

KCNT1 International 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”.

Featuring
KCNT1 EPILEPSY
FOUNDATION

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

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

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

Featuring
KCNT1 EPILEPSY
FOUNDATION

Registration

Terms & Conditions 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 available studies. When you are finished with this page, click “Next”.

Featuring
KCNT1 EPILEPSY
FOUNDATION

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
KCNT1 EPILEPSY
FOUNDATION

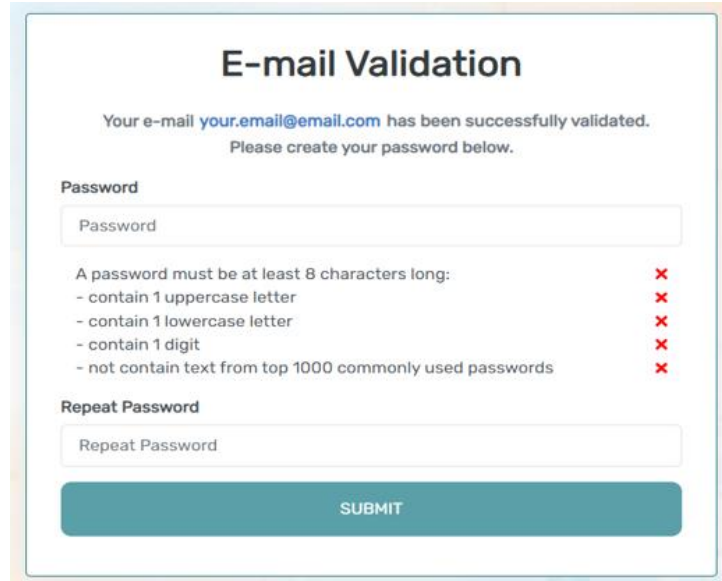
Registration

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

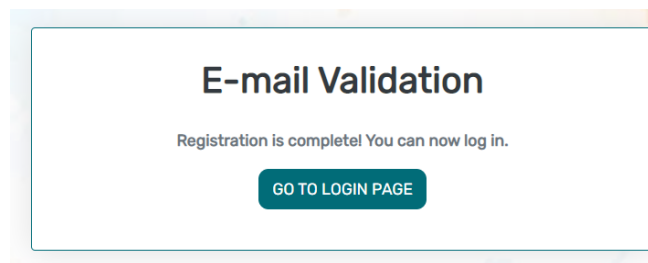
A password must be at least 8 characters long: ✘

- 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”.

