

ileakSM registry 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”.

The screenshot shows the 'Registration' page for the spinal/csf leak FOUNDATION. At the top, it says 'Featuring' and displays the logo with the tagline 'because your dura matters*'. Below the logo is a progress bar with five steps: Terms & Conditions (active), Contact Info, Notifications, Review & Submit, and Confirmation. The main content area contains a paragraph explaining the purpose of the Terms and Conditions and Privacy Guidelines. Below this is a section titled 'Acknowledgements:' with four checkboxes and their corresponding text:

- 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](#) and [Privacy Policy](#), and have read the [Consumer Health Data Privacy Notice](#). *

At the bottom left, there is a link 'Return to login' and at the bottom right, a blue 'Next' button.

- Step 2: Enter your personal information in the spaces provided. When you are finished with this page, click “Next”.

The screenshot shows the 'Registration' page for the spinal/csf leak FOUNDATION, Step 2: Personal Information. The progress bar now shows 'Contact Info' as the active step. The form fields are:

- Country of Residence * (dropdown menu)
- First Name * (text input)
- Last Name * (text input)
- E-mail * (text input)

At the bottom left, there is a link 'Return to login' and at the bottom right, there are two buttons: 'Previous' and '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

spinal/csf leak
FOUNDATION
because your dura matters*

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

spinal/csf leak
FOUNDATION
because your dura matters*

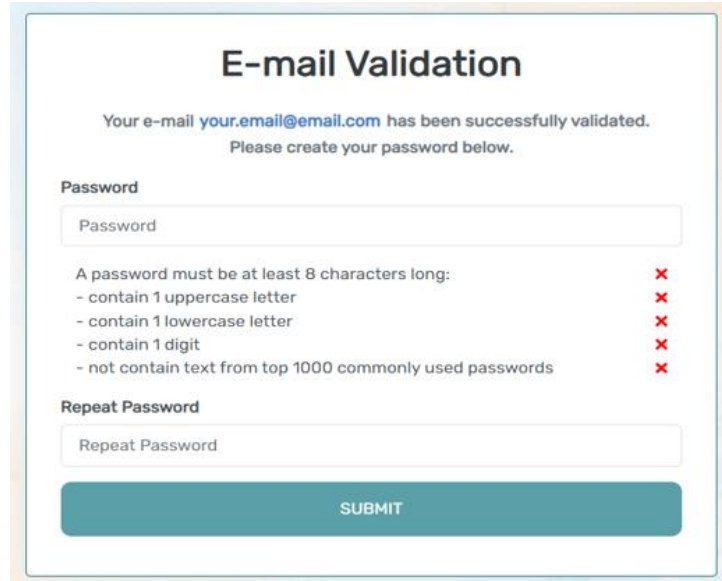
Registration

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 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.

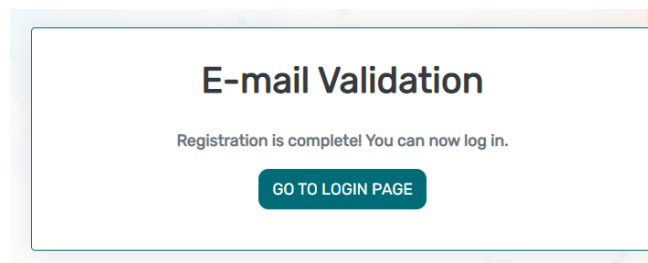
Password

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”.

