




## AGU Registry and Natural History Study Participant User Guide

### Register for an Account

- Step 1: Select the appropriate Account Type. If you need more information, click “Not sure? Help me choose”.
  - If you have a diagnosis of AGU, select **Participant Account**.
  - If you are entering information for **someone else** who has AGU, select **Caregiver Account**.
  - If you are entering information for an AGU patient who has passed away, select **Caregiver Account**.



---

### Select Account Type

I have a rare disease, condition, and/or diagnosis.

Participant Account

I am a family member or guardian of someone with a rare disease.

Caregiver Account

[Return to login](#) [Not sure? Help me choose.](#)

[Return to login](#)

[Not sure? Help me choose.](#)

- Step 2: Read the Terms and Conditions and Privacy Policy, then attest to the provided statements. When you have completed this page, click “Next”.

Featuring  
**Raise Your**  
**HOPE FUND**

## Caregiver 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 3: Enter your personal information in the fields provided. When you have completed this page, click “Next”.

Featuring  
**Raise Your**  
**HOPE FUND**

## Caregiver Registration

Terms & Conditions   Contact Info   Notifications   Review & Submit   Confirmation

Country of Residence \*

First Name \*   Last Name \*

E-mail \*

[Return to login](#) Previous   Next

- Step 4: Select whether you are interested in being contacted by NORD regarding other studies that are available at NORD. When you are finished with this page, click “Next”.

Featuring  
Rare Treat  
HOPE FUND

## Caregiver 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 5: Select “Next” to have an activation link sent to your e-mail to complete registration.

Featuring  
Rare Treat  
HOPE FUND

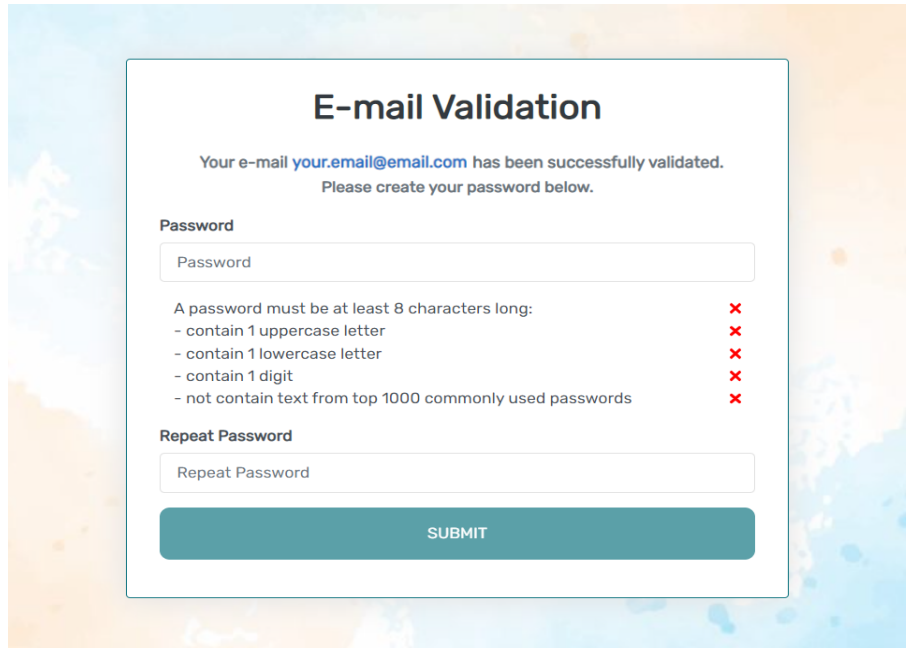
## Caregiver Registration

Terms & Conditions   Contact Info   Notifications   Review & Submit   Confirmation

An activation link will be sent to [youremail@email.com](mailto:youremail@email.com). Click "Next" to send this e-mail and continue.

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

- Step 6: Click the link sent to your e-mail. If you do not see the email, please check your Spam folder. You will be directed to the following screen in a new tab in 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.

