



**LIVING
RARE**Study

Participant User Guide


This guide details how to register a new account on the IAMRARE platform. If you already have an account associated with another study on the IAMRARE platform, do **not** create a new account for the Living Rare study. Log in to your existing account and use the “Search Studies” tab on your dashboard to find and consent to the Living Rare study.

If you do not yet have an account on the IAMRARE platform, click “+ Create an Account”.

IAMRARE®


LOGIN

e-mail

password 

☐ Keep me logged in


➔ LOGIN

 Forgot Password

+ Create an Account

By logging in, you agree to the [Privacy Policy](#) & [Terms and Conditions](#) of NORD.

Featuring

 **LIVING
RARE**Study

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

NORD
National Organization
for Rare Disorders

**LIVING
RARE Study**

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

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for Rare Disorders

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RARE Study**

Registration

Terms & Conditions | Contact Info | Notifications | Review & Submit | Confirmation

Country of Residence *

First Name * Last Name *

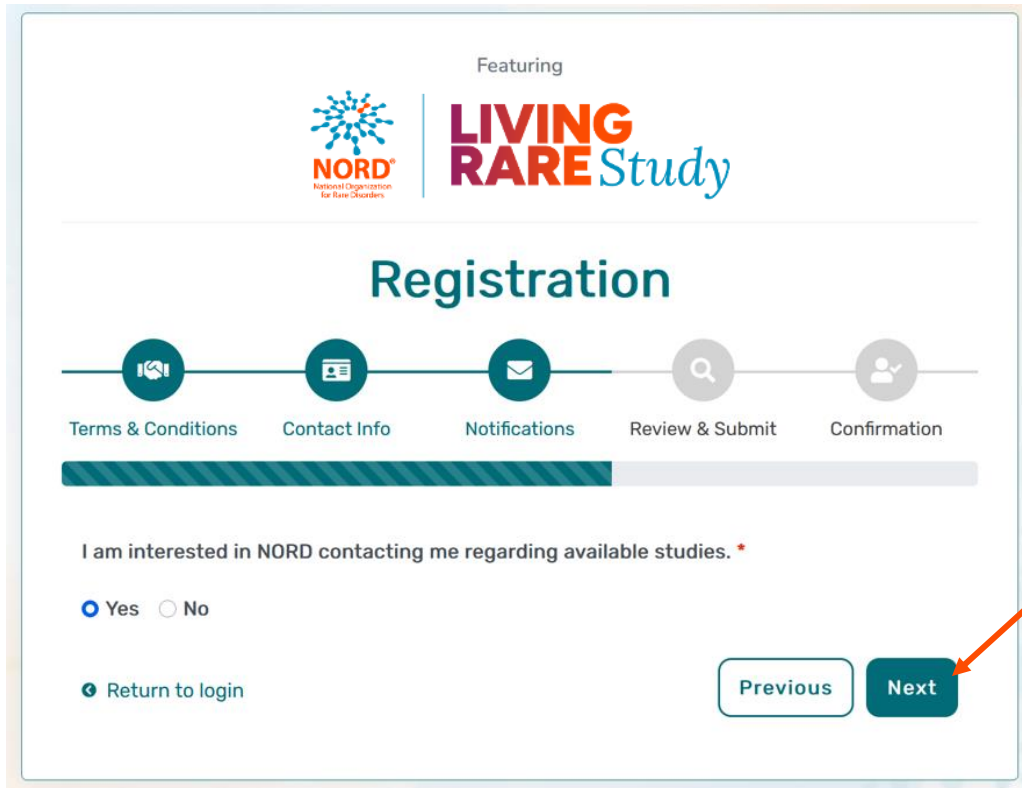
First Name Last Name

E-mail *


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

 **LIVING RARE** Study

Registration

Terms & Conditions Contact Info Notifications Review & Submit Confirmation

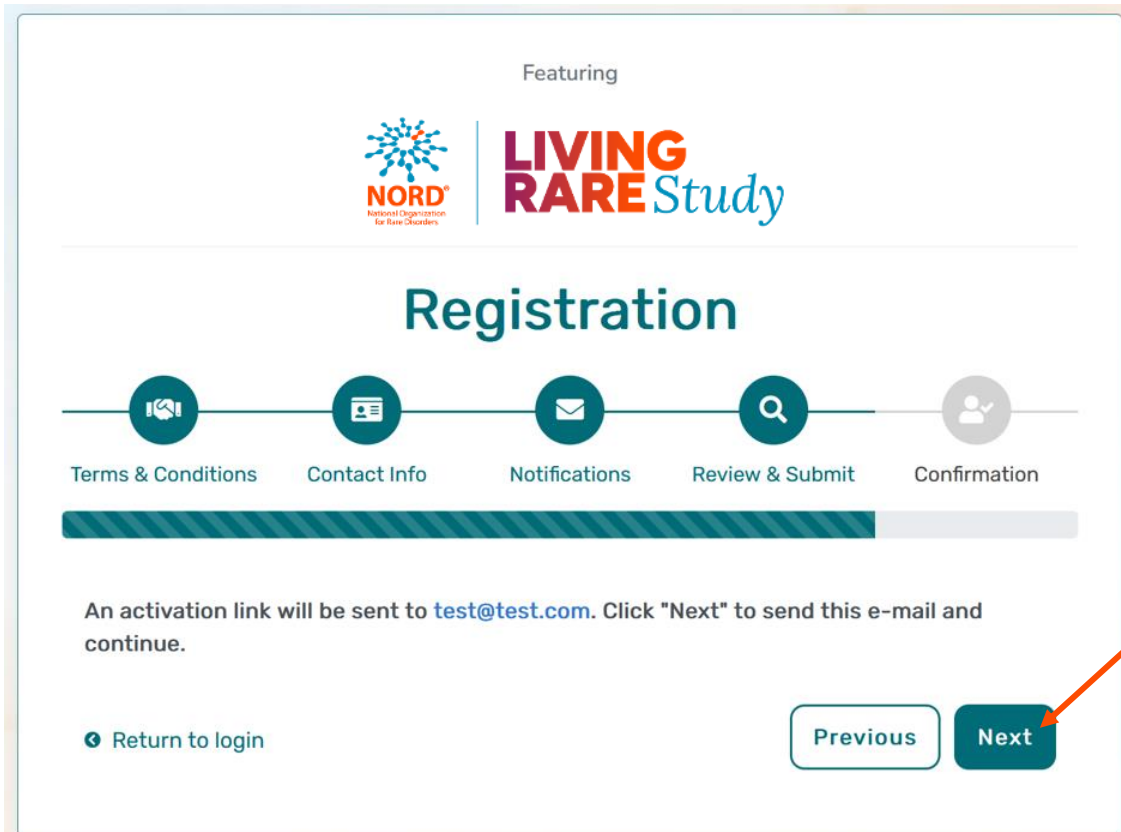
I am interested in NORD contacting me regarding available studies. *

☒ Yes ☐ No


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

An orange arrow points to the "Next" button.

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



Featuring

 **LIVING RARE** Study

Registration

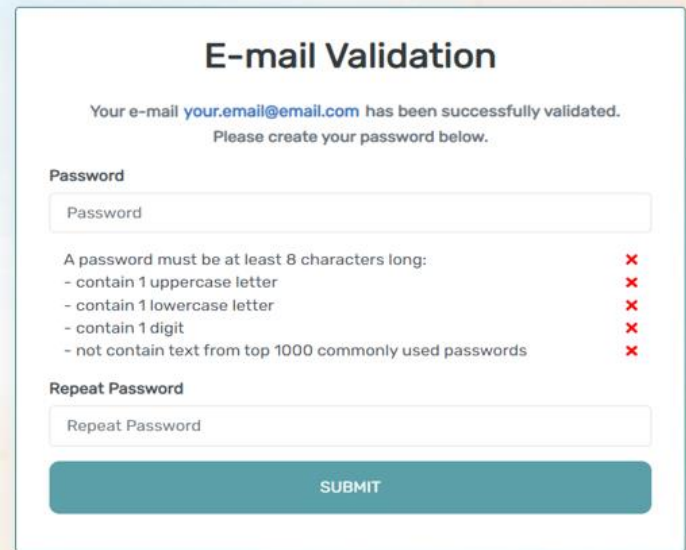
Terms & Conditions Contact Info Notifications Review & Submit Confirmation

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

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

An orange 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.

