




AGU Registry and Natural History Study Participant User Guide

Register for an Account

- Step 1: Read the Terms and Conditions and Privacy Policy, then attest to the provided statements. When you have completed this page, click “Next”.

Featuring



Registration

1

Terms & Conditions

2

Contact Info

3

Notifications

4

Review & Submit

5

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.

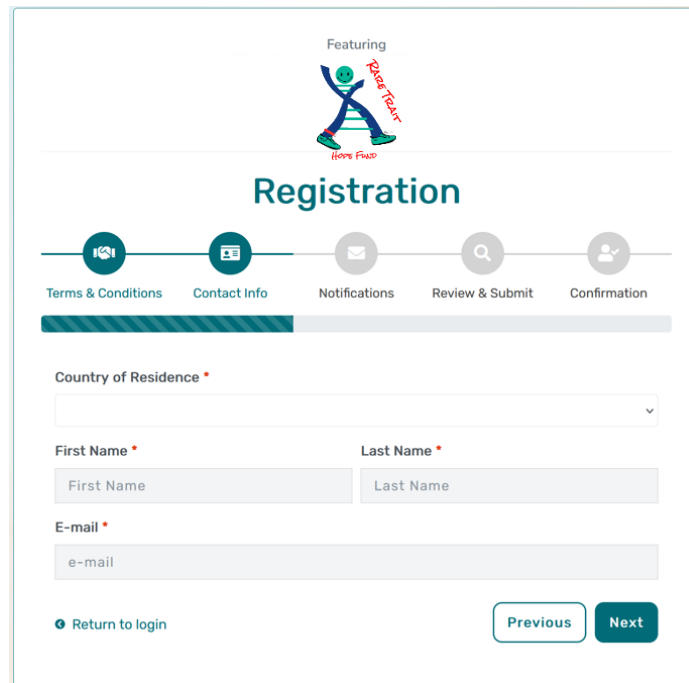
Acknowledgements:


- ☐ 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 fields provided. When you have completed this page, click “Next”.



Featuring 

Registration

Progress bar: Terms & Conditions (active), Contact Info, Notifications, Review & Submit, Confirmation