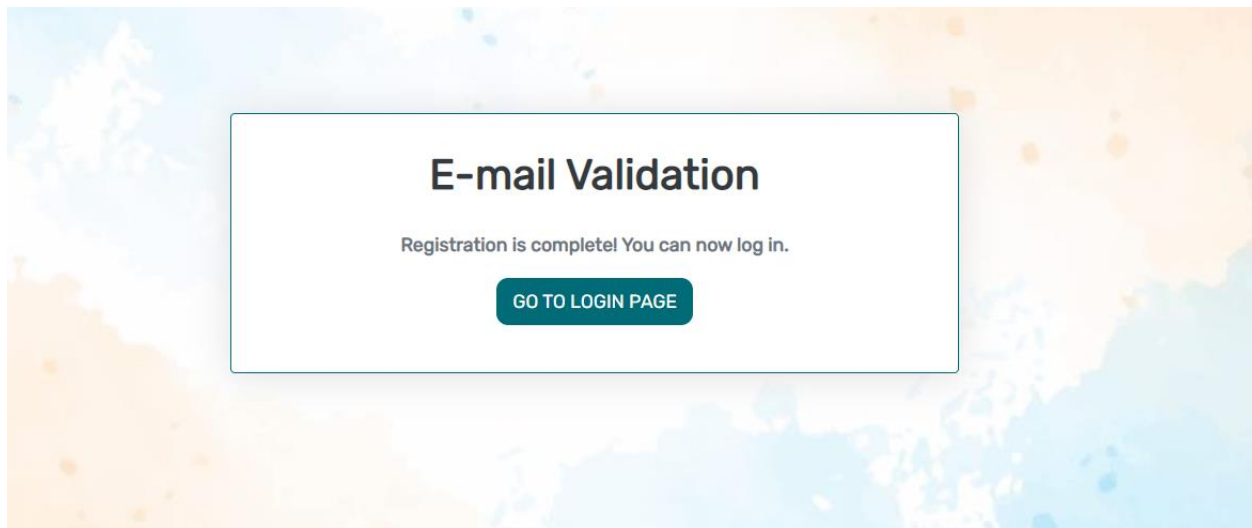
**Password**

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 7: Your validation is now complete. Select “Go to Login Page” to proceed.



**E-mail Validation**

Registration is complete! You can now log in.

**GO TO LOGIN PAGE**

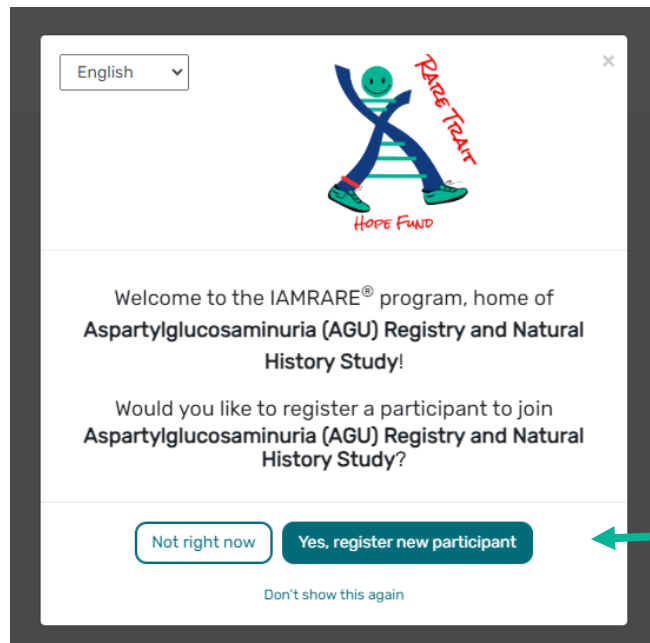
- Step 8: Log in using your new e-mail and password.



The image shows the IAMRARE LOGIN page. At the top, the text "IAMRARE®" is displayed in a large, bold, black font, with "LOGIN" centered below it. There are two input fields: "e-mail" and "password" (with an eye icon for visibility). Below the password field is a checkbox labeled "Keep me logged in". A large teal button with a right-pointing arrow and the text "LOGIN" is centered. Below the button are two smaller buttons: "Forgot Password" (with a warning icon) and "Create an Account" (with a plus icon). At the bottom, a line of text reads "By logging in, you agree to the [Privacy Policy](#) & [Terms and Conditions](#) of NORD." Below this is a logo for "Featuring RARE TRAIT HOPE FUND" featuring a stylized figure with a green head and blue body.

### Add a Participant

- Step 1: To start, click Yes, register new participant. A participant refers to a person with AGU.