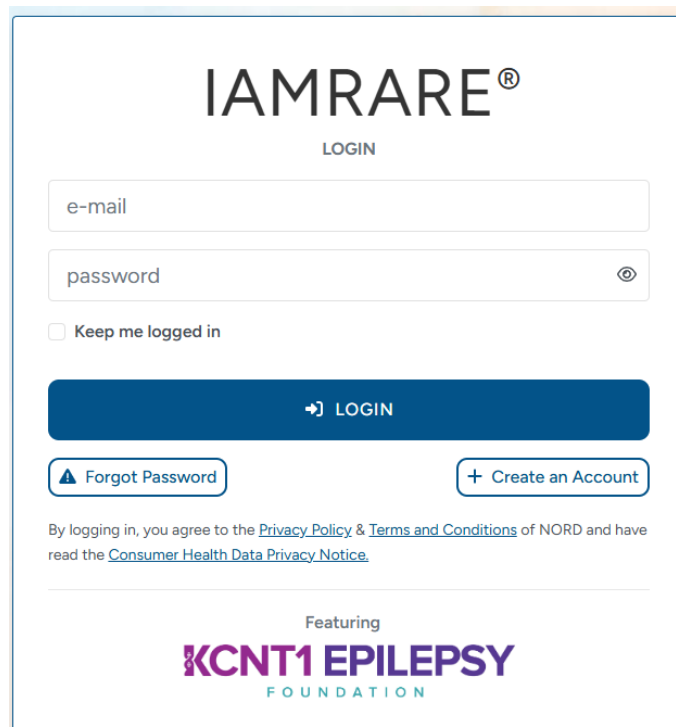


E-mail Validation

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

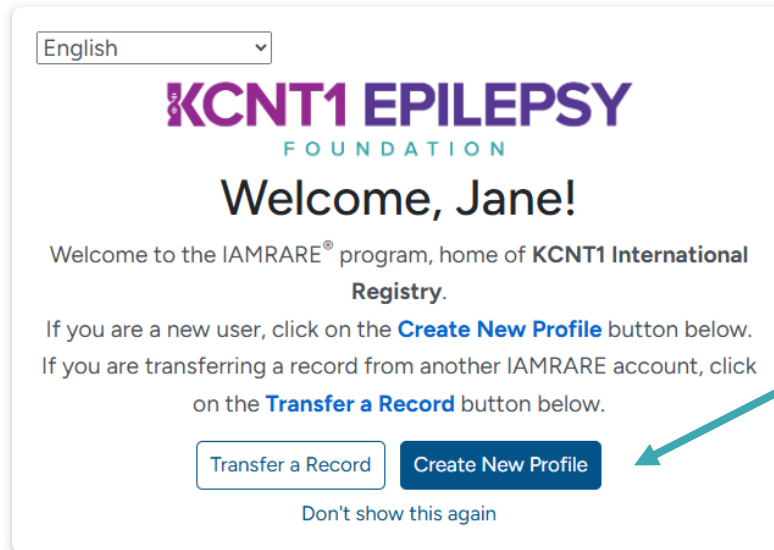
+ Create an Account

By logging in, you agree to the [Privacy Policy & Terms and Conditions](#) of NORD and have read the [Consumer Health Data Privacy Notice](#).

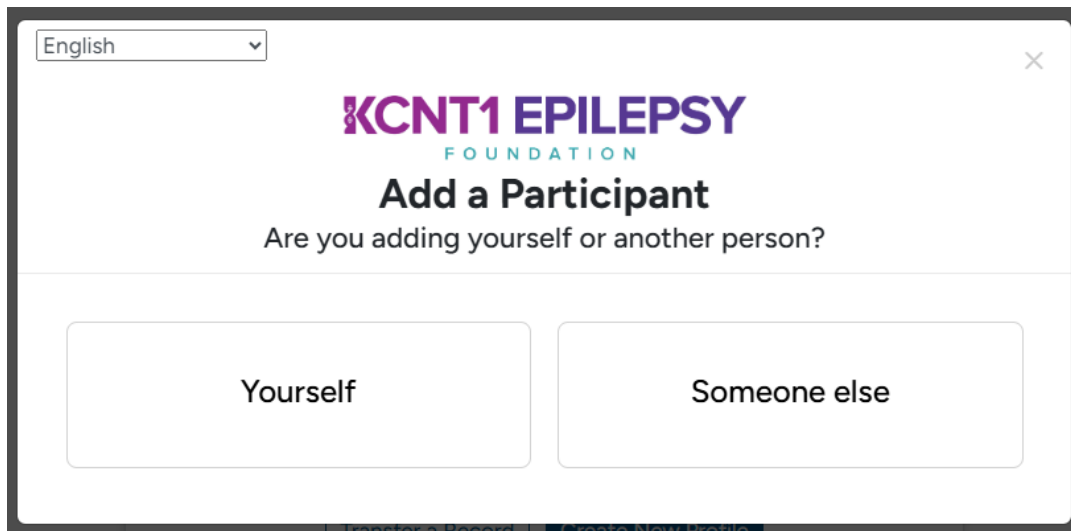
Featuring
KCNT1 EPILEPSY
FOUNDATION

Add a Participant

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



- Step 2: Select who you will be providing information about. If you are reporting information about your child, select "Someone else".

