




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





The Cute Syndrome
FOUNDATION
www.TheCuteSyndrome.com


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. *

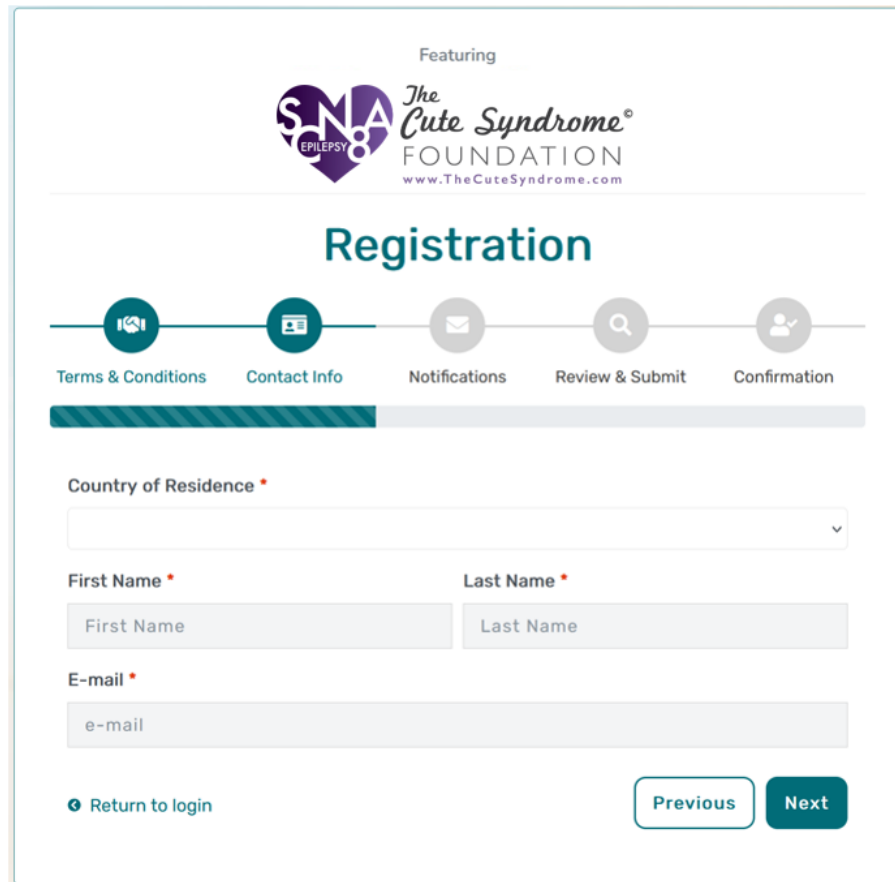
☐ You agree to support the Platform's research activities by providing truthful, appropriate information and to not do anything that will put the Services or the information in the Platform at risk. *

☐ 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”.