The image shows a dialog box for adding a participant. At the top left, there is a language dropdown menu set to "English". In the center is the "RARE TRAIT HOPE FUND" logo. Below the logo, the text reads: "Welcome to the IAMRARE® program, home of Aspartylglucosaminuria (AGU) Registry and Natural History Study!" followed by "Would you like to register a participant to join Aspartylglucosaminuria (AGU) Registry and Natural History Study?". At the bottom, there are two buttons: "Not right now" and "Yes, register new participant". A green arrow points to the "Yes, register new participant" button. Below the buttons is a link that says "Don't show this again".

- Step 2: Fill out the Participant’s information. A participant refers to a person with AGU.

Add Participant ✕

**Acknowledgement\***

By checking this box, you acknowledge that information collected on this platform will only be used for research purposes by NORD and in ways that will not reveal who you are. Federal or state laws may require us to show information to university or government officials (or sponsors) who are responsible for monitoring the safety of any studies running on this platform. You will not be identified in any publications.

**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 of Residence \***


**Country 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.”



Thank you for registering your first participant!

Would you like to consent to participate in **Aspartylglucosaminuria (AGU) Registry and Natural History Study?**

- Step 2: Scroll down and read the consent form thoroughly. After completing each page, click the “Next” button. When you reach the Authorization form, carefully read through the statements. 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 **Aspartylglucosaminuria (AGU) Registry and Natural History Study**

### Consent Overview

Those eligible to participate in our study include:

**Participant:** An individual diagnosed with Aspartylglucosaminuria (AGU) 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 Aspartylglucosaminuria (AGU), defined as a spouse, parent, sibling, offspring, close relative, close friend, guardian and/or significant other of the individual and who had knowledge of 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 Aspartylglucosaminuria (AGU) and have since passed away. I participated in their medical care.

**Next**



Consent to **Aspartylglucosaminuria (AGU) Registry and Natural History Study**

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

Consent to Participate in the **Aspartylglucosaminuria (AGU) Registry and Natural History Study (AGU Registry)** and to Allow Data to be Shared for Future Research

Title: Aspartylglucosaminuria (AGU) Registry and Natural History Study (AGU Registry)

Principal Investigator: Julia Taravella MS, ME

Phone: +1 504 408 1126

Email: [registry@raretrait.com](mailto:registry@raretrait.com)


Sponsor: Rare Trait Hope Fund

#### Key Information

You, as a guardian or legally authorized representative of a person with AGU, are invited to join a research study about Aspartylglucosaminuria (AGU). The goal of the study is to better understand the disease, its progression, its treatment responses, and how to best care for people with AGU. This form will help you decide if you want to participate. If you have any questions, you can call or e-mail the study staff using the contacts above.

Things you should know:

**Previous** **Next**



**Consent to Aspartylglucosaminuria (AGU) Registry and Natural History Study**

### 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
- Agreed 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; 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 AGU 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 AGU Registry have been answered to my satisfaction, and I understand the purpose of the registry and the risks

[Previous](#) [Next](#)

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

**Consent to Aspartylglucosaminuria (AGU) Registry and Natural History Study**

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 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 Aspartylglucosaminuria (AGU) Registry and Natural History Study**

