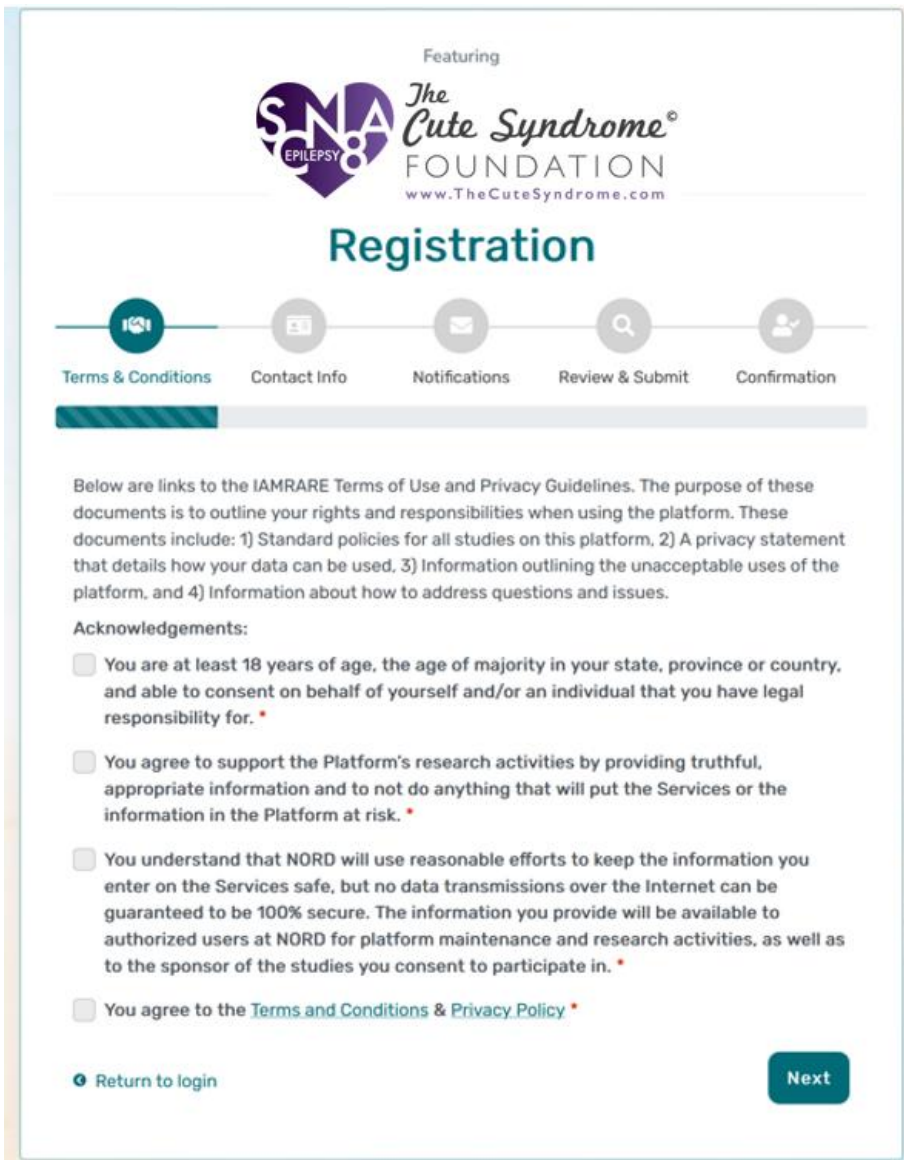
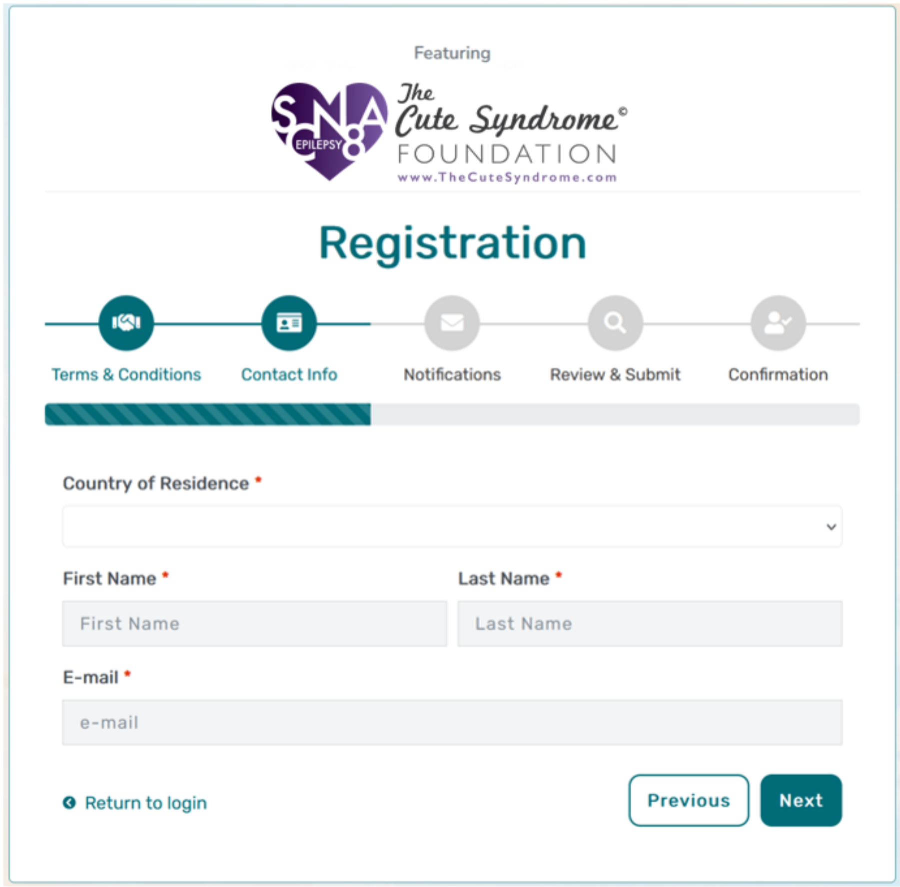
Participant User Guide

