



## 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



NORD®  
National Organization  
for Rare Disorders

LIVING  
RARE Study

## Register for an Account

- Step 1: Select the appropriate Account Type. If you need more information to help you choose, click “Not sure? Help me choose”.
  - If you have been diagnosed with or are suspected to have a rare disease, select **Participant Account**.
  - If you are entering information for **someone else** who has been diagnosed with or is suspected to have a rare disease, select **Caregiver Account**.

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## 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.](#)

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

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## Participant Registration

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

Below are links to the IAMPARE 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 spaces provided. When you are finished with this page, click “Next”.

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## Participant Registration

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

**Country of Residence \***

United States

**First Name \*** **Last Name \***

Jane Doe

**E-mail \***

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

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

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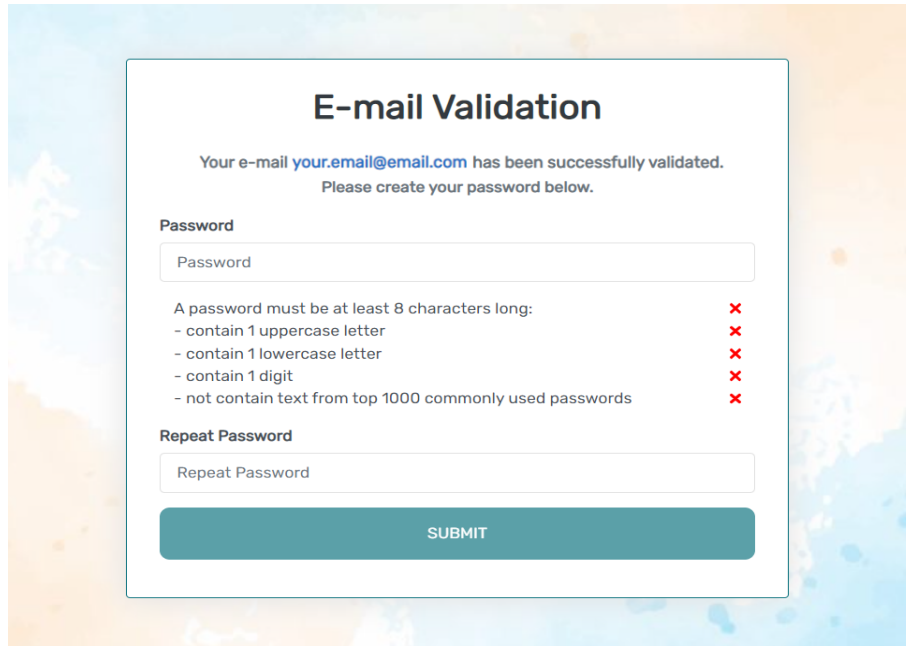
## Participant Registration

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

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 6: 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.