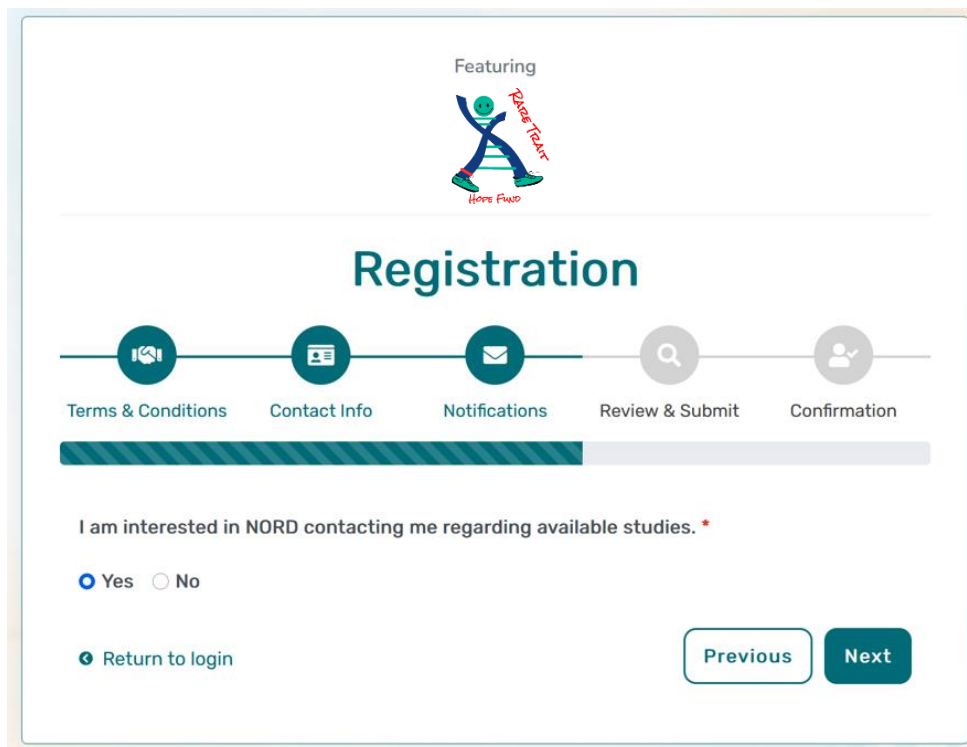
Country of Residence *


First Name * Last Name *

E-mail *

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

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



Featuring 

Registration

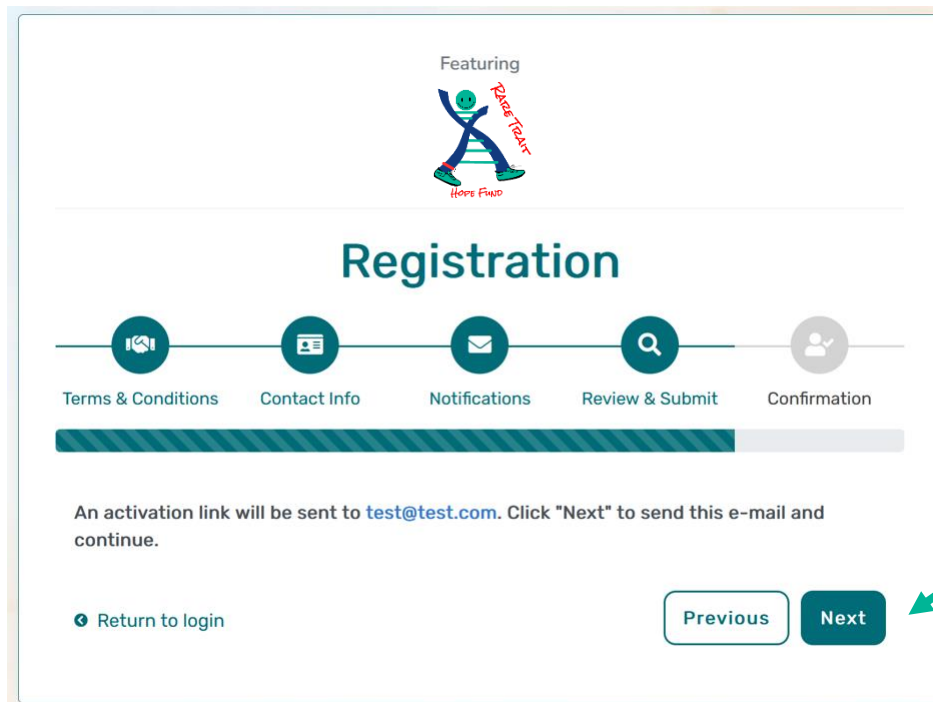
Progress bar: Terms & Conditions, Contact Info, Notifications (active), Review & Submit, Confirmation

I am interested in NORD contacting me regarding available studies. *


☒ Yes ☐ No

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

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



The image shows a registration progress bar with five steps: Terms & Conditions, Contact Info, Notifications, Review & Submit, and Confirmation. The progress bar is currently at the 'Review & Submit' step. Below the progress bar, a message states: 'An activation link will be sent to test@test.com. Click "Next" to send this e-mail and continue.' At the bottom, there is a 'Return to login' link and two buttons: 'Previous' and 'Next'. A green arrow points to the 'Next' button.