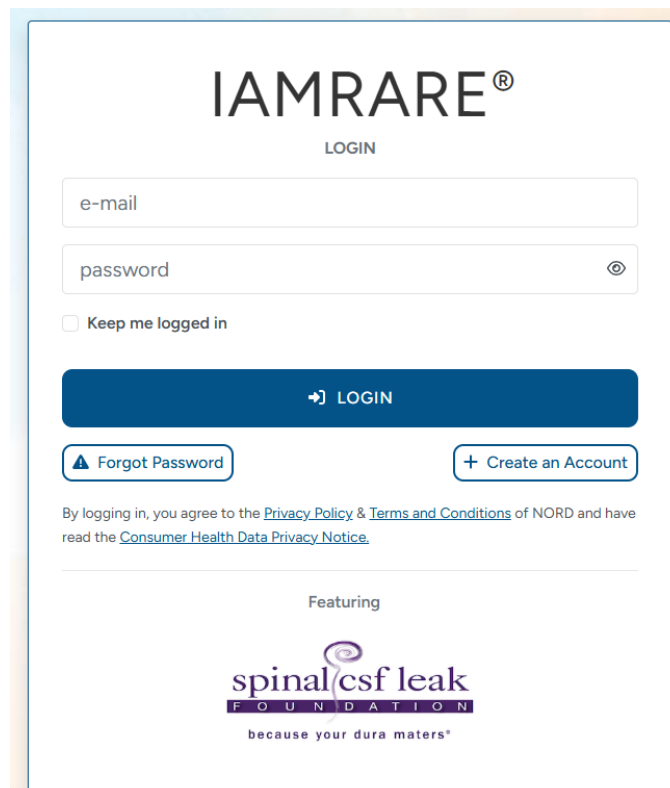


E-mail Validation

Registration is complete! You can now log in.

GO TO LOGIN PAGE

- Step 7: Log in using your new e-mail and 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 and have read the [Consumer Health Data Privacy Notice](#).

Featuring

spinal|csf leak
FOUNDATION
because your dura matters®

Add a Participant

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

English

spinal/csf leak
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because your dura maters*

Welcome, Jane!

Welcome to the IAMRARE® program, home of ileak registry(SM).
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.

English

spinal/csf leak
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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 *** [?](#)

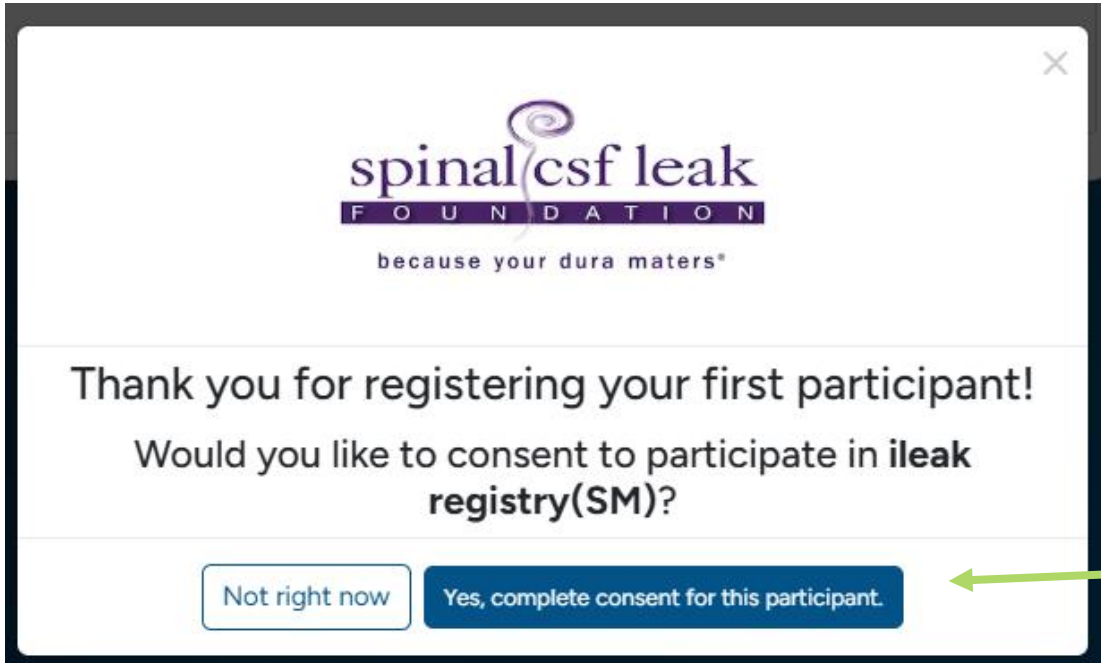
Sex Recorded on Birth Certificate * [?](#)