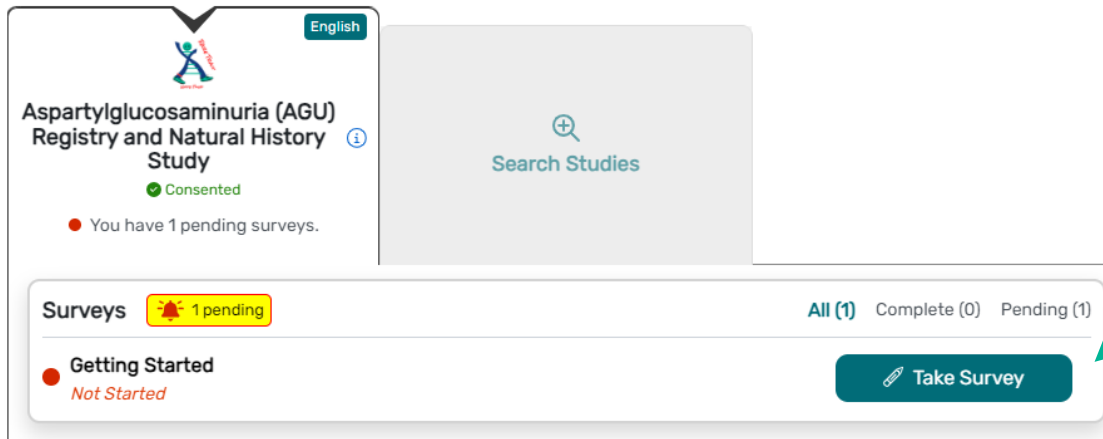
Select Opt-Ins for this study

- Interest in hearing about other studies from [Rare Trait Hope Fund](#)
- Interest in hearing about relevant clinical trials
- Interest in donating specimens or DNA (biobanking) for future research
- Interest in learning more about [Rare Trait Hope Fund](#)
- Interest in signing up for a [Rare Trait Hope Fund](#) newsletter
- Support from [Rare Trait Hope Fund](#) Ambassador / Care Coordinator
- If eligible, I have interest in receiving [Rare Trait Hope Fund](#) merchandise that would be sent via electronic or postal mail
- Interest in learning about upcoming events such as conferences, webinars, and support groups

[Save and Review](#)

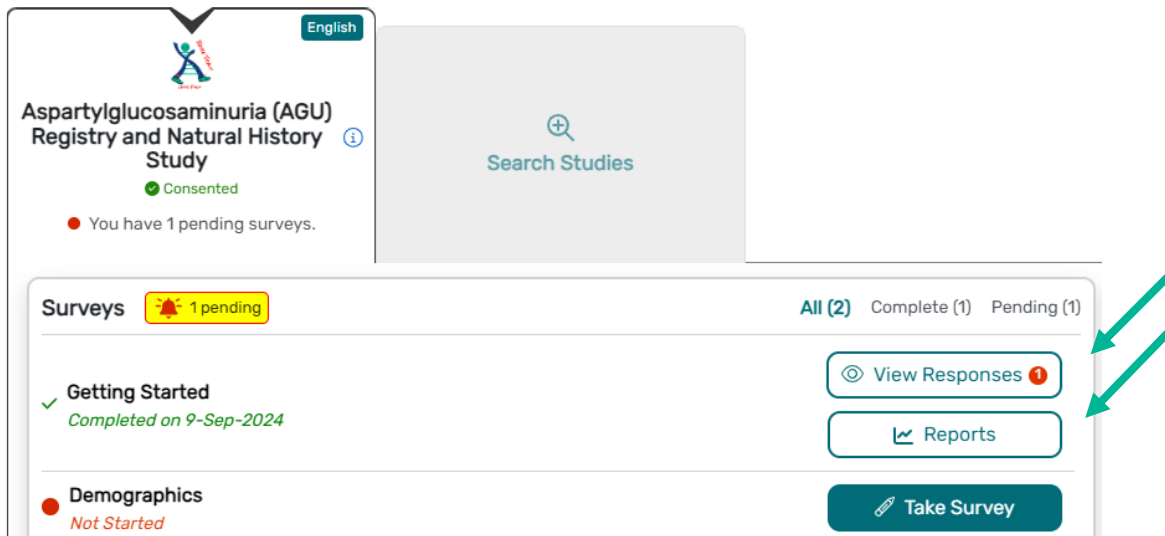


- Step 4: Once you have reviewed your consent, click “Close”. You will then be able to start taking surveys.



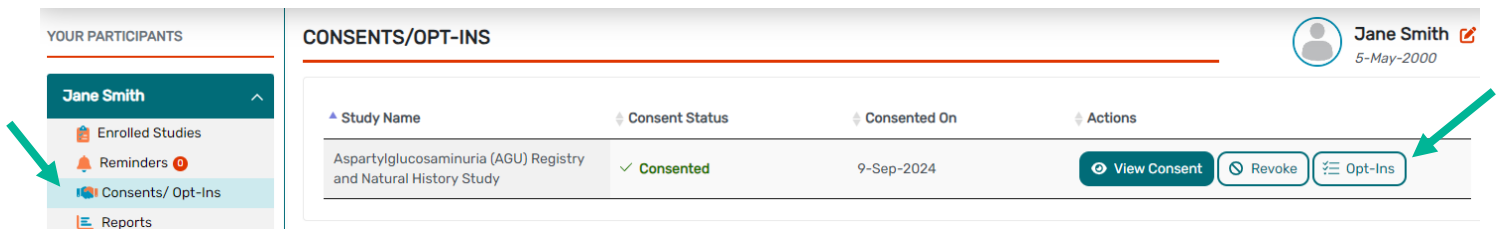
### View Responses and Reports

- Step 1: Once you have submitted a survey, you can view your responses to that survey as well as the graphs for questions that are programmed to display them. Click “View Responses” to see your completed survey. Click “Reports” to see any available graphs.



