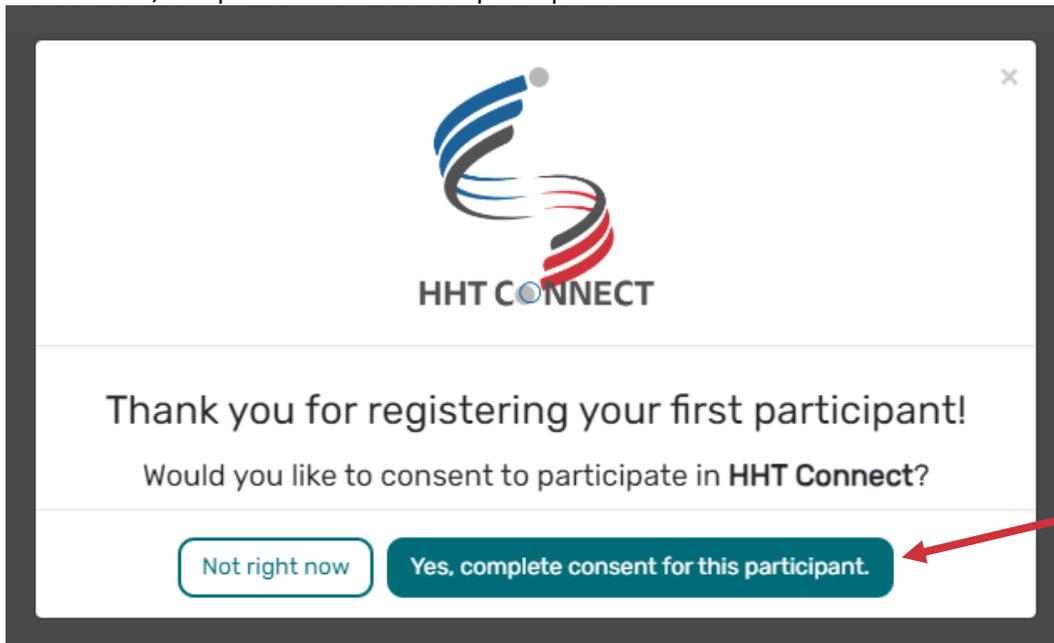


The screenshot shows a web form titled "Add Participant" with a close button (X) in the top right corner. The form is organized into several sections:

- Who Is Being Added as a Participant?** with radio buttons for "Self" and "Other" (selected).
- Preferred First Name \*** and **Current Last name \*** (text input fields).
- First Name on Birth Certificate \*** and **Middle Name on Birth Certificate \*** (text input fields, with a note "Type 'NA' if none").
- Last Name on Birth Certificate \*** and **Date of Birth \*** (text input field and a date picker).
- Sex Recorded on Birth Certificate \*** (dropdown menu).
- Country of Residence \*** and **State/Province/Region of Residence \*** (dropdown menus).
- Country of Birth \*** and **City/Municipality of Birth \*** (dropdown menus).
- What Is Your Relationship to ? \*** (dropdown menu).

### Consent to the Study

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



The screenshot shows a dialog box with the HHT Connect logo at the top. The text inside the dialog reads:

Thank you for registering your first participant!  
Would you like to consent to participate in HHT Connect?

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 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 HHT Connect

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

Title: HHT Connect

Principal Investigator: Cassi Friday, PhD, Director of Research Programs & Grants

Phone: (410) 357-9932

E-mail: [hhtconnect@curehht.org](mailto:hhtconnect@curehht.org)

Sponsor: Cure HHT

#### Key Information

You are invited to take part in a research study for individuals with HHT (Hereditary Hemorrhagic Telangiectasia) on behalf of the person in your care. We hope that this form will help you decide whether or not to participate, but you can also call or e-mail the study staff at the contacts above if you have any other questions.

#### Things you should know:

We are doing this research to better understand the HHT patient journey. We hope to capture information on HHT signs and symptoms, treatments and their

Previous

Next

### Consent to HHT Connect

- 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 HHT Connect 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 HHT Connect 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 research data to HHT Connect for the purposes described above under Study Aims.