Country of Residence * [?](#) **State/Province/Region of Residence *** [?](#)

Country of Birth * **City/Municipality of Birth ***

Consent to the Study

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

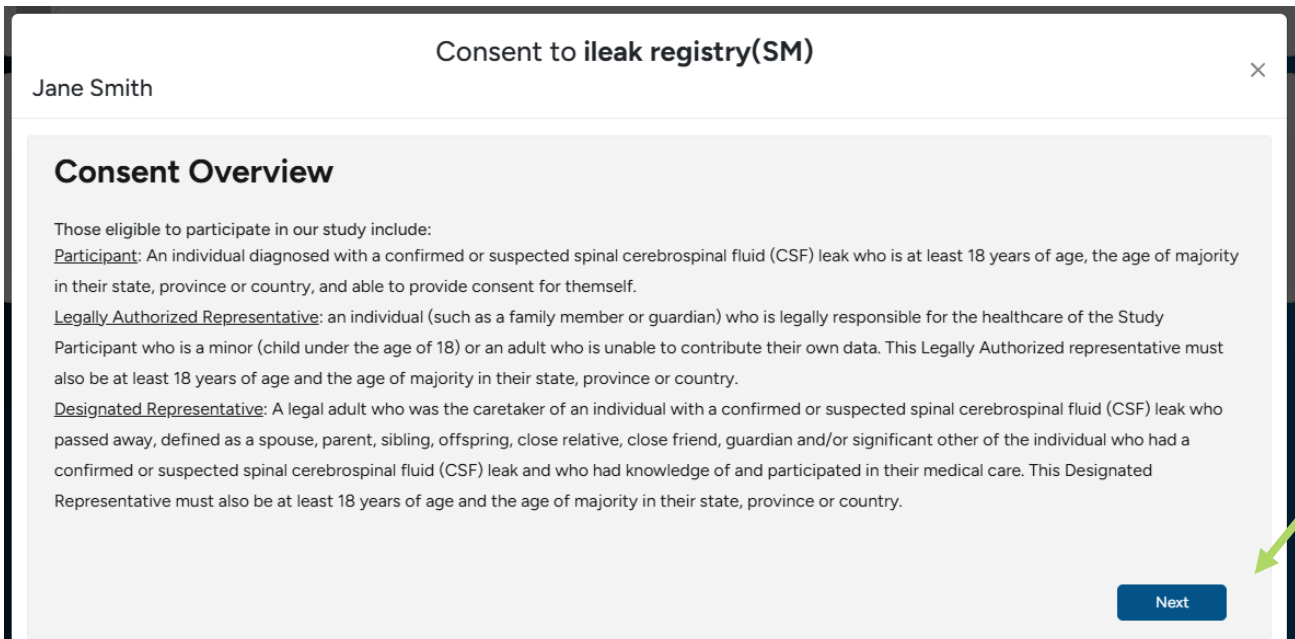


spinal csf leak
FOUNDATION
because your dura matters®

Thank you for registering your first participant!
Would you like to consent to participate in ileak registry(SM)?

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 ileak registry(SM)

Jane Smith

Consent Overview

Those eligible to participate in our study include:

Participant: An individual diagnosed with a confirmed or suspected spinal cerebrospinal fluid (CSF) leak 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 Legally Authorized representative 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 with a confirmed or suspected spinal cerebrospinal fluid (CSF) leak who passed away, defined as a spouse, parent, sibling, offspring, close relative, close friend, guardian and/or significant other of the individual who had a confirmed or suspected spinal cerebrospinal fluid (CSF) leak and who had knowledge of and participated in their medical care. This Designated Representative must also be at least 18 years of age and the age of majority in their state, province or country.