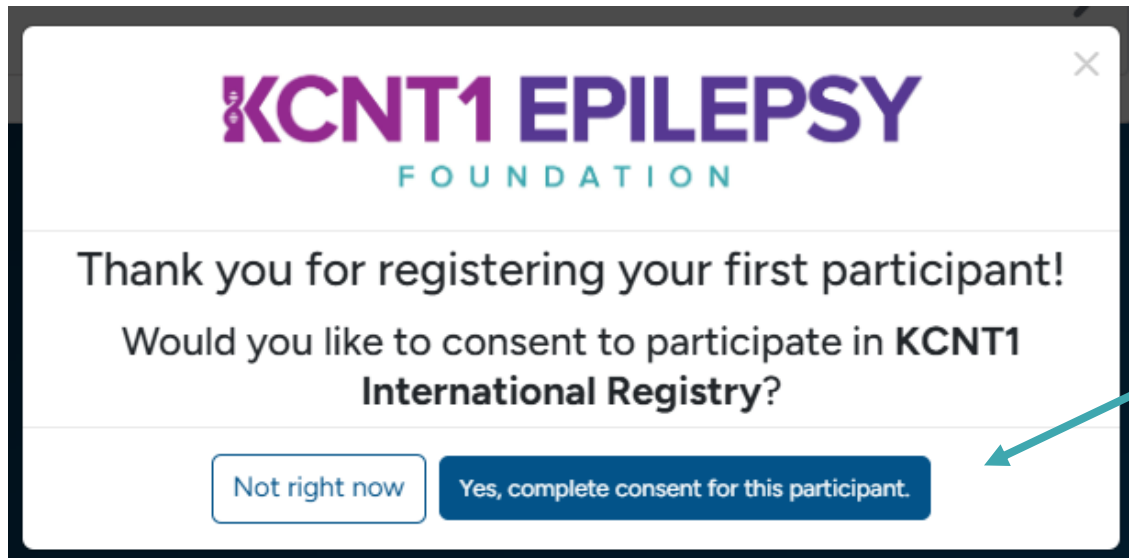


- Step 3: Fill out the Participant’s information.

The screenshot shows a web form titled "Add Participant" with a close button (X) in the top right corner. The form is divided into two columns. At the top, it asks "Who Is Being Added as a Participant?" with two radio button options: "Self" and "Other", where "Other" is selected. Below this are several input fields, each with a red asterisk indicating a required field. The left column contains: "Preferred First Name", "First Name on Birth Certificate", "Last Name on Birth Certificate", "Sex Recorded on Birth Certificate" (a dropdown menu), "Country of Residence" (a dropdown menu), "Country of Birth" (a dropdown menu), and "What Is Your Relationship to?" (a dropdown menu). The right column contains: "Current Last name", "Middle Name on Birth Certificate" (with a note "Type 'NA' if none"), "Date of Birth" (with a calendar icon), "State/Province/Region of Residence" (a dropdown menu), and "City/Municipality of Birth" (a dropdown menu). Each field has a placeholder text or a question mark icon for help.

Consent to the Study

- Step 1: Click on “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.”

Francesca Smith

Consent to KCNT1 International Registry

Consent Overview

Those eligible to participate in our study include:

Participant: An individual diagnosed with a KCNT1-related disorder 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 with a KCNT1-related disorder 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, defined as a spouse, parent, sibling, offspring, close relative, close friend, guardian and/or significant other of the individual who had a KCNT1-related disorder and who had knowledge 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 a KCNT1-related disorder and have passed away. I participated in their medical care.

Next

Francesca Smith

Consent to KCNT1 International Registry

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

Consent to Participate in the KCNT1 International Registry and to Allow Data to be Shared for Future Research

Title: KCNT1 International Registry

Principal Investigator: Anna Pfalzer, PhD, Chief Scientific Officer

Phone: (833) 217-7728

E-mail: kcnt1_registry@Kcnt1epilepsy.org

Sponsor: KCNT1 Epilepsy Foundation

Key Information

You are invited to take part in a research study for individuals with KCNT1-related disorders on behalf of the person in your care who is not able or no longer able to provide their own consent. Your role is called Legally Authorized Representative (LAR). 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