Register for an Account

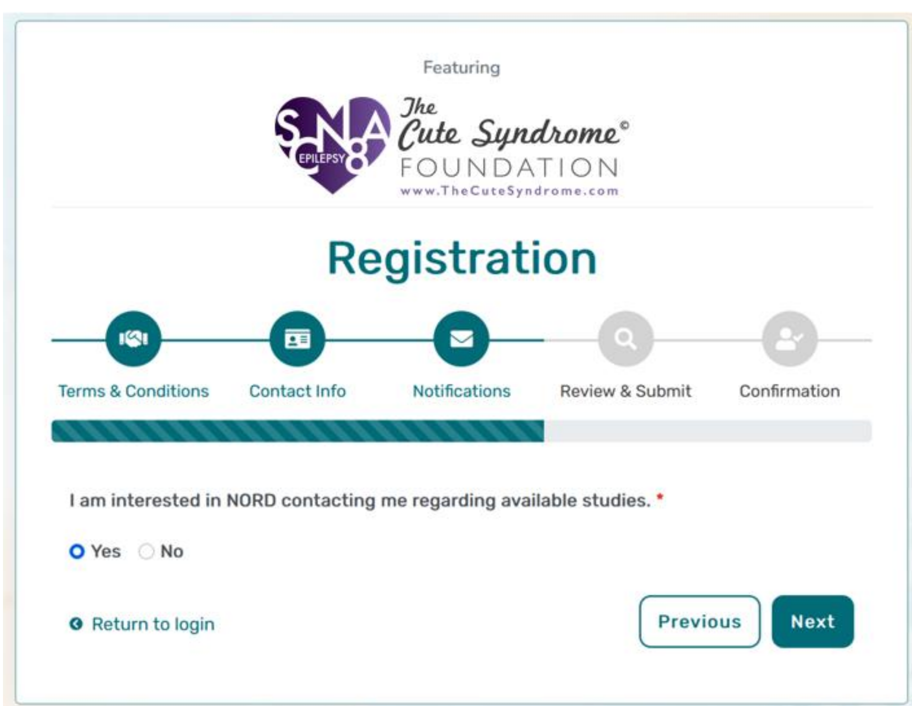
- Step 1: Read the Terms and Conditions and Privacy Policy and attest to the statements provided. When you are finished with this page, click “Next”.