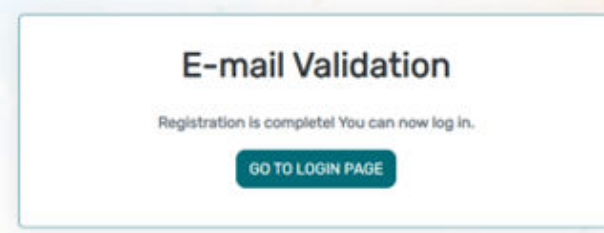
Password

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”.

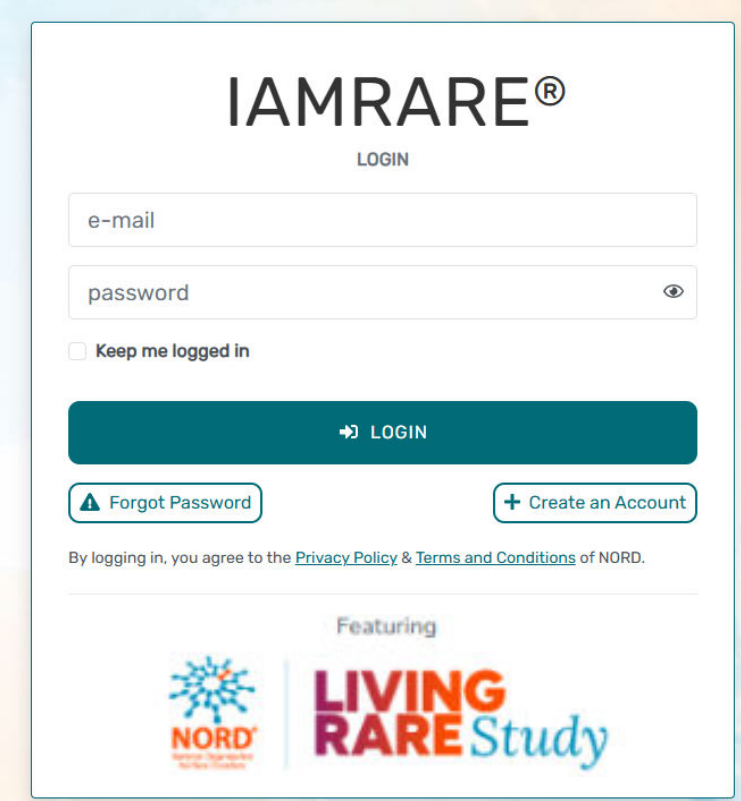


E-mail Validation

Registration is complete! You can now log in.


GO TO LOGIN PAGE

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




IAMRARE®

LOGIN




☐ Keep me logged in

→ LOGIN

 [Forgot Password](#) [+ Create an Account](#)

By logging in, you agree to the [Privacy Policy](#) & [Terms and Conditions](#) of NORD.


Featuring

 **LIVING RARE** Study

Add a Participant

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

English ▾



**LIVING
RARE**Study

Welcome, Jane!

Welcome to the IAMRARE[®] program, home of **Living Rare 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.



**LIVING
RARE**Study

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 *

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 * ?

Sex Recorded on Birth Certificate

▼

Country of Residence * ?

Choose country

▼

State/Province/Region of Residence * ?

Country of Birth *

Choose country of birth

▼


City/Municipality of Birth *

What Is Your Relationship to ? * ?


Choose relationship

▼

Profile Image

 Choose Avatar

OR

 Upload Your Own Image

No image selected

CANCEL

SUBMIT

Consent to the Study

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

The screenshot shows a registration confirmation window. At the top left is the NORD logo (National Organization for Rare Disorders). To its right is the 'LIVING RARE Study' logo. The main text reads: 'Thank you for registering your first participant! Would you like to consent to participate in the Living Rare Study?'. At the bottom are two buttons: 'Not right now' (light blue) and 'Yes, complete consent for this participant.' (dark blue).

- 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.”