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Registration

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

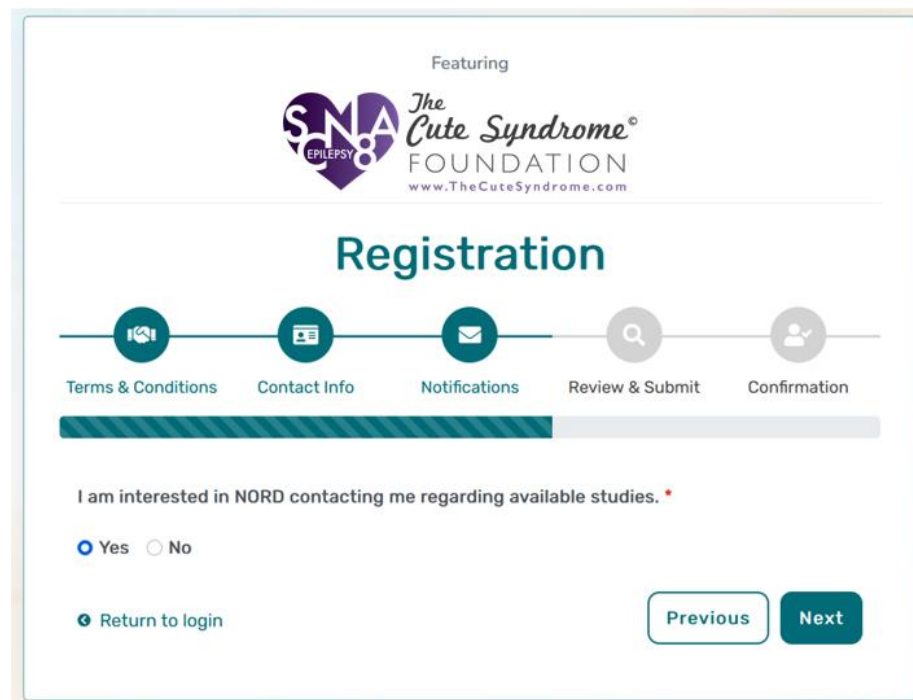
Country of Residence *

First Name * Last Name *


E-mail *

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

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



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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” so that an activation link is sent to your e-mail to complete registration.

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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.

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A red 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

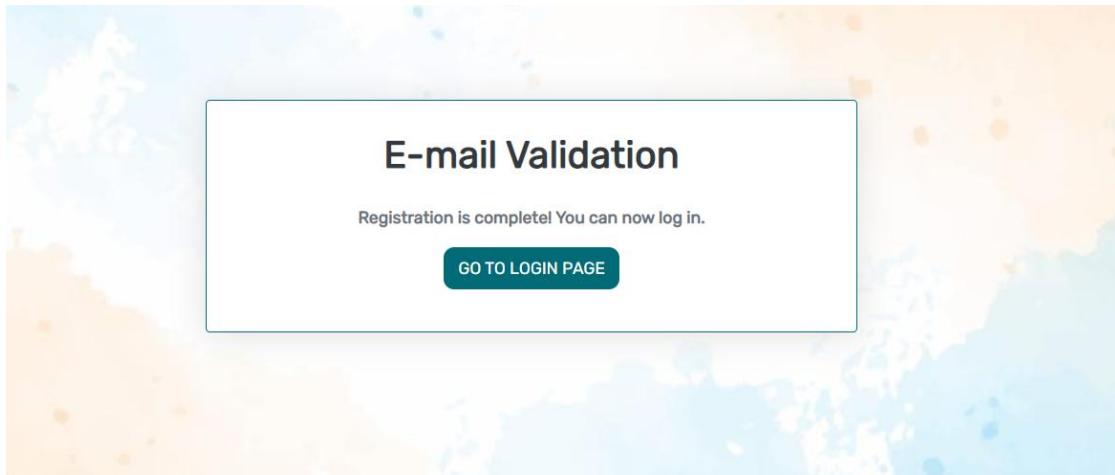
A password must be at least 8 characters long: ×

- contain 1 uppercase letter ×
- contain 1 lowercase letter ×
- contain 1 digit ×
- not contain text from top 1000 commonly used passwords ×