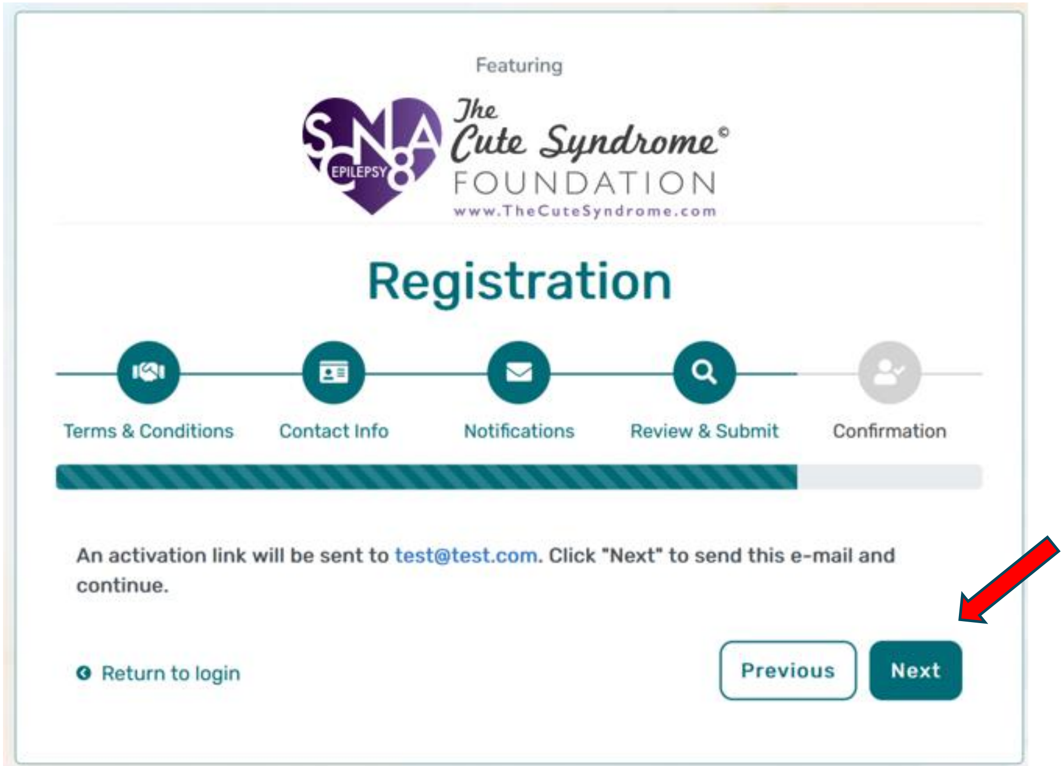
- Step 2: Enter your personal information in the spaces provided. When you are finished with this page, click “Next”.