This is the 'Consent Overview' page for 'John Doe'. It contains the following text: 'Those eligible to participate in our study include: Participant: An individual diagnosed with Rare Disease or suspected to have a Rare Disease who is at least 18 years of age, the age of majority in their state, 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. All study participants need to live in the United States.' A blue 'Next' button is in the bottom right corner, with an orange arrow pointing to it.

This is the 'Consent for a Person with a Legally Authorized Representative (Caregiver)' page for 'John Doe'. It includes contact information for the Principal Investigator (Edward Neilan, MD, PhD), phone number (475) 252-2144 extension 416, and email LRStudy@rarediseases.org. The sponsor is the National Organization for Rare Disorders. The 'Key Information' section explains the study's purpose and lists five topics to be explored: 1. Learning more about the resources, time and challenges it takes to manage the healthcare for someone with a rare disease. 2. Understanding the challenges that the Participant faces living with a rare disease and the impact on them, their daily life, their family, and friends. 3. Understanding the challenges that you face living with or caring for someone with a rare disease and their impact on you and your life, your family, and friends. 4. Exploring how the Participant manages their mental health and wellness and the challenges they face and strategies they use. 5. Exploring how you manage your mental health and wellness, the challenges you face in doing so and strategies for taking care of yourself. At the bottom, it states: 'If you choose to participate, you will be asked to answer questions about your experiences with rare diseases, once a year using your computer, tablet or mobile phone. The amount of time the surveys take will vary'. There are 'Previous' and 'Next' buttons at the bottom right, with an orange arrow pointing to the 'Next' button.

John Doe

Consent to Living Rare 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 study;
- 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 study and your and the Study Participant's participation;
- That you wish to provide the Study Participant's personal data to the study 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 Living Rare Study 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 Living Rare Study have been answered to my satisfaction, and I understand the purpose of the study and the risks of participation.

☐ I wish to provide the Study Participant's research data to the Living Rare Study for the purposes described above under Study Aims.

☐ I wish to provide the Study Participant's research data to the Living Rare Study for future research within recognized ethical standards for scientific research, as described under How We Use the Data.

☐ I wish to provide research data about myself as described under How You Provide Data, where applicable, to the Living Rare Study only for the purposes described under How We Use the Data.

☐ I have explained the study to the Study Participant to the extent they are able to understand, and the Study Participant has given their assent to participate in this study.

Previous Next

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

John Doe

Consent to Living Rare 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 Living Rare Study

Select Opt-Ins for this study

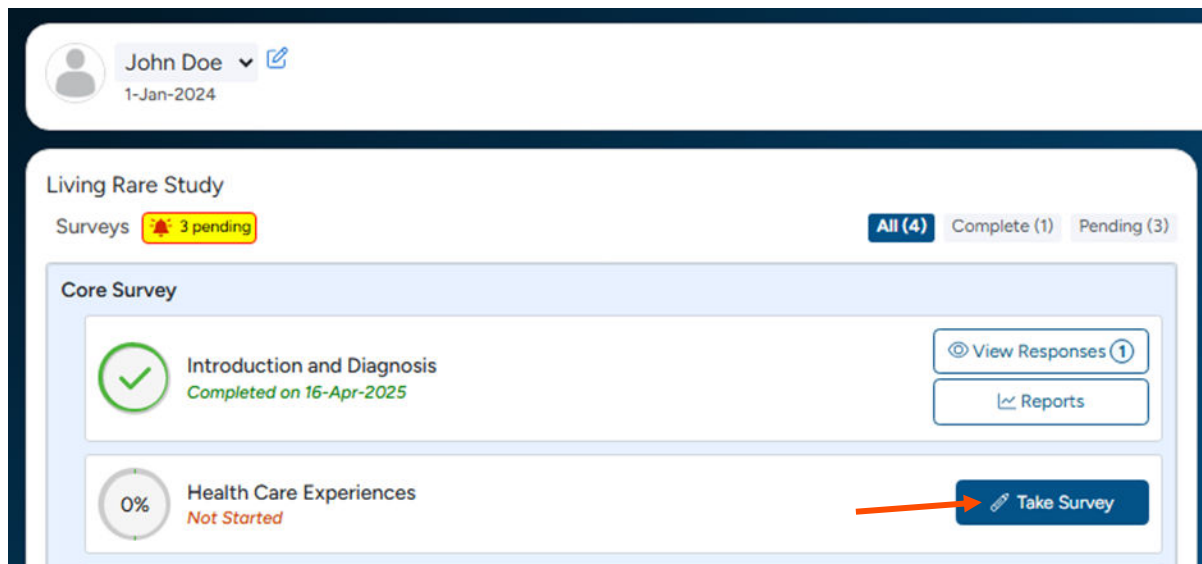
☐ Interest in hearing about other studies from **National Organization for Rare Disorders**