Featuring  Blue Text Hope Fund

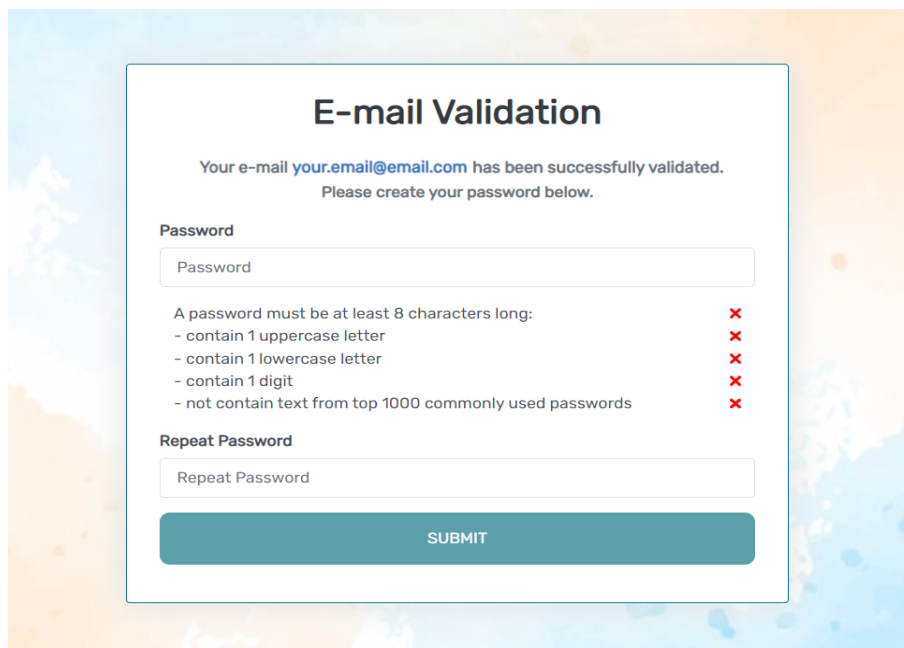
Registration

Terms & Conditions Contact Info Notifications Review & Submit Confirmation

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

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

- Step 5: 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”.



The image shows the 'E-mail Validation' screen. It states: 'Your e-mail your.email@email.com has been successfully validated. Please create your password below.' There are two password input fields: 'Password' and 'Repeat Password'. Below the 'Password' field, there are four requirements for a strong password, each with a red 'X' indicating it is not met: 'A password must be at least 8 characters long:', 'contain 1 uppercase letter', 'contain 1 lowercase letter', and 'contain 1 digit'. A fifth requirement, 'not contain text from top 1000 commonly used passwords', is also listed with a red 'X'. At the bottom, there is a 'SUBMIT' button.

E-mail Validation

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

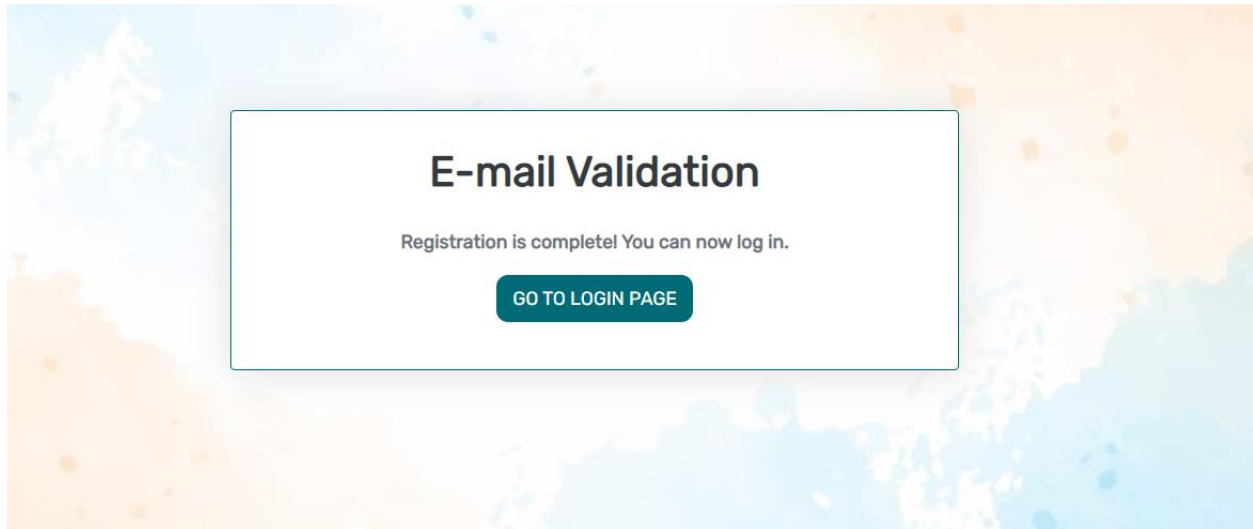
Password

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” to proceed.