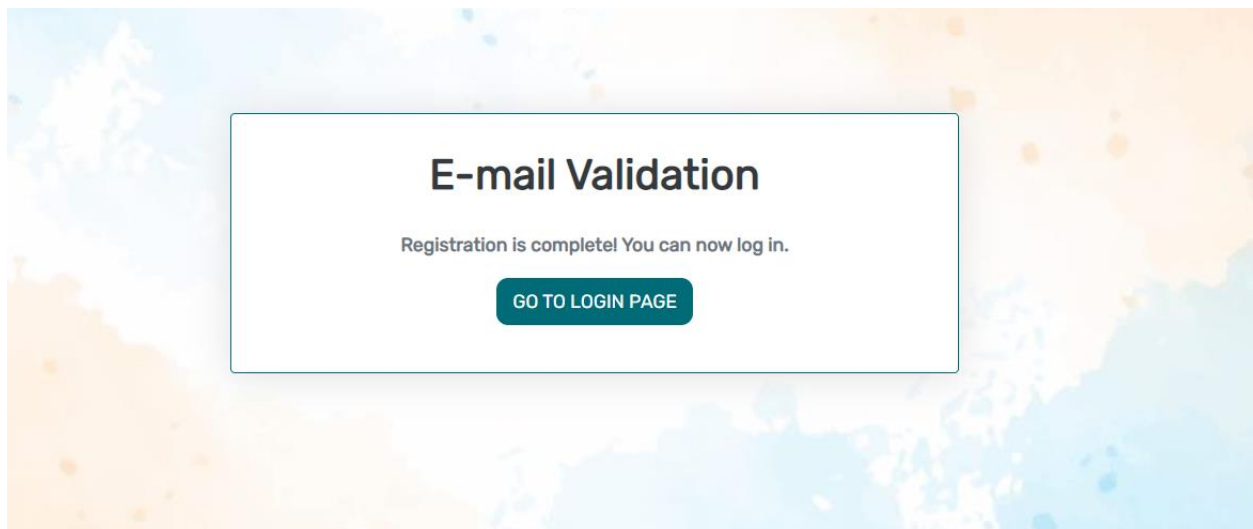
**Password**

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 7: 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 8: 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.

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National Organization  
for Rare Disorders




**LIVING  
RARE** Study

## Add a Participant

- Step 1: If you created a Participant account, click “Create New Profile” to start. If you created a Caregiver account, click “Yes, register new participant”.

### Participant:

English



**LIVING RARE Study**

Hi, Janel

Welcome to the IAMRARE® program powered by NORD.

If you are a new user, click on [Create new profile](#) button below.


If you are transferring a record from a Caregiver's account (such as a parent's account), click on the [Transfer My Record](#) button below. **Living Rare Study**

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

Don't show this again

### Caregiver:

English



**LIVING RARE Study**

Welcome to the IAMRARE® program, home of **Living Rare Study!**

Would you like to register a participant to join **Living Rare Study?**

[Not right now](#) [Yes, register new participant](#)

Don't show this again

- Step 2: Fill out the Participant's information.

### Complete Participant Profile

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/Region of Residence \*

Country of Birth \*

City/Municipality of Birth \*

Profile Image

OR

No image selected

## Consent to the Study

- Step 1: If you are the Participant, click “Yes, complete consent for this study.” If you are a Caregiver, click “Yes, complete consent for this participant.”

**Participant:**

**Caregiver:**

Would you like to consent to participate in **Living Rare Study**?

Thank you for registering your first participant!  
Would you like to consent to participate in **Living Rare Study**?

Not right now Yes, complete consent for this study.

Not right now Yes, complete consent for this participant.

- 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 **Living Rare Study**

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.

I acknowledge that I am at least 18 years of age and the age of majority in my state, and able to provide consent on behalf of the Study Participant. For validation purposes, I am providing my date of birth. This is requested to abide by good research practices and will be used for no other purpose than to confirm current age.

Previous Next

- Step 3: Once you click “Next” and reach the next screen, click “Continue to Opt-Ins”.



## 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.

The screenshot shows the user's dashboard for the Living Rare Study. At the top left, there is a logo for the study and a language selector set to 'English'. Below the logo, it says 'Living Rare Study' and 'Consented'. A notification indicates 'You have 1 pending surveys.' In the center, there is a 'Search Studies' button. Below this, a 'Surveys' section shows '1 pending' survey. The survey card is titled 'Core Survey' and contains a sub-card for 'Introduction and Diagnosis' which is 'Not Started'. A red arrow points to a 'Take Survey' button on the right side of the sub-card. On the far right, there is a 'Contact' sidebar with information for the sponsor, contact details, and email addresses.

## 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

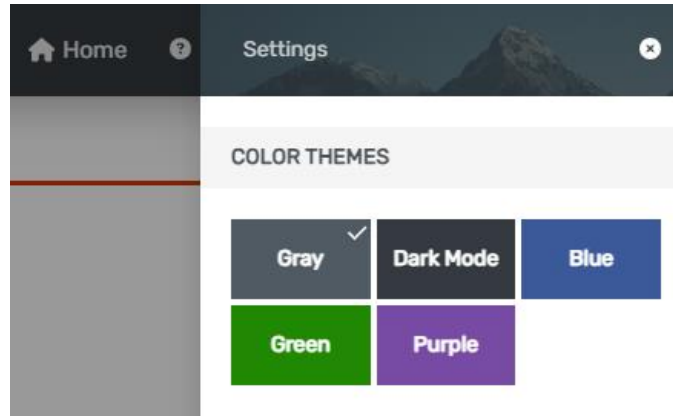
- Once you have consented to the study, you are able to view your consent at any time. Click “Consents/Opt-Ins” to see your consent and opt-ins. You may revoke your consent at any time by clicking “Revoke”. You may also edit your Opt-Ins by clicking “Opt-Ins”.