☐ Interest in hearing about relevant clinical trials

☐ Interest in learning more about **National Organization for Rare Disorders**

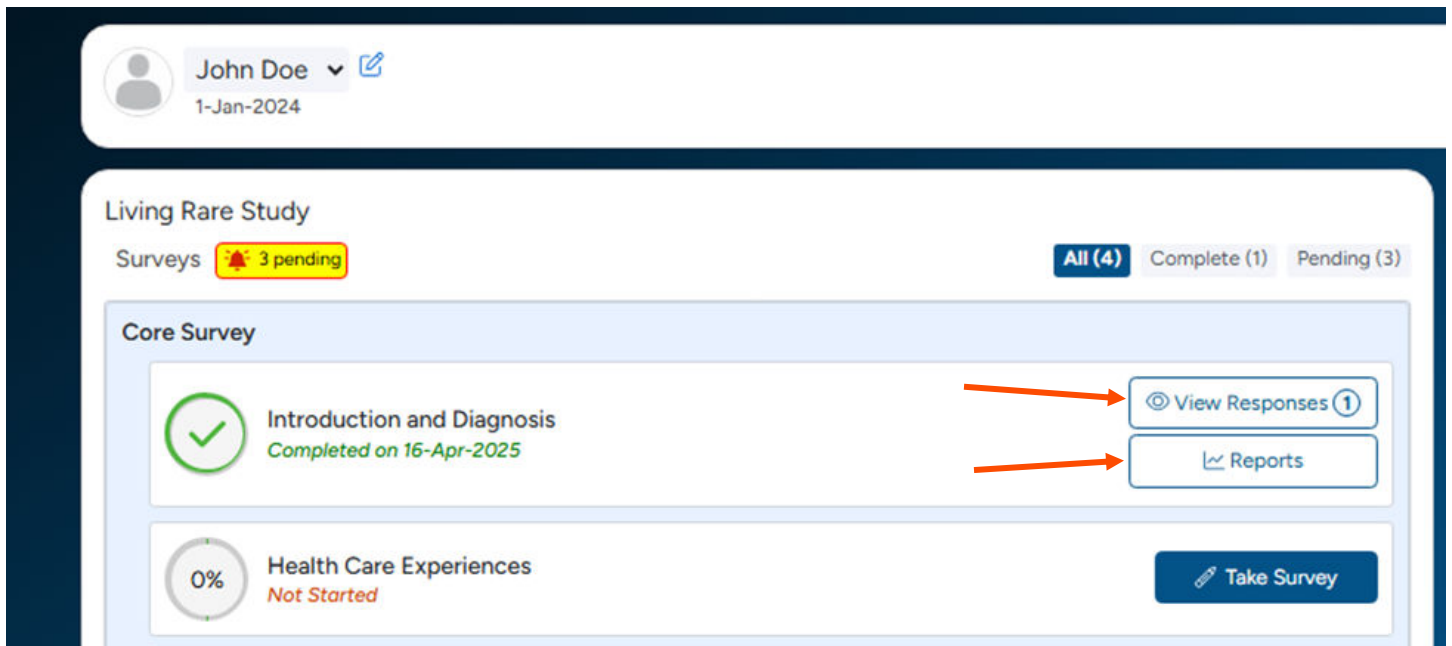
Save and Review

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



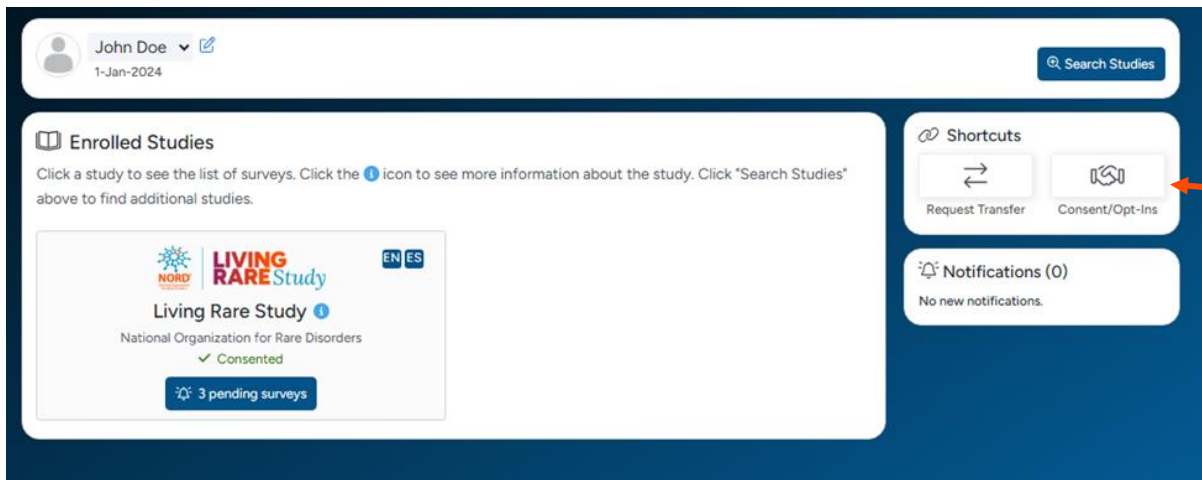
View Responses and Reports