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

A screenshot of the IAMRARE LOGIN page. The page has a white background with a light blue and orange border. At the top, the text "IAMRARE®" is displayed in a large, bold, black font, with "LOGIN" in a smaller, black font below it. There are two input fields: "e-mail" and "password". The "password" field has a small eye icon to its right. Below the input fields is a checkbox labeled "Keep me logged in". A large, dark teal button with the text "→ LOGIN" is positioned below the checkbox. Below the button are two smaller buttons: "⚠️ Forgot Password" and "+ Create an Account". Below these buttons is a line of text: "By logging in, you agree to the [Privacy Policy](#) & [Terms and Conditions](#) of NORD." At the bottom of the page is a logo for the "RARE T2ART HOPE FUND". The logo features a stylized figure with a green head, blue body, and red shoes, with the text "Featuring RARE T2ART HOPE FUND" around it.

Add a Participant

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

English ▾



Welcome, Jane!


Welcome to the IAMRARE® program, home of
Aspartylglucosaminuria (AGU) Registry and 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. A participant refers to a person with AGU.



Add a Participant

Are you adding yourself or another person?

Yourself

Someone else

- Step 3: Fill out the Participant's information. A participant refers to a person with AGU.

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.”



Thank you for registering your first participant!

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

Not right now

Yes, complete consent for this participant.

- 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

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

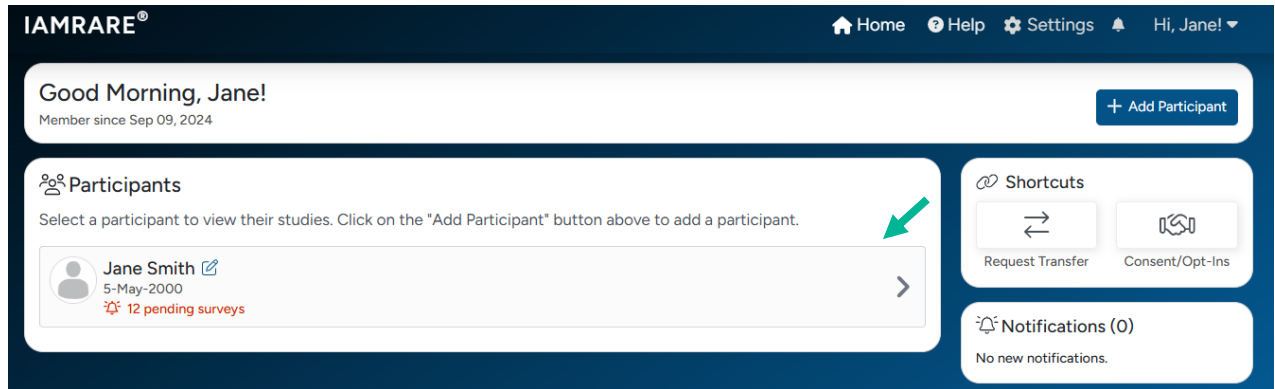
- ☐ Interest in hearing about other studies from [Rare Trait Hope Fund](#)
- ☐ Interest in hearing about relevant clinical trials
- ☐ Interest in donating specimens or DNA (biobanking) for future research
- ☐ Interest in learning more about [Rare Trait Hope Fund](#)
- ☐ Interest in signing up for a [Rare 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](#)