Next

Jane Smith

Consent to ileak registry(SM)

Adult Consent

Consent to Participate in the ileak registrySM and to Allow Your Data to be Shared for Future Research

Title: ileak registrySM

Principal Investigator: Jill Rau, MD, PhD

Phone: 509-425-0568


E-mail: registry@spinalcsfleak.org

Sponsor: Spinal CSF Leak Foundation

Key Information

You are invited to take part in a research study for individuals with confirmed or suspected spinal cerebrospinal fluid (CSF) leak. 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.

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



Jane Smith

Consent to ileak registry(SM)

Authorization

The following statements are intended to:


- Make sure that you have had the time and opportunity to consider whether you want to participate in this registry;
- 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 registry and your participation;
- That you wish to provide personal data to the registry for the purposes of the Study;
- That you allow for your 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 ileak registrySM. 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

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



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

Consent to ileak registry(SM) ×

Jane Smith

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 ileak registry(SM) ×

Select Opt-Ins for this study

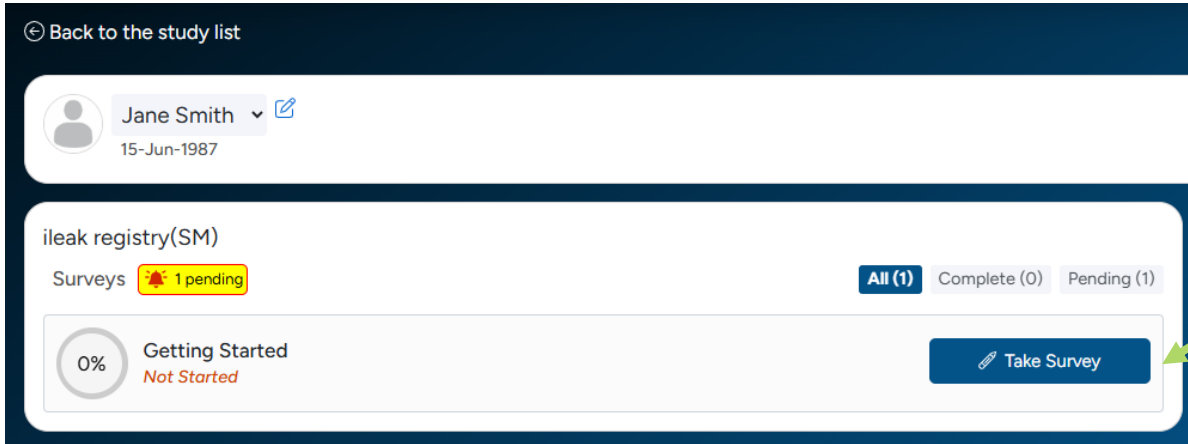
- Interest in receiving information about other studies from the **Spinal CSF Leak Foundation**.
- Interest in receiving information about initiatives from the **Spinal CSF Leak Foundation**, including advocacy efforts, community engagement opportunities, and other programming.
- Interest in receiving information about potential research opportunities related to genetic testing, donation of biological specimens and/or DNA (biobanking), if/when these opportunities become available.
- Interest in receiving information about potential research opportunities related to radiologic image banking, if/when this opportunity becomes available.
- Interest in subscribing to the **Spinal CSF Leak Foundation** newsletter to receive updates about **spinal cerebrospinal fluid (CSF) leak / intracranial hypotension**, including webinars, conferences, and other educational opportunities.