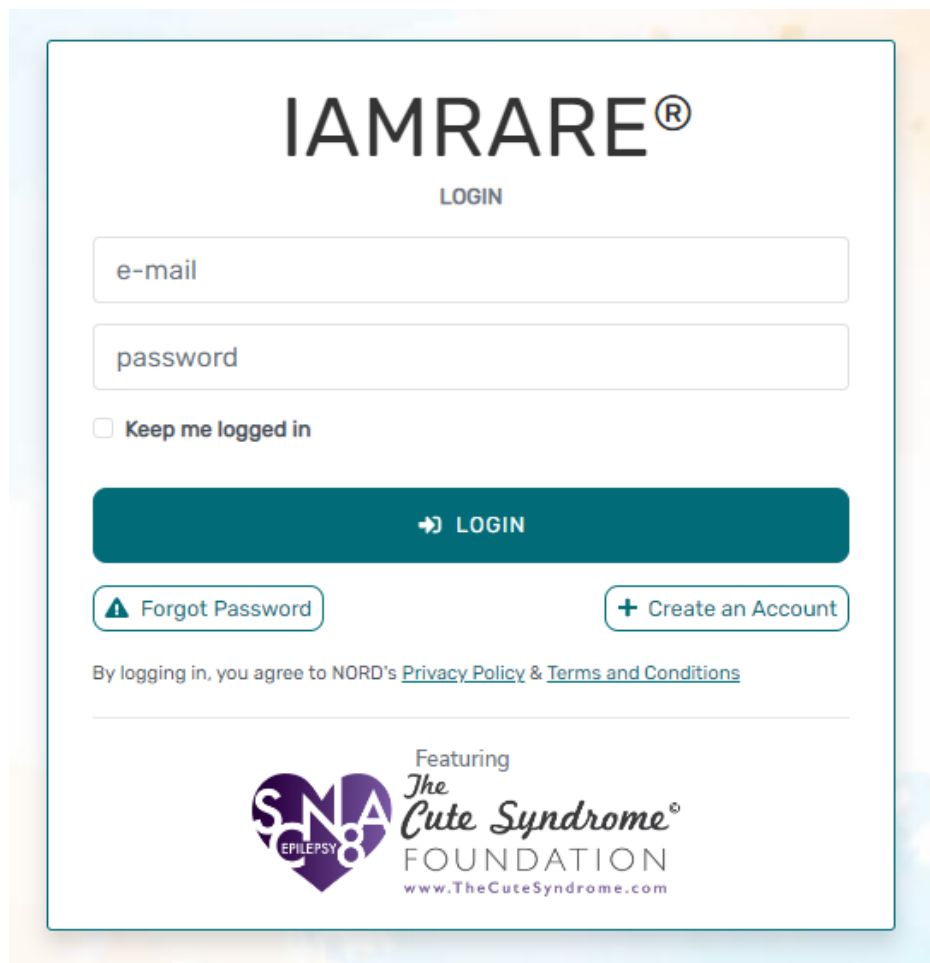
Repeat Password

[SUBMIT](#)

- Step 6: Your validation is now complete. Select “Go to Login Page”.




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

A screenshot of the IAMRARE LOGIN page. The page has a light blue and orange watercolor background. The main content is a white rectangular box with a thin blue border. At the top of the box, the text "IAMRARE®" is centered in a large, black, sans-serif font. Below it, the word "LOGIN" is centered in a smaller, blue, sans-serif font. There are two input fields: the first is labeled "e-mail" and the second is labeled "password". Below the input fields is a checkbox labeled "Keep me logged in". Below the checkbox is a large, dark teal button with the text "→ LOGIN" in white, sans-serif font. 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 NORD's [Privacy Policy](#) & [Terms and Conditions](#)". At the bottom of the box is a logo for "Featuring The Cute Syndrome® FOUNDATION" with the website "www.TheCuteSyndrome.com". The logo consists of a purple heart shape with the letters "SCN8" inside, and the word "EPILEPSY" written below it.

Add a Participant

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

English ▾




Welcome, Jane!

Welcome to the IAMRARE® program, home of **The Cute Syndrome Foundation Global SCN8A Survey Series**.


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.

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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 *

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 **The Cute Syndrome Foundation Global SCN8A Survey Series?**

- 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.”

Jane Smith

Consent to The Cute Syndrome Foundation Global SCN8A Survey Series

✕

Answered 0/1 questions

Consent Overview

Those eligible to participate in our study include:

Participant: An individual diagnosed with SCN8A 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 SCN8A, defined as a spouse, parent, sibling, offspring, close relative, close friend, guardian and/or significant other of the individual who had Rare Disease 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 SCN8A. I participated in their medical care.

Next

Jane Smith

Consent to The Cute Syndrome Foundation Global SCN8A Survey Series

✕

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

Consent to Participate in The Cute Syndrome Foundation Global SCN8A Survey Series Registry and to Allow Your Data to be Shared for Future Research

Title: The Cute Syndrome Foundation Global SCN8A Survey Series

Co-Investigator: Shelley Frappier

Phone: 514-629-7757

Email: surveysupport@thecutesyndrome.com

Key Information

You are invited to take part in a research study for individuals with SCN8A on behalf of the person in your care. 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.

Things you should know:

We are doing this research to conduct a prospectively planned and efficient study that will result in the most comprehensive understanding of SCN8A and its course and pace over time.

If you choose to participate on behalf of the Study Participant, you will be asked to contribute data at varying intervals throughout the course of the study. Data will be

PreviousNext

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 Cute Syndrome Foundation Global SCN8A Survey Series. After signing, a copy of the consent form will be emailed 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 Cute Syndrome Foundation Global SCN8A Survey Series have been answered to my satisfaction, and I understand the purpose of the Registry and the risks of participation.