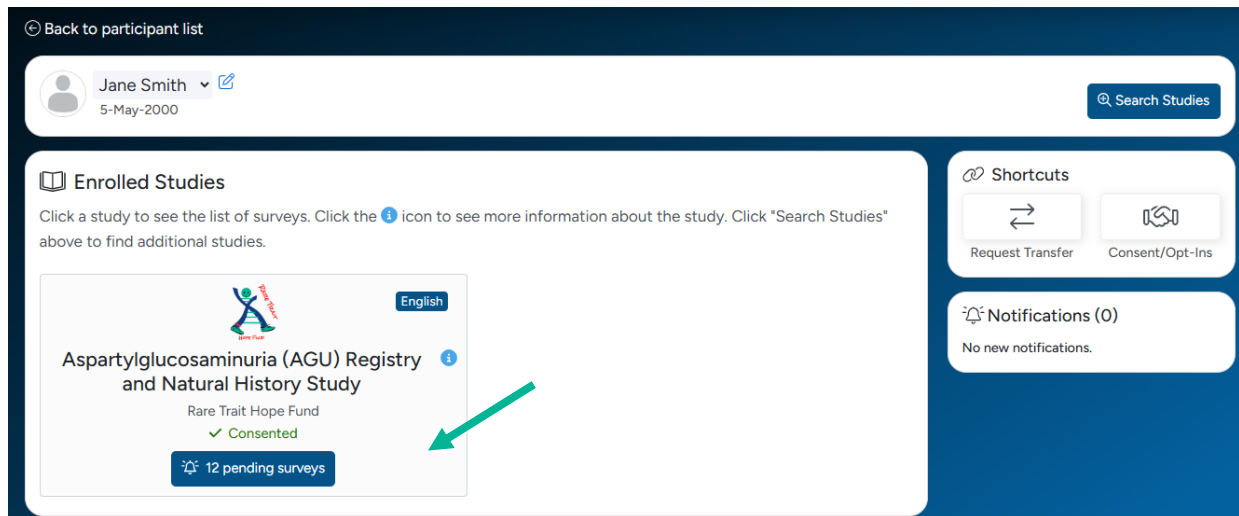
- Step 5: Once you have reviewed your consent, click "Close". You will then be able to start taking surveys.

Taking Surveys

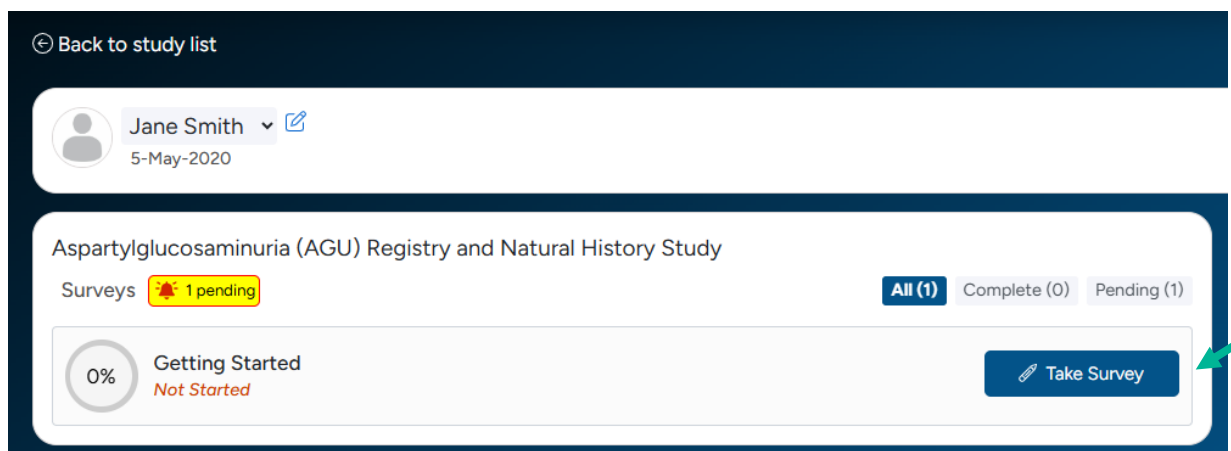
- Step 1: Click on your Participant.



- Step 2: Click on the appropriate study.



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



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.

Back to study list

Jane Smith 5-May-2000

Aspartylglucosaminuria (AGU) Registry and Natural History Study

Surveys 11 pending All (13) Complete (2) Pending (11)

Getting Started Completed on 9-Sep-2024	View Responses 1 Reports
Demographics Completed on 27-Mar-2025	View Responses 1 Reports

View Consent and Opt-Ins

- Step 1: After consenting to the study, you can view your consent at any time. Navigate to the Enrolled Studies page. Then, 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”.