Previous

Next

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

### Consent to HHT Connect

Please continue to select your opt-ins. Opt-Ins are topics about which you would like to receive information in the future. 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 HHT Connect ×

Select Opt-Ins for this study

- Interest in hearing about other studies from [Cure HHT](#)
- 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 [Cure HHT](#)
- Interest in signing up for a [Cure HHT](#) newsletter
- Interest in learning about the physician-entered CHORUS registry (Comprehensive HHT Outcomes Registry of the United States) and HHT biorepositories

Save and Review

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

## Taking Surveys

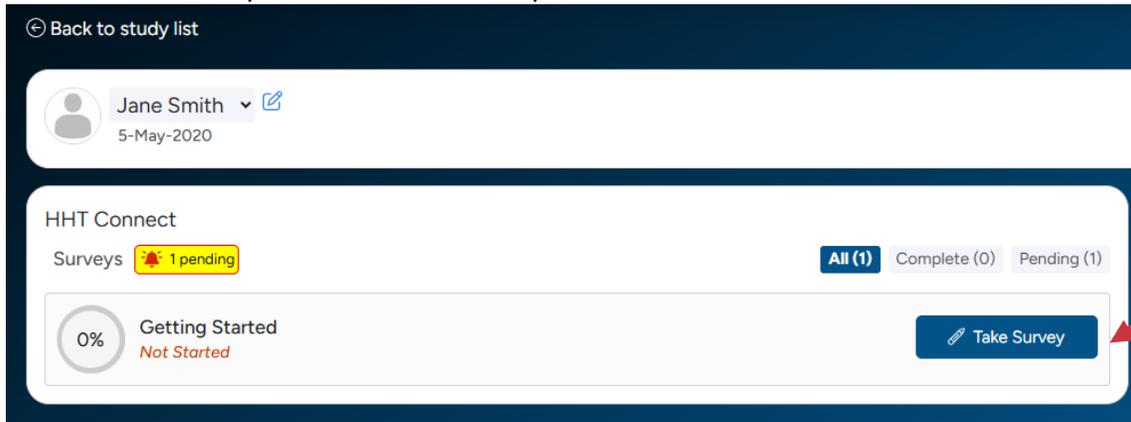
- **Step 1:** Click on your Participant.

The screenshot shows the IAMRARE user interface. At the top, there is a navigation bar with 'Home', 'Help', 'Settings', and a user greeting 'Hi, Jane!'. Below this, a 'Good Morning, Jane!' message is displayed with 'Member since Oct 25, 2024'. A '+ Add Participant' button is visible. The main area is divided into two sections: 'Participants' and 'Shortcuts'. The 'Participants' section shows a list of participants, with 'Jane Smith' (5-May-2000) and '7 pending surveys' highlighted. A red arrow points to the right arrow icon next to her name. The 'Shortcuts' section includes 'Request Transfer' and 'Consent/Opt-Ins' buttons. A 'Notifications (0)' section shows 'No new notifications.'

- **Step 2:** Click on the appropriate study.