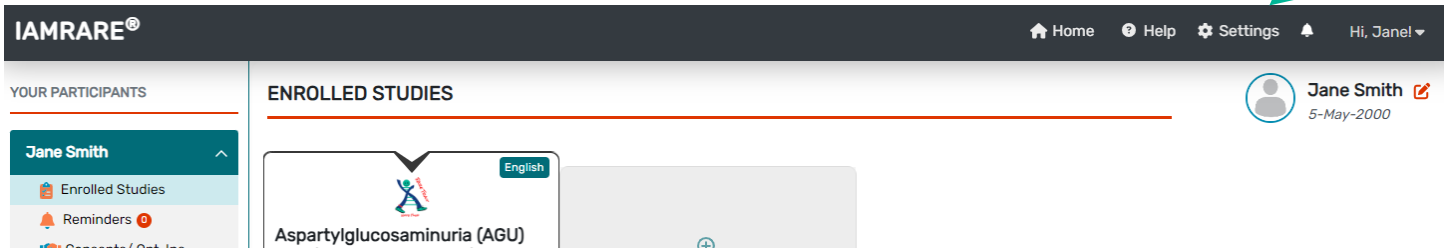
### View Consent and Opt-Ins

- Step 1: After consenting to the study, you can view your consent at any time. Click “Consents/Opt-Ins” to review your consent and opt-ins. You can revoke your consent at any time by clicking “Revoke” or edit your Opt-Ins by clicking “Opt-Ins”.

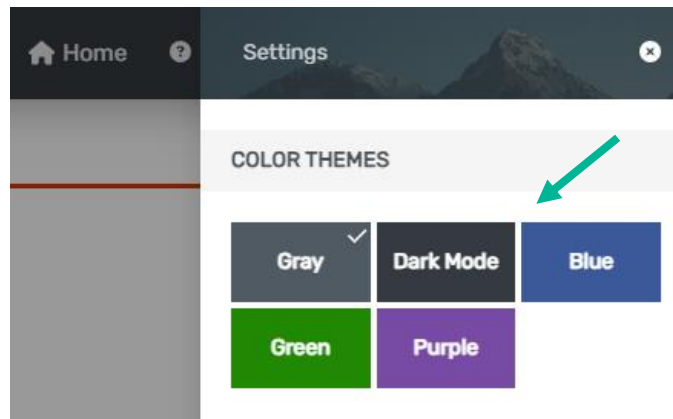


## Dark Mode Settings

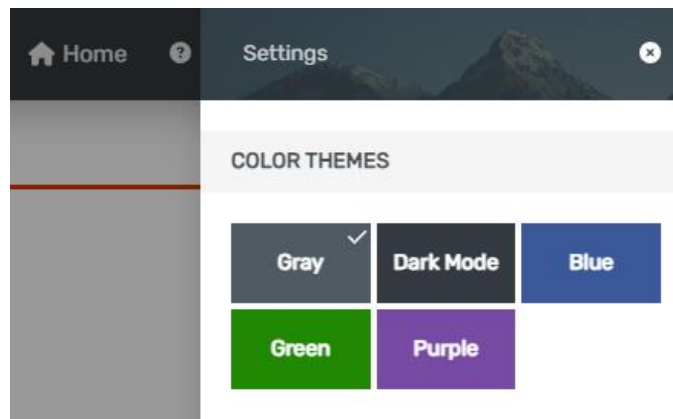
- Step 1: You can view the platform in Dark Mode. First, click Settings.



- Step 2: Select Dark Mode.