Back to participant list

Jane Smith 5-May-2020 [Search Studies](#)

Enrolled Studies
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.

Shortcuts

- Request Transfer
- Consent/Opt-Ins

Back to study list

Jane Smith 5-May-2020

Consents/Opt-Ins

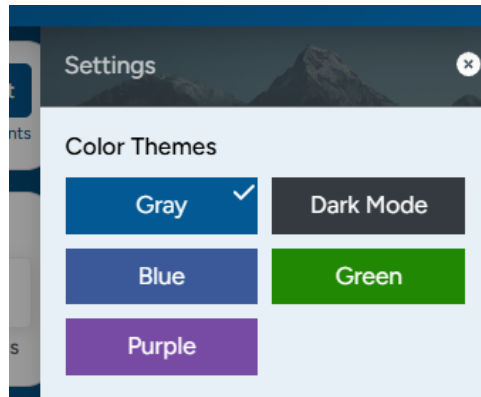
Study Name	Consent Status	Consented On	Actions
Aspartylglucosaminuria (AGU) Registry and Natural History Study	Consented	27-Mar-2025	View Consent Revoke Opt-Ins

Dark Mode Settings

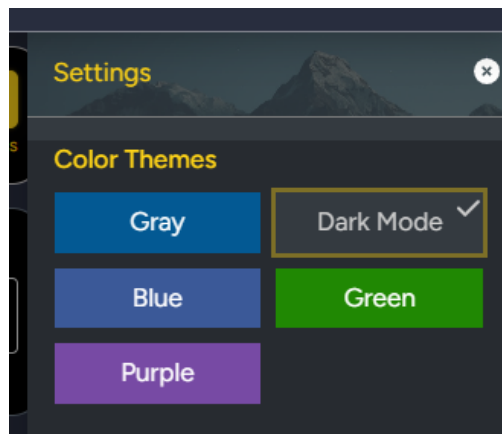
- Step 1: You can view the platform in Dark Mode. First, click Settings.



- Step 2: Select Dark Mode.



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

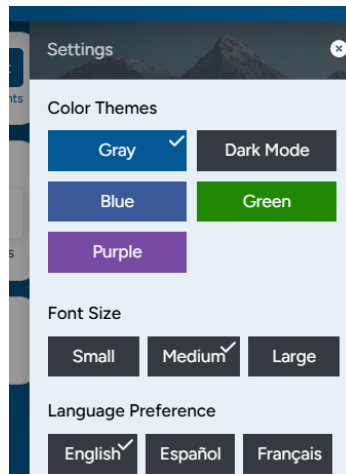


Display Settings

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



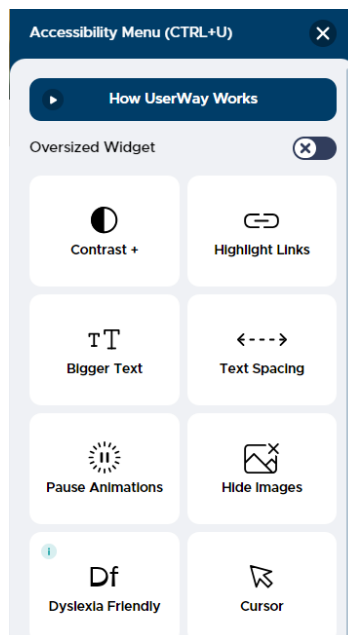
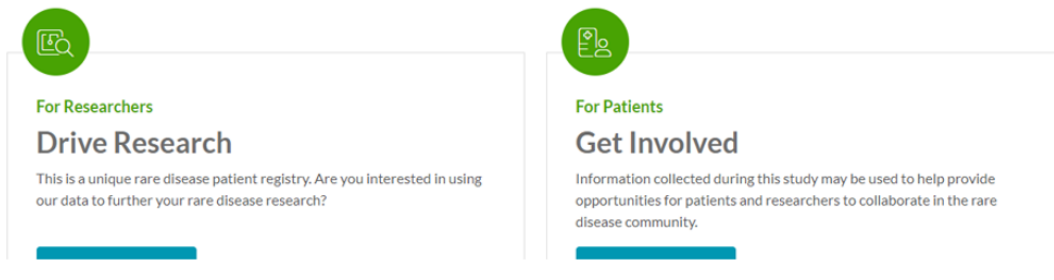
- Step 2: Select a color theme, a font size, or language preference.