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

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 The Cute Syndrome Foundation Global SCN8A Survey Series

Select Opt-Ins for this study

- ☐ Interest in hearing about other studies from [The Cute Syndrome 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 [The Cute Syndrome Foundation](#)
- ☐ Interest in signing up for [The Cute Syndrome Foundation's](#) newsletter
- ☐ Support from [The Cute Syndrome Foundation](#) Ambassador / Care Coordinator
- ☐ If eligible, I have interest in receiving [The Cute Syndrome Foundation's](#) merchandise that would be sent via electronic or postal mail

[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 on your Participant.

The screenshot shows the IAMRARE® dashboard. At the top, there's a navigation bar with 'Home', 'Help', 'Settings', and a user greeting 'Hi, Jane!'. Below this, a welcome message says 'Good Afternoon, Jane!' with 'Member since Apr 02, 2025'. A '+ Add Participant' button is in the top right. The main section is titled 'Participants' and includes instructions: 'Select a participant to view their studies. Click on the "Add Participant" button above to add a participant.' A participant card for 'Jane Smith' (5-May-2000) is shown with '1 pending surveys'. To the right, there are 'Shortcuts' for 'Request Transfer' and 'Consent/Opt-Ins', and a 'Notifications (0)' section stating 'No new notifications.' A red arrow points to the '+ Add Participant' button.

- Step 2: Click on the appropriate study.

This screenshot shows the 'Enrolled Studies' section for Jane Smith. It includes a 'Back to participant list' link and a 'Search Studies' button. The 'Enrolled Studies' section has instructions: '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.' A study card for 'The Cute Syndrome Foundation Global SCN8A Survey Series' is highlighted with a red arrow. The card shows 'English', 'The Cute Syndrome Foundation', 'Consented', and '1 pending surveys'. To the right, there are 'Shortcuts' for 'Request Transfer' and 'Consent/Opt-Ins', and a 'Notifications (0)' section stating 'No new notifications.'

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

This screenshot shows the survey page for 'The Cute Syndrome Foundation Global SCN8A Survey Series'. It includes a 'Back to study list' link and a 'Search Studies' button. The survey card shows 'Surveys' with '1 pending' (indicated by a yellow tag) and a progress bar at '0% Getting Started' with 'Not Started' in red. A 'Take Survey' button is in the bottom right corner, highlighted by a red arrow. At the top, there's a navigation bar with 'Home', 'Help', 'Settings', and a user greeting 'Hi, Jane!'. Below this, a welcome message says 'Good Afternoon, Jane!' with 'Member since Apr 02, 2025'. A '+ Add Participant' button is in the top right. The main section is titled 'Participants' and includes instructions: 'Select a participant to view their studies. Click on the "Add Participant" button above to add a participant.' A participant card for 'Jane Smith' (5-May-2000) is shown with '1 pending surveys'. To the right, there are 'Shortcuts' for 'Request Transfer' and 'Consent/Opt-Ins', and a 'Notifications (0)' section stating 'No new notifications.'

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 a user profile for Jane Smith (5-May-2000) at the top. Below is the title 'The Cute Syndrome Foundation Global SCN8A Survey Series'. A 'Surveys' section indicates '1 pending' with a clock icon. A filter bar shows 'All (3)', 'Complete (2)', and 'Pending (1)'. Two survey cards are listed: 'Getting Started' (Completed on 2-Apr-2025) and 'Demographics' (Completed on 2-Apr-2025). Each card has a 'View Responses' button (with a circled '1') and a 'Reports' button. Red arrows point from the 'Getting Started' card to its respective buttons.

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 Jane Smith. A red arrow points to the 'Consent/Opt-Ins' shortcut in the 'Shortcuts' section. The 'Enrolled Studies' section includes a 'Back to participant list' link, a search bar, and instructions: '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.'

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

The screenshot shows the 'Consents/Opt-Ins' page for Jane Smith. A table lists the study 'The Cute Syndrome Foundation Global SCN8A Survey Series' with a 'Consented' status and a date of '2-Apr-2025'. The 'Actions' column contains three buttons: 'View Consent', 'Revoke', and 'Opt-Ins'. Red arrows point to the 'Revoke' and 'Opt-Ins' buttons.