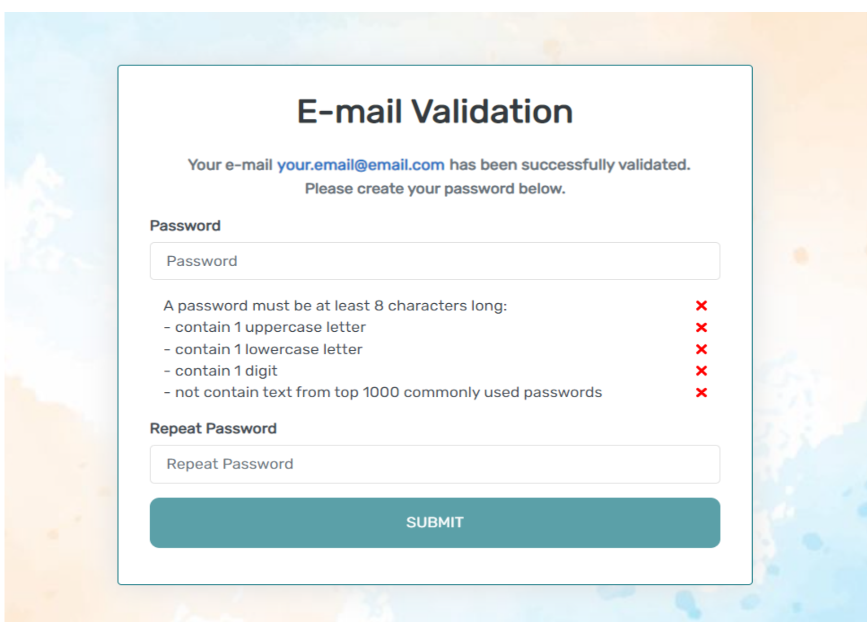
- Step 3: Select whether you are interested in being contacted by NORD regarding available studies. When you are finished with this page, click “Next”.



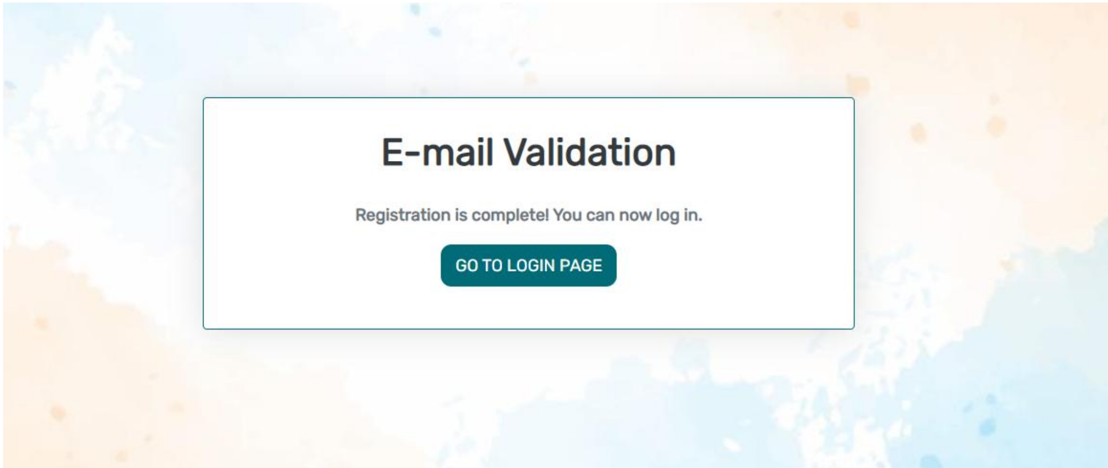
- Step 4: Select "Next" so that an activation link is sent to your e-mail to complete registration.