- 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.

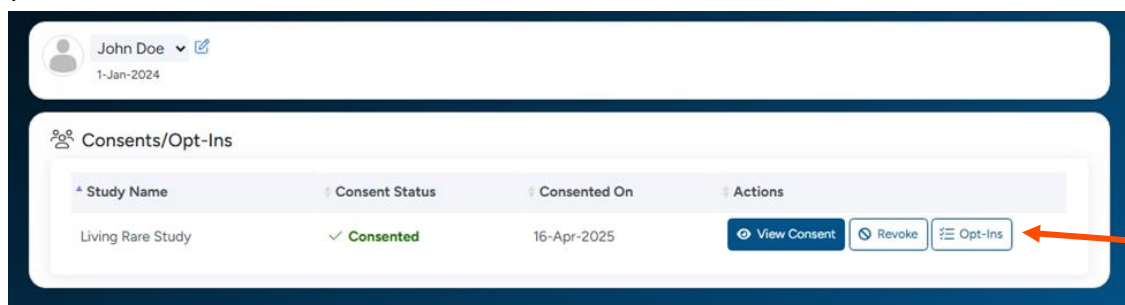


View Consent and Opt-Ins

- 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”.

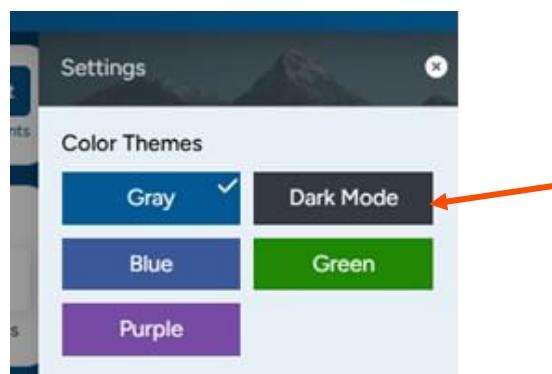


Dark Mode Settings

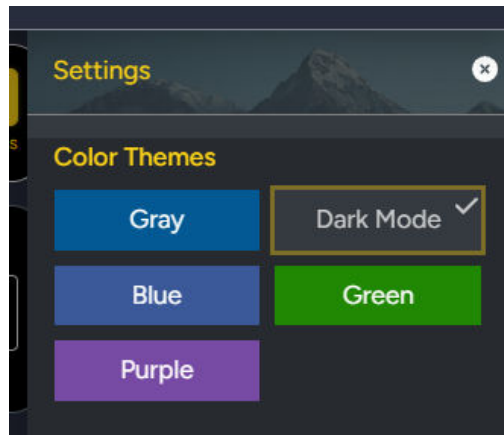
- Step 1: You can view the platform in Dark Mode. First, click Settings.