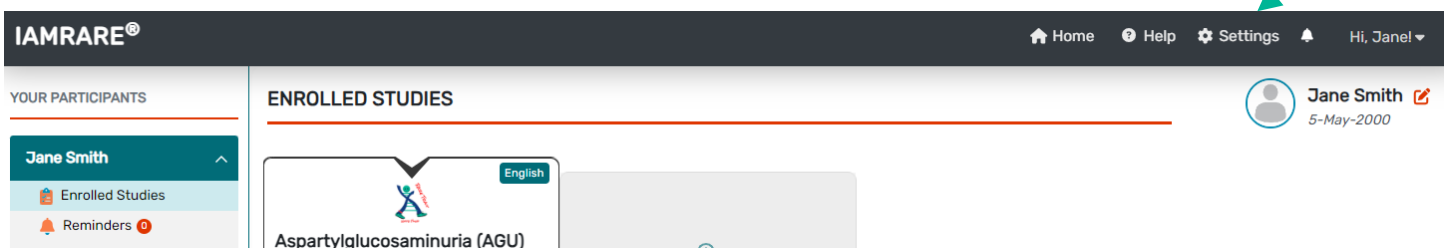


- Step 3: Exit the Settings menu, and your selection will be saved.

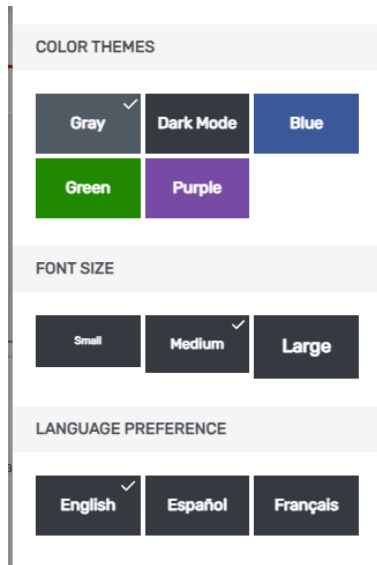


## Display Settings

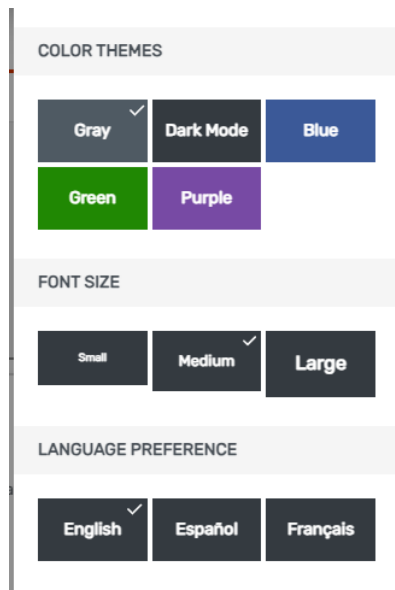
- Step 1: You can change the platform display settings. First, click Settings.



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

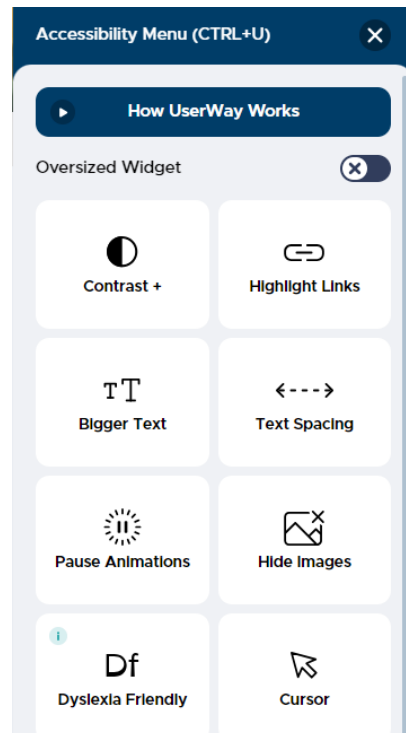
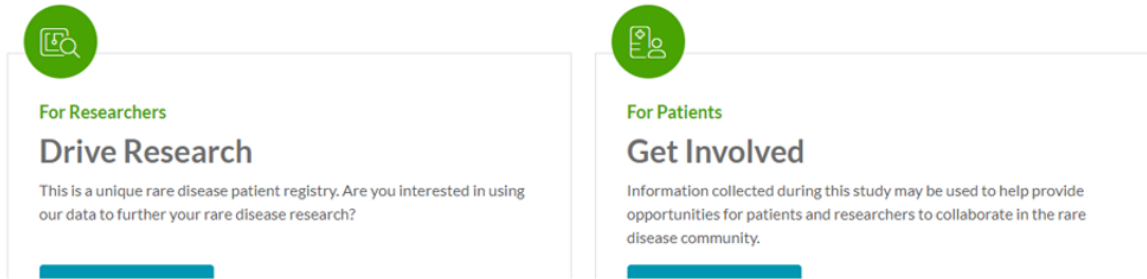


- Step 3: Exit the Settings menu, and your selection will be saved.