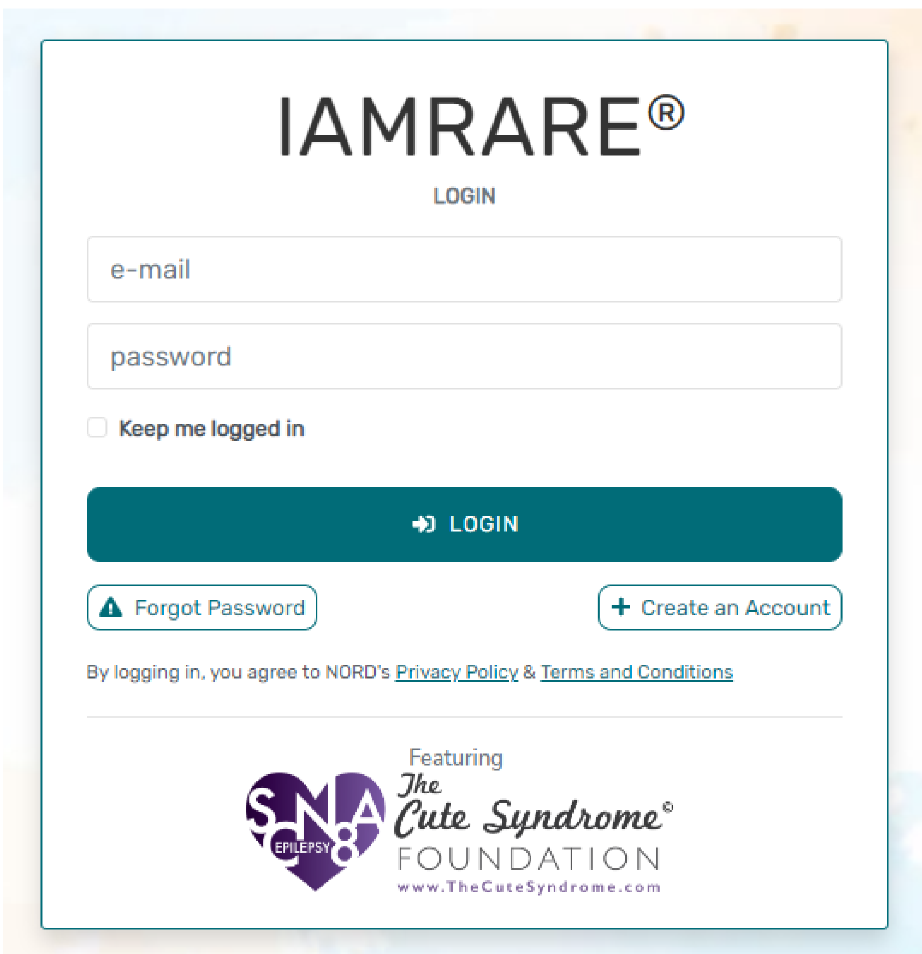
- Step 5: Click the link you are sent via e-mail. Please check your Spam folder if you do not see the e-mail. You will be taken to the following screen in a new tab within your browser. Set your password and click "Submit".



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

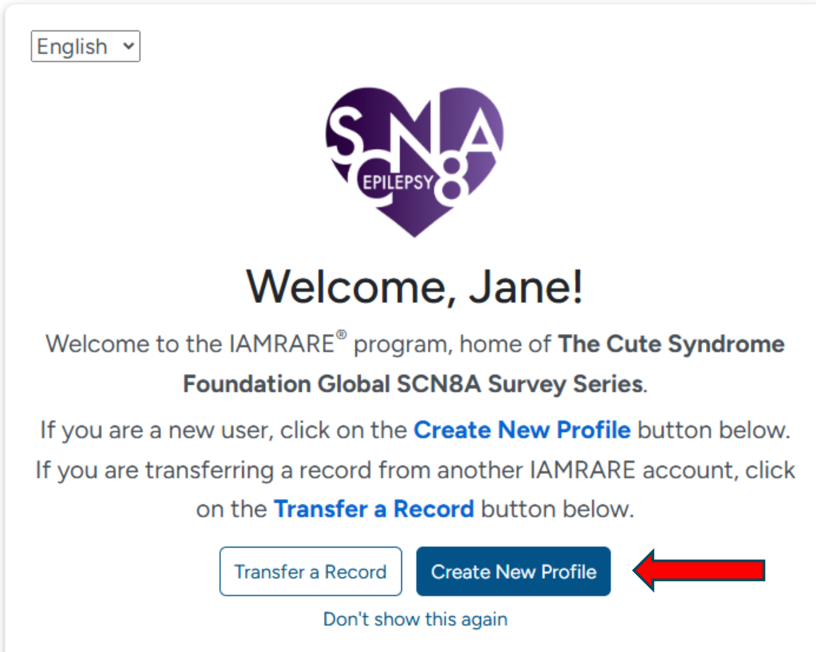


- Step 7: Log in using your new e-mail and password.