[Cancel](#) [Save Changes](#)

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

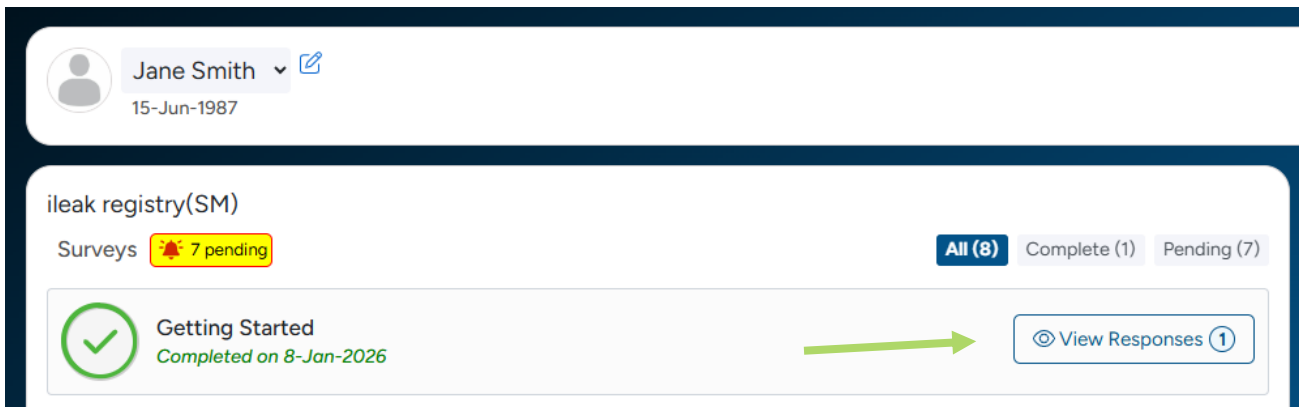
Taking Surveys

- Step 1: Click “Take Survey” for an available survey.



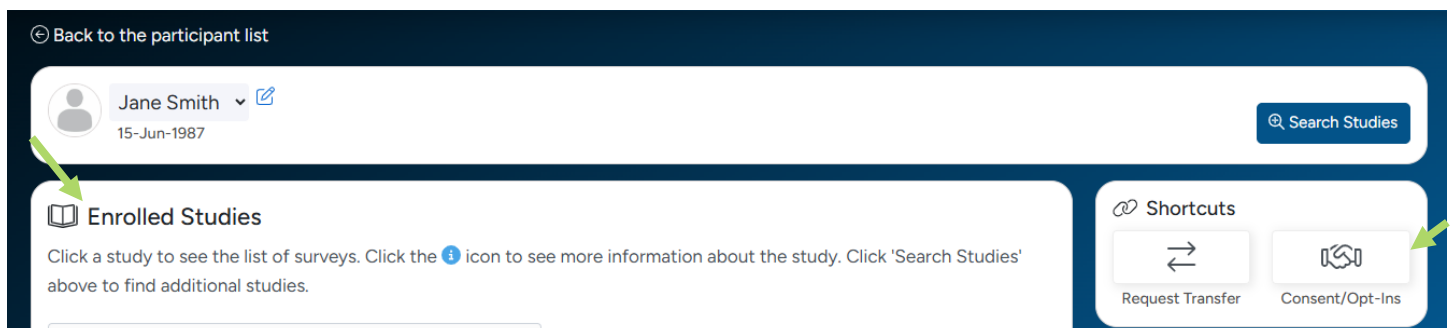
View Responses and Reports

- Step 1: Once you have submitted a survey, you are able to view your responses to that survey. 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.



- Step 2: You may revoke your consent at any time by clicking “Revoke”. You may also edit your Opt-Ins by clicking “Opt-Ins”.

Back to the participant list

Jane Smith 15-Jun-1987

Consents/Opt-Ins

Study Name	Consent Status	Consented On	Actions
ileak registry(SM)	✓ Consented	4-Mar-2026	View Consent Revoke Opt-Ins

Dark Mode Settings

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

IAMRARE®

Home Help Settings Hi, Jane!

Good Morning, Jane!
Member since Jan 08, 2026

+ Add Participant

Participants Shortcuts

- Step 2: Select Dark Mode.