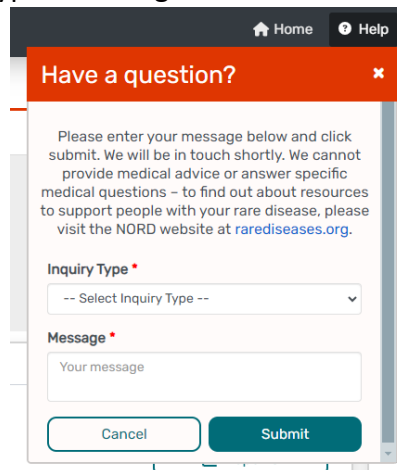
## Microsite Visibility

- Step 1: You can change how you view the microsite (AGU.iamrare.org) using an Accessibility menu. Click the “Person” icon at the bottom of the screen. From there, you can change settings such as contrast, text size, and text spacing.



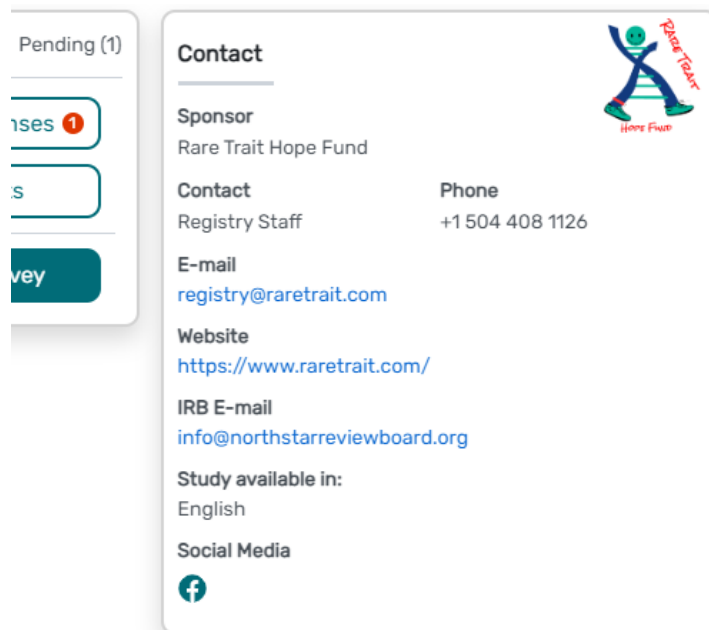
## Need Assistance?

- Step 1: If you need assistance 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 top bar containing 'Home' and 'Help' icons. A red modal window titled 'Have a question?' is open. Inside the modal, there is a text area with instructions: '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](http://rarediseases.org).' Below this is a dropdown menu for 'Inquiry Type' with the text '-- Select Inquiry Type --'. Underneath is a text input field labeled 'Message' with the placeholder 'Your message'. At the bottom of the modal are two buttons: 'Cancel' and 'Submit'.

- Step 3: Click Submit.
- You can also contact the study sponsor directly using the contact information provided on your dashboard or the study website.



The screenshot shows a contact information card. On the left, there is a sidebar with a 'Pending (1)' notification and buttons for 'Messages 1', 'Search', and 'Survey'. The main card is titled 'Contact' and features the 'Rare Trait Hope Fund' logo. The contact details are as follows:

Contact	Phone
Sponsor Rare Trait Hope Fund	
Registry Staff	+1 504 408 1126
E-mail <a href="mailto:registry@raretrait.com">registry@raretrait.com</a>	
Website <a href="https://www.raretrait.com/">https://www.raretrait.com/</a>	
IRB E-mail <a href="mailto:info@northstarreviewboard.org">info@northstarreviewboard.org</a>	
Study available in: English	
Social Media 