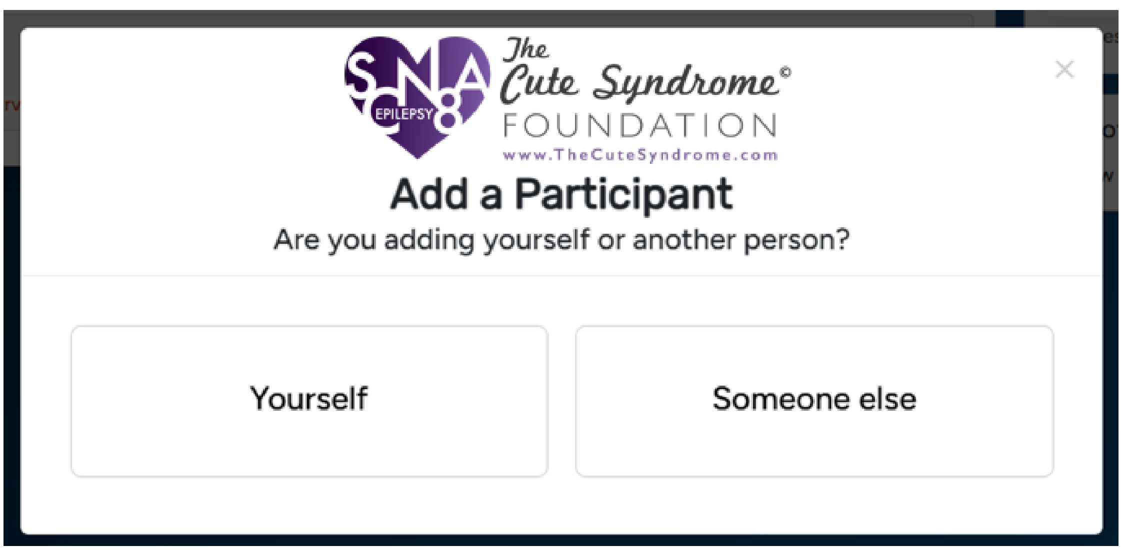


Add a Participant

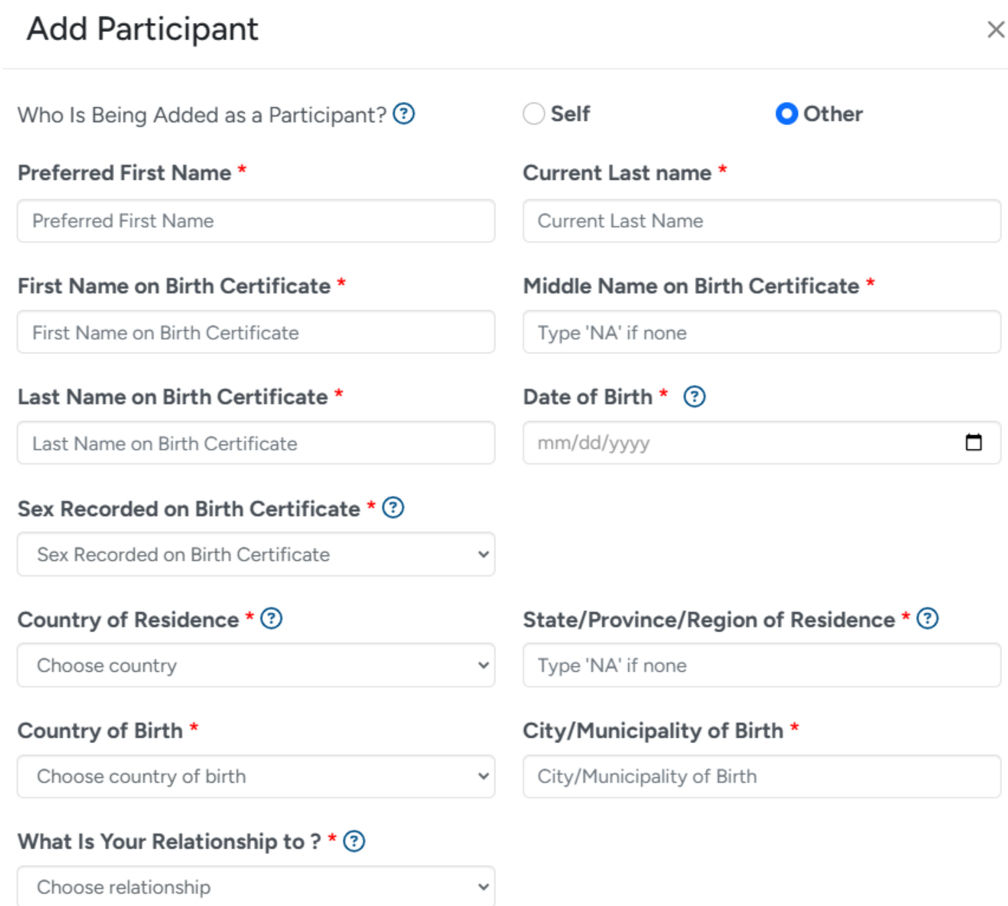
- Step 1: To start, click Create New Profile.



- Step 2: Select who you will be providing information about.