Study Name	Consent Status	Consented On	Actions
Living Rare Study	✓ Consented	18-Sep-2024	View Consent Revoke Opt-Ins

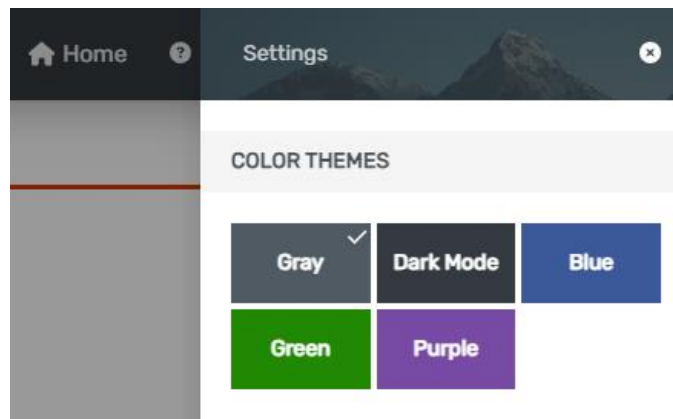
## Dark Mode Settings

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

- Step 2: Select Dark Mode.

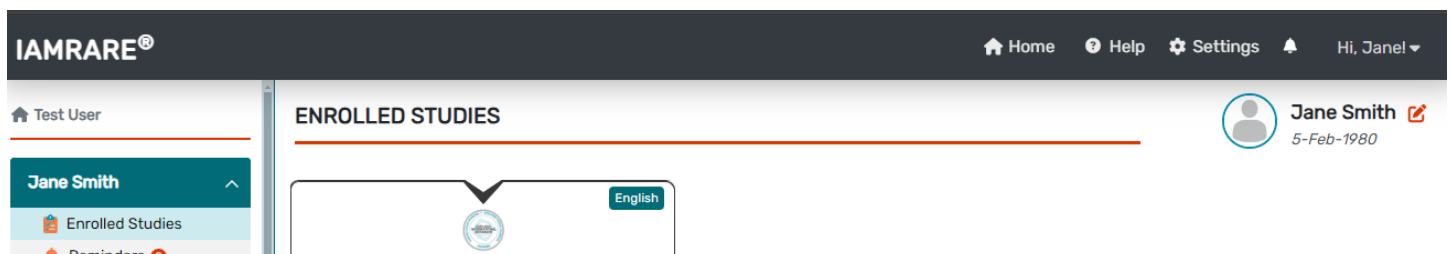


- Step 3: Exit the Settings menu, and your selection will be saved.

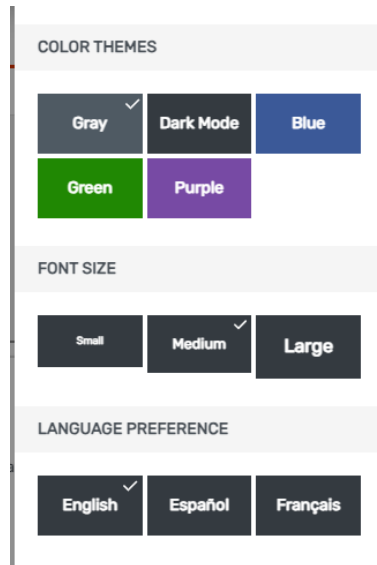


## Display Settings

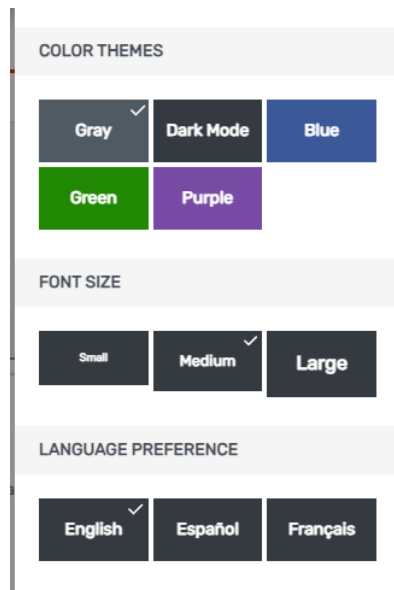
- Step 1: You can change the platform display settings. First, click Settings.