- Step 2: Select Dark Mode.



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

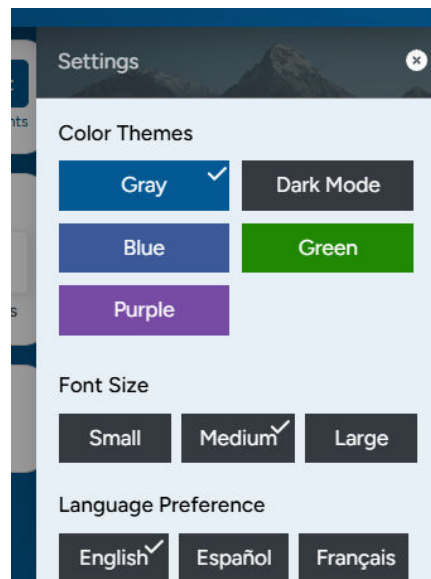


Display Settings

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



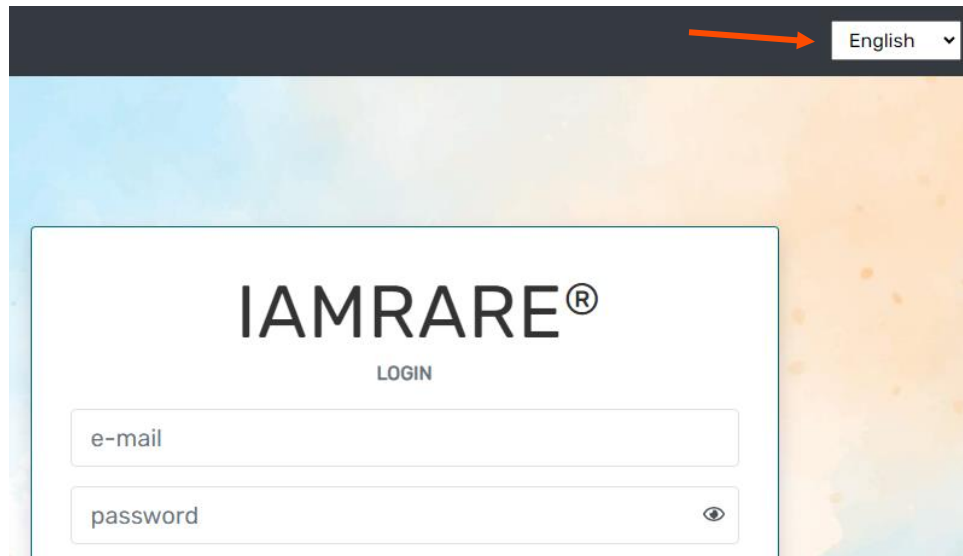
- Step 2: Select a color theme, a font size, or language preference.



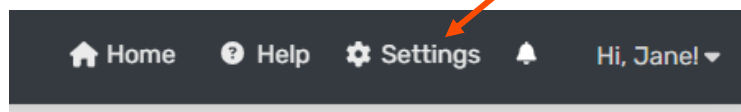
- Step 3: Exit the Settings menu, and your selection will be saved.

Language Selection

- To change your platform language selection on the login/register page, select the dropdown that says “English”, and choose your preferred language.

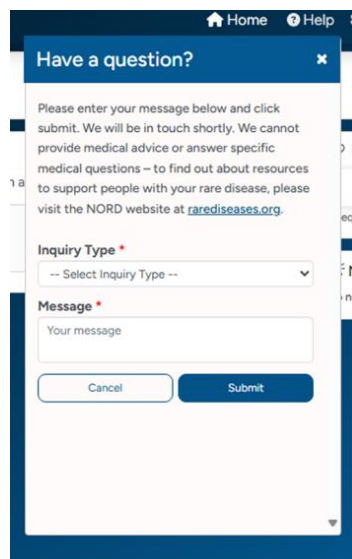


- To change your platform language selection after you’ve logged in, click “Settings”, and choose your preferred language.



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.