Consent to KCNT1 International Registry

Francesca Smith

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
- 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 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;
- 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 KCNT1 International Registry on behalf of the Study Participant. After signing, a copy of the consent form will be e-mailed to you. If you

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



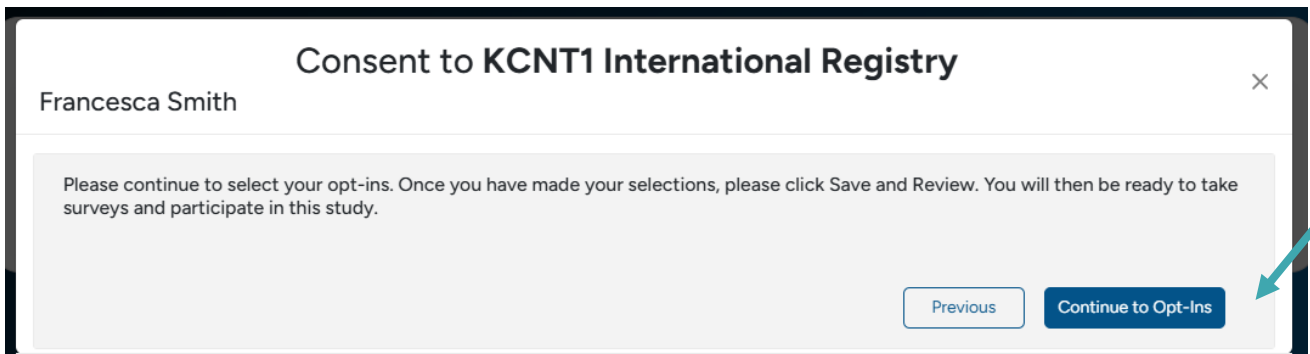
- Step 3: Once you click "Next" and reach the Thank You page, click "Continue to Opt-Ins".

Consent to KCNT1 International Registry

Francesca 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 KCNT1 International Registry ×

Select Opt-Ins for this study

- Interest in hearing about other studies from **KCNT1 Epilepsy Foundation**
- Interest in hearing about relevant clinical trials
- Interest in donating specimens or DNA (biobanking) for future research
- Interest in genetic testing
- Interest in learning more about **KCNT1 Epilepsy Foundation**
- Support from **KCNT1 Epilepsy Foundation** Ambassador / Care Coordinator
- If eligible, I have interest in receiving **KCNT1 Epilepsy Foundation** merchandise that would be sent via electronic or postal mail
- Support from other Patient Advocacy Groups
- I agree to be contacted by **KCNT1 Epilepsy Foundation** regarding their initiatives.
- Interest in learning about upcoming events such as conferences, webinars, and support groups
- Interest in receiving news and updates from **KCNT1 Epilepsy Foundation**

Save and Review

- 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.

[Back to the study list](#)

Francesca Smith ▼ [✎](#)
22-Jan-2021

KCNT1 International Registry

Surveys 🔔 1 pending **All (1)** Complete (0) Pending (1)

0% **Diagnosis**
Not Started

Take Survey

View Responses and Reports

- Step 1: 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.

The screenshot shows the user profile for Francesca Smith, dated 22-Jan-2021. Below the profile is the 'KCNT1 International Registry' section. It displays a summary of surveys: 'All (8)', 'Complete (3)', and 'Pending (5)'. A yellow badge indicates '5 pending' surveys. The list of surveys includes:

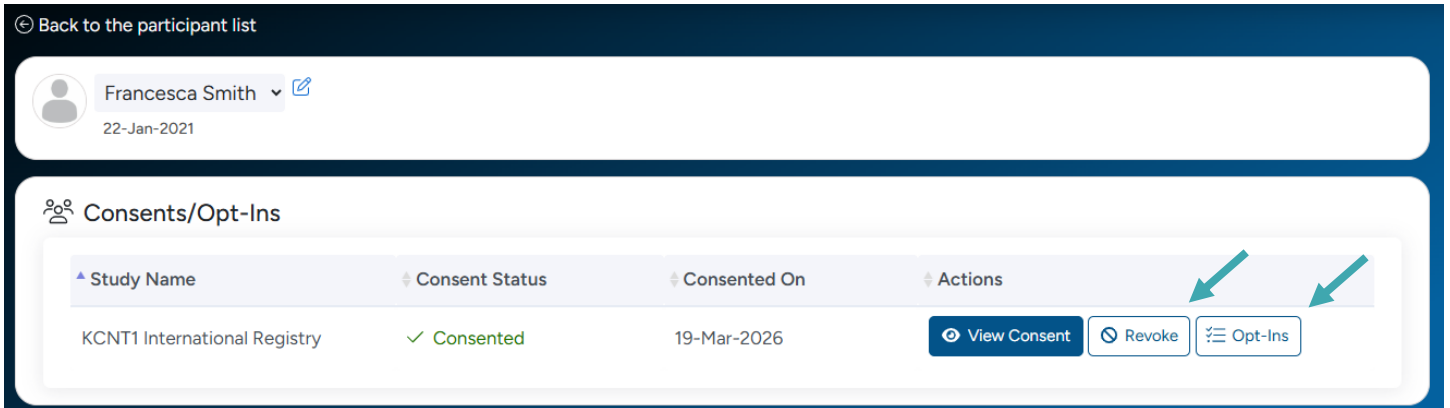
- Diagnosis**: Completed on 9-Feb-2026. A green checkmark icon is shown. A teal arrow points to the 'View Responses (1)' button.
- Demographics Survey**: Completed on 9-Feb-2026. A green checkmark icon is shown. A 'View Responses (1)' button is present.
- Clinical Research ID (CRID) Survey**: Not Started (0%). A teal arrow points to the 'Take Survey' button.
- Medical History**: Completed on 9-Feb-2026. A green checkmark icon is shown. A teal arrow points to the 'Reports' button.

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.

The screenshot shows the 'Enrolled Studies' page for Francesca Smith, dated 22-Jan-2021. At the top left, there is a 'Back to the participant list' link. The user profile is displayed at the top. A teal arrow points to the 'Enrolled Studies' section, which contains the following text: 'Click a study to see the list of surveys. Click the **i** icon to see more information about the study. Click 'Search Studies' above to find additional studies.' On the right side, there is a 'Search Studies' button and a 'Shortcuts' section. The 'Shortcuts' section includes two buttons: 'Request Transfer' and 'Consent/Opt-Ins'. A teal arrow points to the 'Consent/Opt-Ins' button.

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

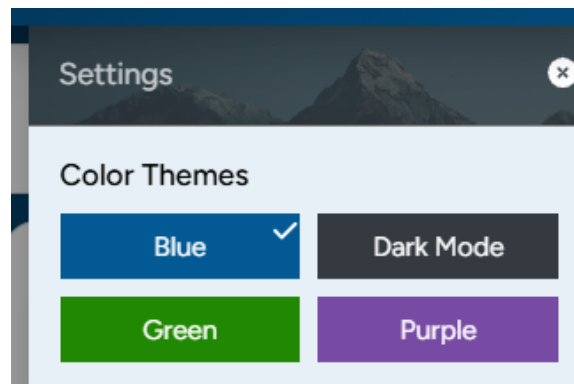


Dark Mode Settings

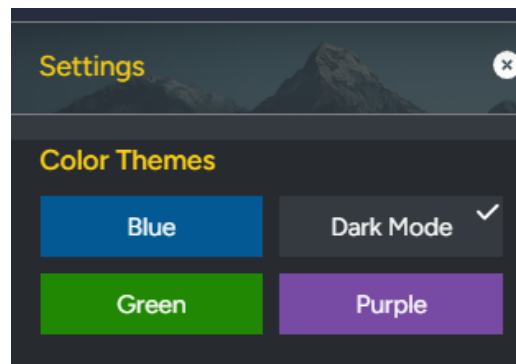
- Step 1: You can view the platform in Dark Mode. First, click Settings.