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

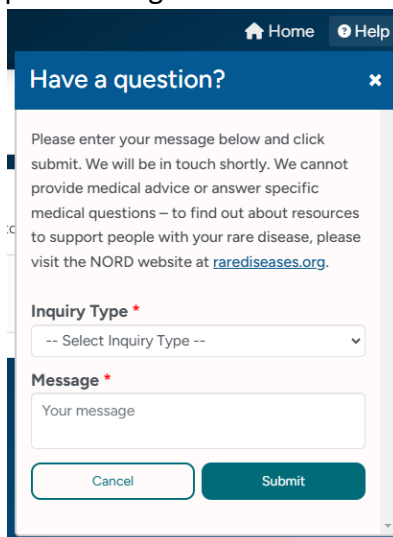
Microsite Visibility

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



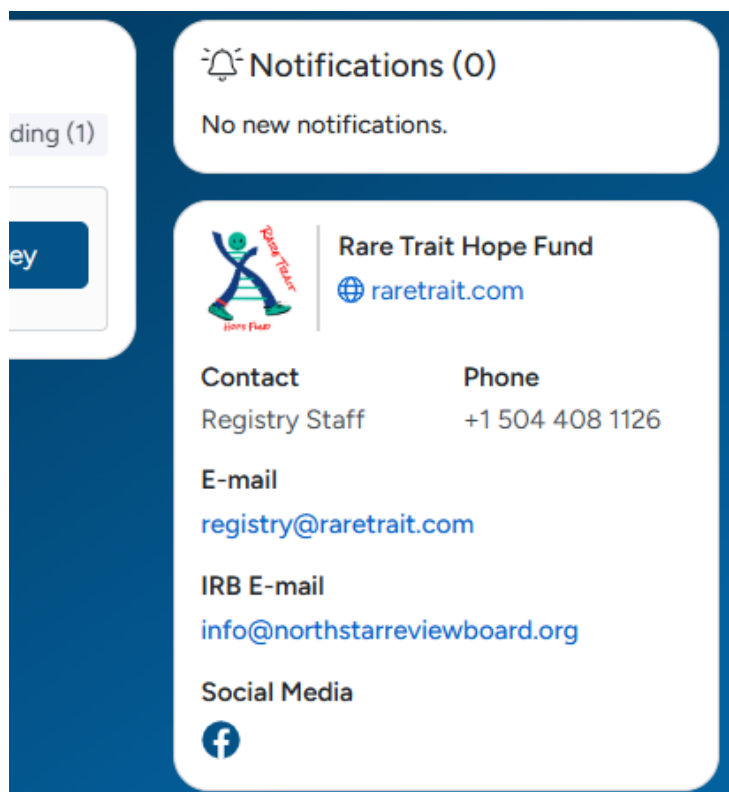
Need Assistance?

- 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 blue header containing 'Home' and 'Help' icons. A white modal box titled 'Have a question?' with a close button is displayed. Inside the modal, 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 for 'Inquiry Type' with the placeholder '-- Select Inquiry Type --'. Underneath is a text input field for '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 section on a dashboard. It features a 'Notifications (0)' header with a bell icon and the text 'No new notifications.' Below this is a section for the 'Rare Trait Hope Fund' with a logo and the website 'raretrait.com'. The contact information is organized into two columns: 'Contact' and 'Phone'. The 'Contact' column lists 'Registry Staff', 'E-mail' (with the address 'registry@raretrait.com'), 'IRB E-mail' (with the address 'info@northstarreviewboard.org'), and 'Social Media' (with a Facebook icon). The 'Phone' column lists the number '+1 504 408 1126'.