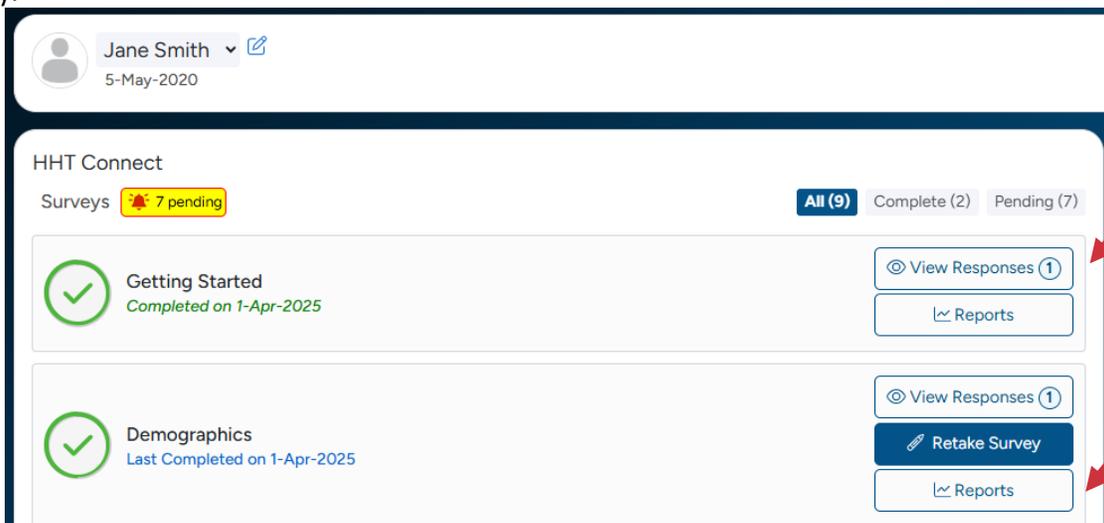
The screenshot shows the 'Enrolled Studies' page for Jane Smith. At the top, there is a 'Back to participant list' link. Below this, the participant's name 'Jane Smith' and date '5-May-2020' are displayed. The 'Enrolled Studies' section contains a list of studies. The first study is 'HHT Connect' by 'Cure HHT', with a status of 'Consented' and '1 pending surveys'. A red arrow points to the '1 pending surveys' button. The study card also features the HHT Connect logo, an 'English' language selector, and an information icon.

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



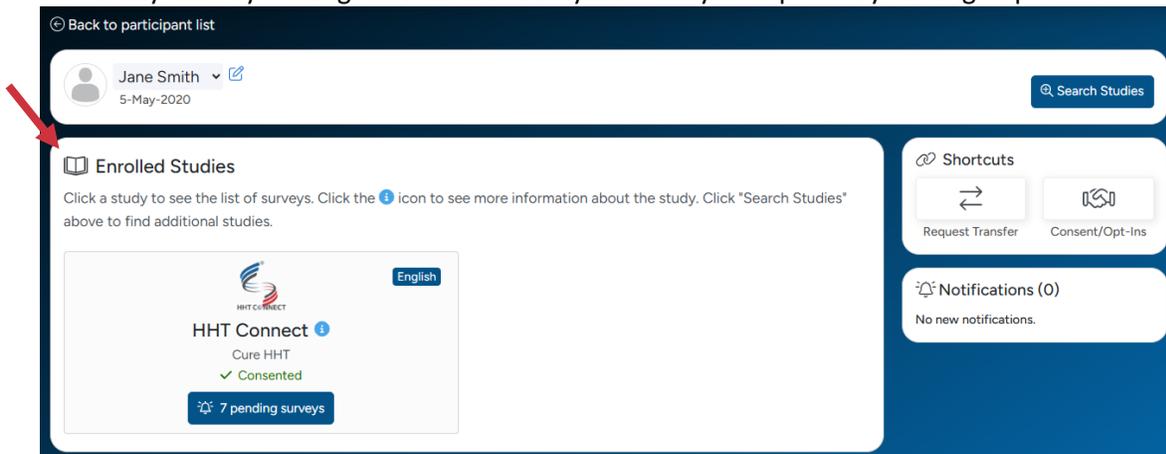
### View Responses and Reports

- 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.