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

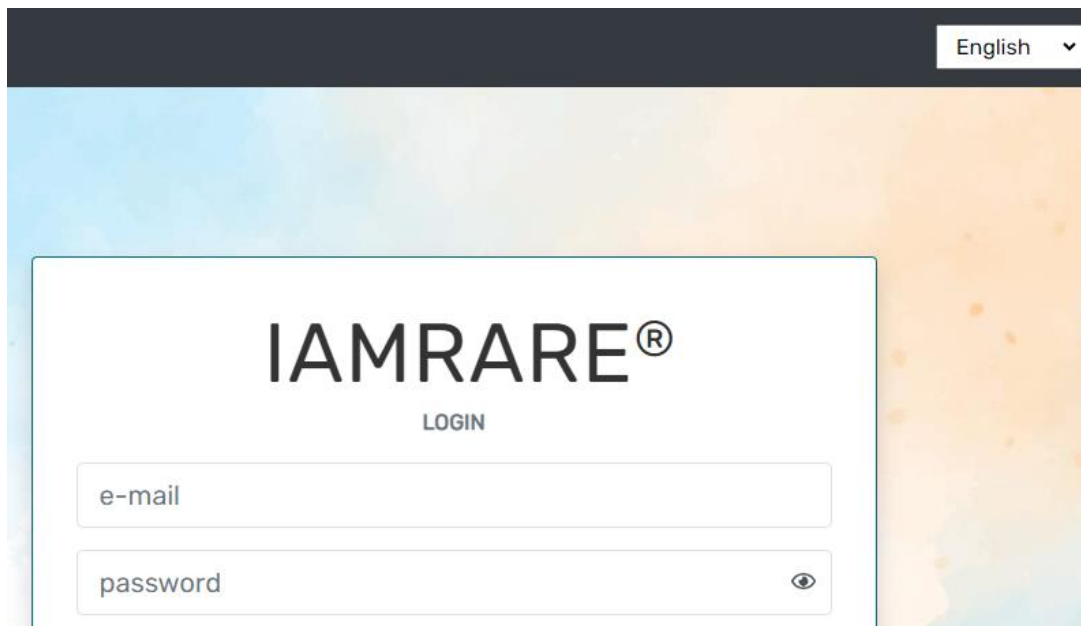


- Step 3: Exit the Settings menu, and your selection will be saved.

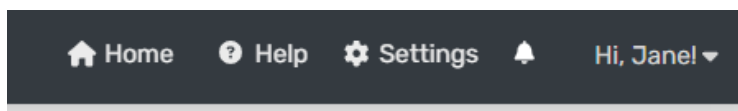


## Language Selection

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

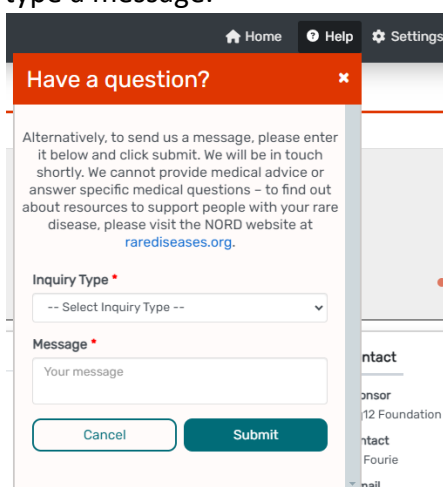


- To change your platform language selection after you've logged in, click "Settings", and choose your preferred language.



### 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.

## Contact

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## Sponsor

National Organization for Rare Disorders

## Contact

Living Rare Study Team

## E-mail

[lrstudy@rarediseases.org](mailto:lrstudy@rarediseases.org)

## IRB E-mail

[info@northstarreviewboard.org](mailto:info@northstarreviewboard.org)

## Study available in:

English