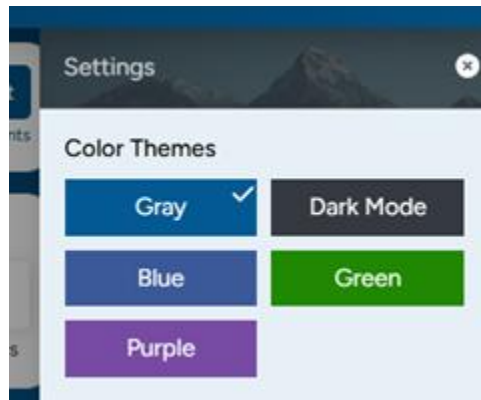
Study Name	Consent Status	Consented On	Actions
The Cute Syndrome Foundation Global SCN8A Survey Series	✓ Consented	2-Apr-2025	View Consent Revoke Opt-Ins

Dark Mode Settings

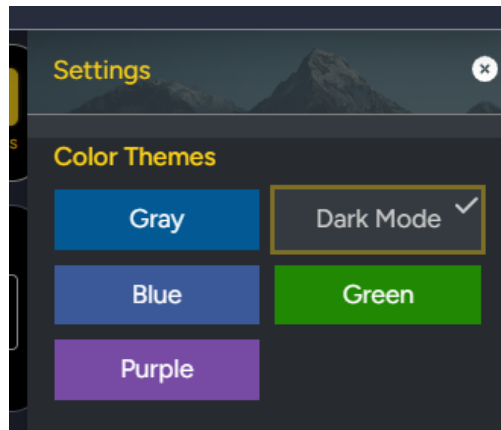
- Step 1: You can view the platform in Dark Mode. First, click Settings.



- Step 2: Select Dark Mode.



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

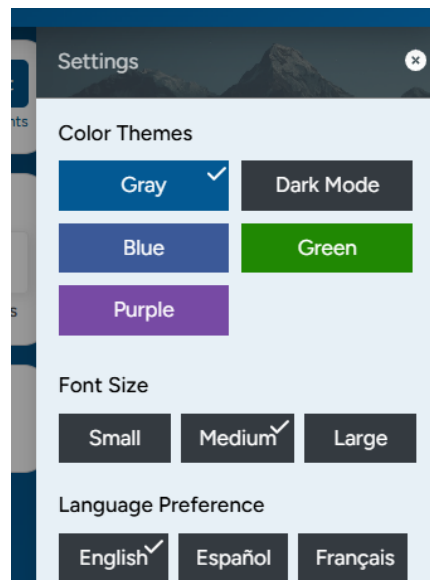


Display Settings

- 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 (Tcsfsurveys.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.



For Researchers

Drive Research

This is a unique rare disease patient registry. Are you interested in using our data to further your rare disease research?

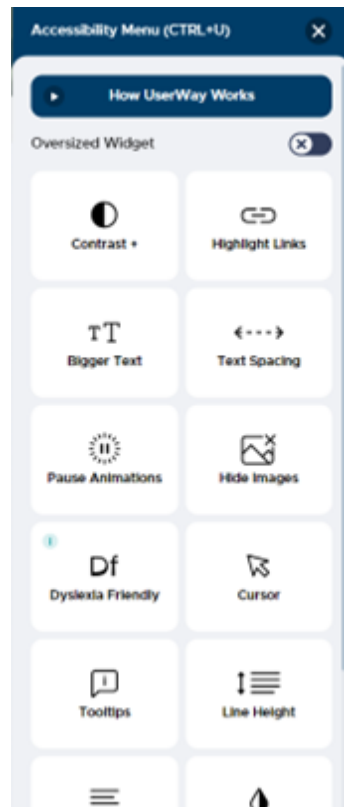


For Patients

Get Involved

Information collected during this study may be used to help provide opportunities for patients and researchers to collaborate in the rare disease community.





Need Assistance?

- Step 1: If you need help while using the platform, click Help.
- Step 2: Select an Inquiry Type and type a message.

A screenshot of a mobile application's "Have a question?" form. The form has a blue header with a home icon and a "Help" button. The title "Have a question?" is in white on a blue background. Below the title 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 labeled "Inquiry Type" with a red asterisk and the text "Select Inquiry Type". Below the dropdown is a text input field labeled "Message" with a red asterisk and the placeholder text "Your message". At the bottom of the form 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.


View Responses ①

Reports

View Responses ①

Reports

Take Survey



The Cute Syndrome
Foundation
thecutesyndrome.com

Contact

Shelley Frappier

Phone

905-683-0141

E-mail

surveysupport@thecutesyndrome.com

IRB E-mail

info@northstarreviewboard.org

Social Media