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



Back to study list

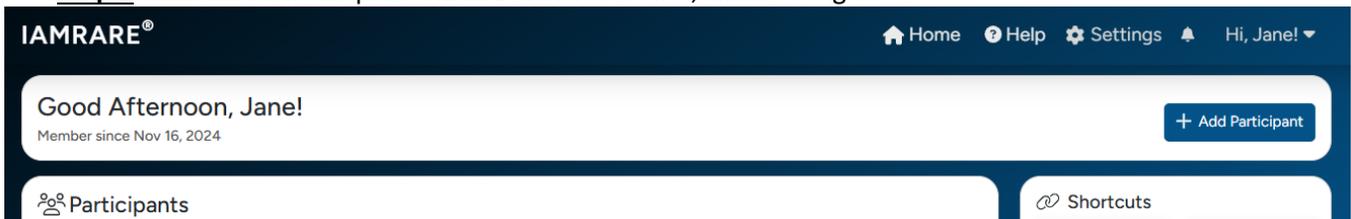
Jane Smith  
5-May-2020

Consents/Opt-Ins

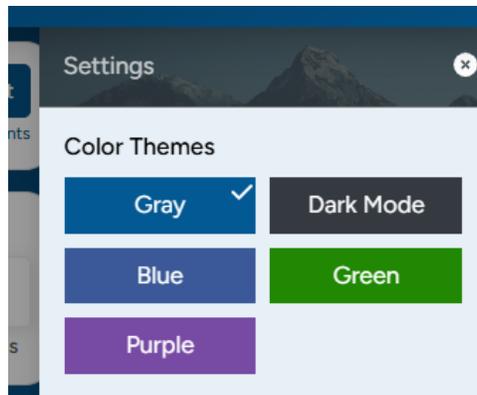
Study Name	Consent Status	Consented On	Actions
HHT Connect	✓ Consented	1-Apr-2025	View Consent Revoke Opt-Ins

## Dark Mode Settings

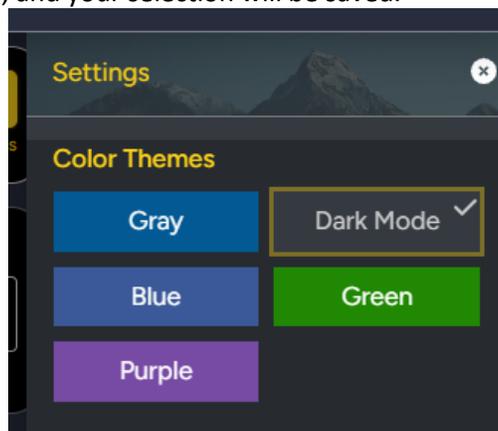
- Step 1:** You can view the platform in Dark Mode. First, click Settings.



- Step 2:** Select Dark Mode.

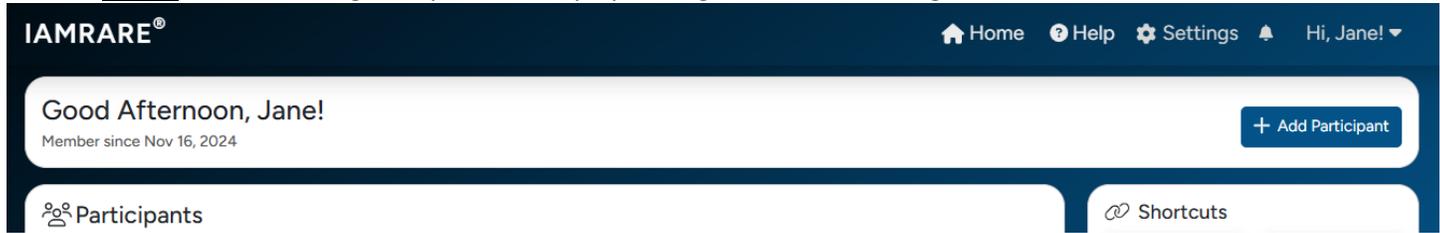


- Step 3:** Exit the Settings menu, and your selection will be saved.