- Step 2: Select Dark Mode.



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

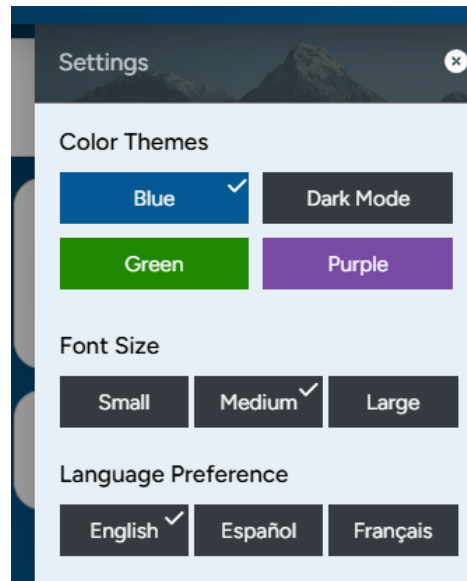


Display Settings

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



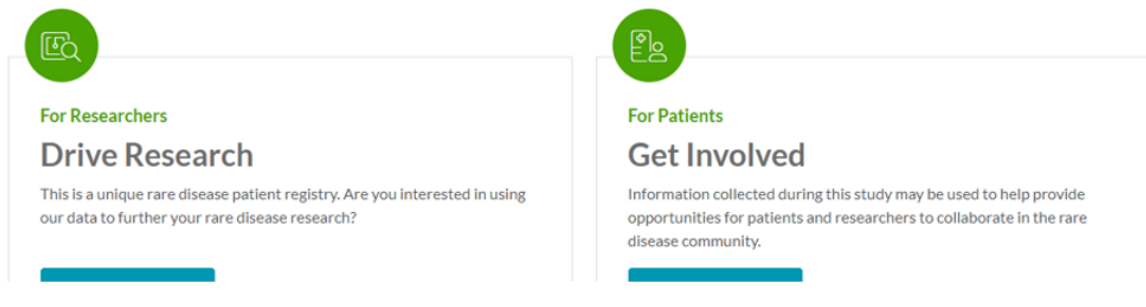
- Step 2: Select a color theme, a font size, or language preference.

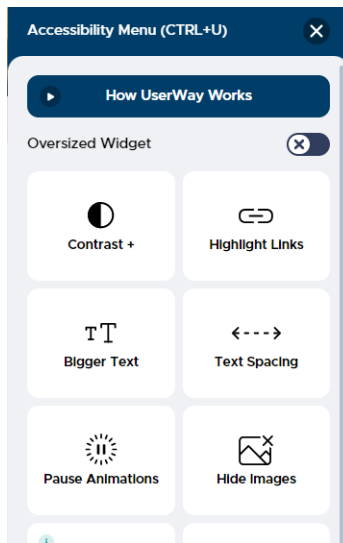


- Step 3: Exit the Settings menu, and your selection will be saved.

Microsite Visibility

- Step 1: You can change how you view the microsite [insert URL] 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.

The image shows a "Have a question?" form. At the top, there are "Home" and "Help" navigation options. The form contains 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 is a dropdown menu for "Inquiry Type" with the placeholder text "-- Select Inquiry Type --". Underneath is a text input field for "Message" with the placeholder text "Your message". At the bottom, there are two buttons: "Cancel" and "Submit".

- 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.

The image is a contact card for the KCNT1 Epilepsy Foundation. It features the foundation's logo on the left. On the right, it lists the name "KCNT1 Epilepsy Foundation" and a website link "kcnt1epileps...". Below this, it provides contact details: "Contact" name "Amanda Abuhl" and "Phone" number "833-217-7728". It also lists "E-mail" addresses: "kcnt1_registry@Kcnt1epilepsy.org" and "IRB E-mail" "info@northstarreviewboard.org". At the bottom, it has a "Social Media" section with icons for Facebook and Instagram.