Settings

Color Themes

Blue ✓ Dark Mode

Green Purple

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

Settings

Color Themes

Blue Dark Mode ✓

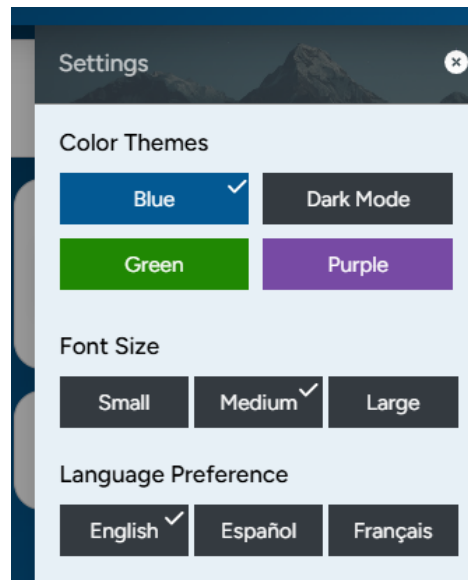
Green Purple

Display Settings

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



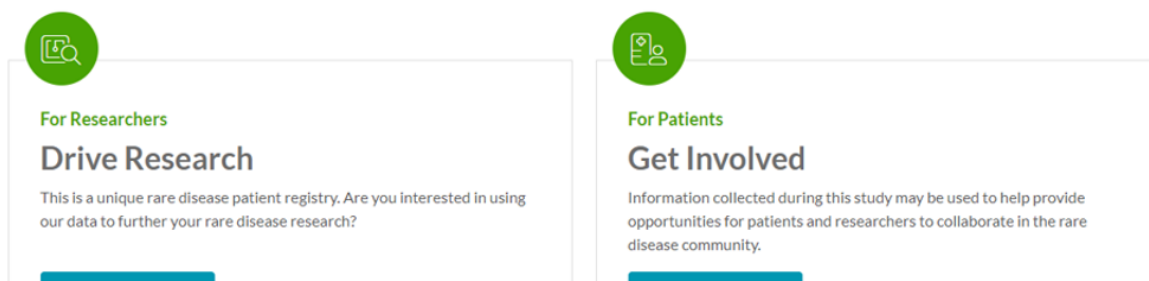
- Step 2: Select a color theme, a font size, or language preference.

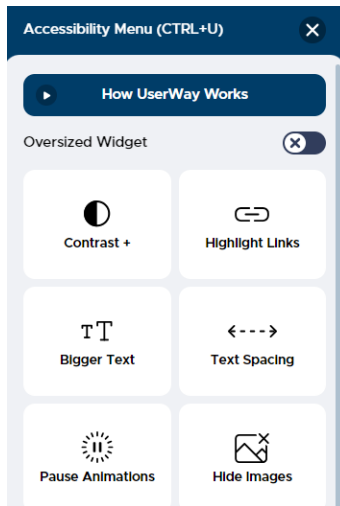


- Step 3: Exit the Settings menu, and your selection will be saved.

Microsite Visibility

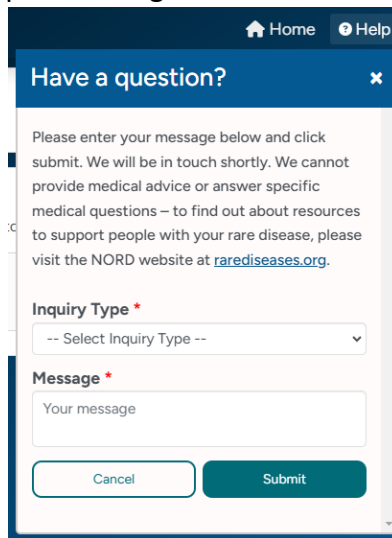
- Step 1: You can change how you view the microsite (ileak.iamrare.org) using an Accessibility menu. Click the icon of a person at the bottom of the screen. You are able to change the settings such as the contrast, text sizing, and text spacing.





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.