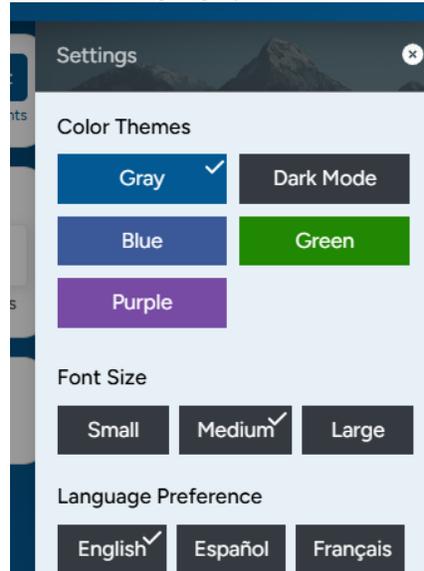


## Display Settings

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



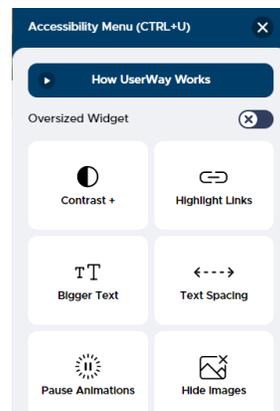
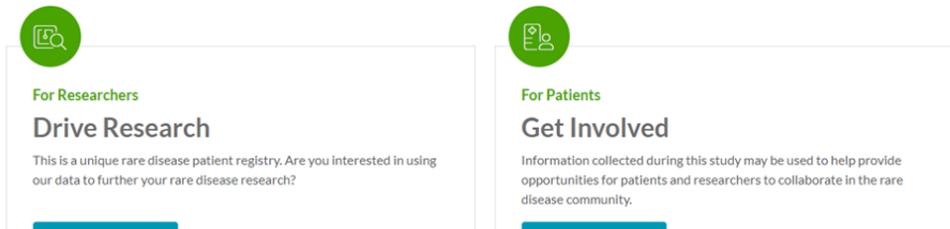
- **Step 2:** Select a color theme, a font size, or language preference.



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

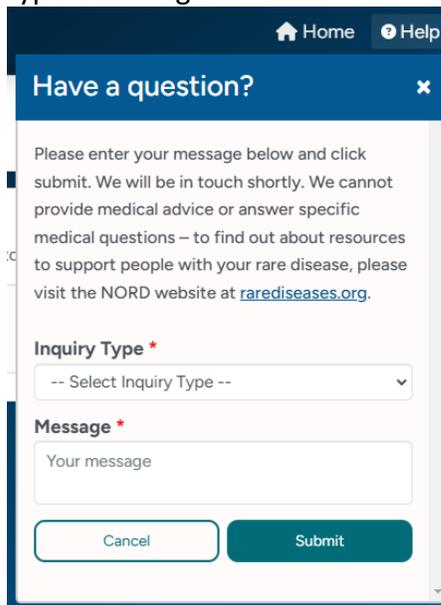
## Microsite Visibility

- **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.

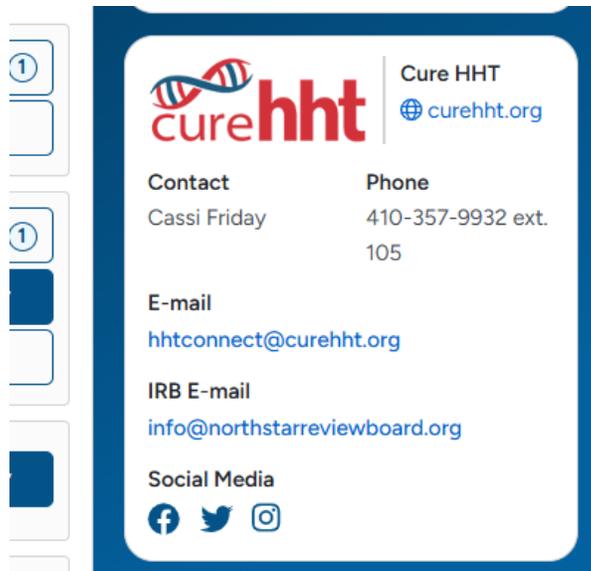


## Need Assistance?

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



- **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.



<b>Contact</b>	<b>Phone</b>
Cassi Friday	410-357-9932 ext. 105
<b>E-mail</b>	
hhtconnect@curehht.org	
<b>IRB E-mail</b>	
info@northstarreviewboard.org	
<b>Social Media</b>	
  	