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

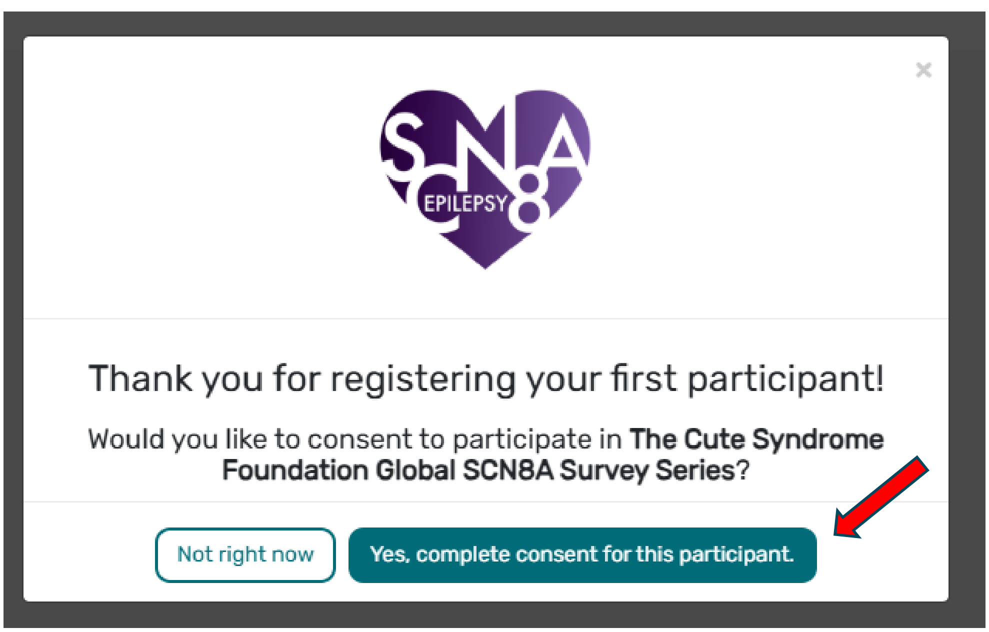

Add Participant ×

Who Is Being Added as a Participant? ? ○ Self ◉ Other

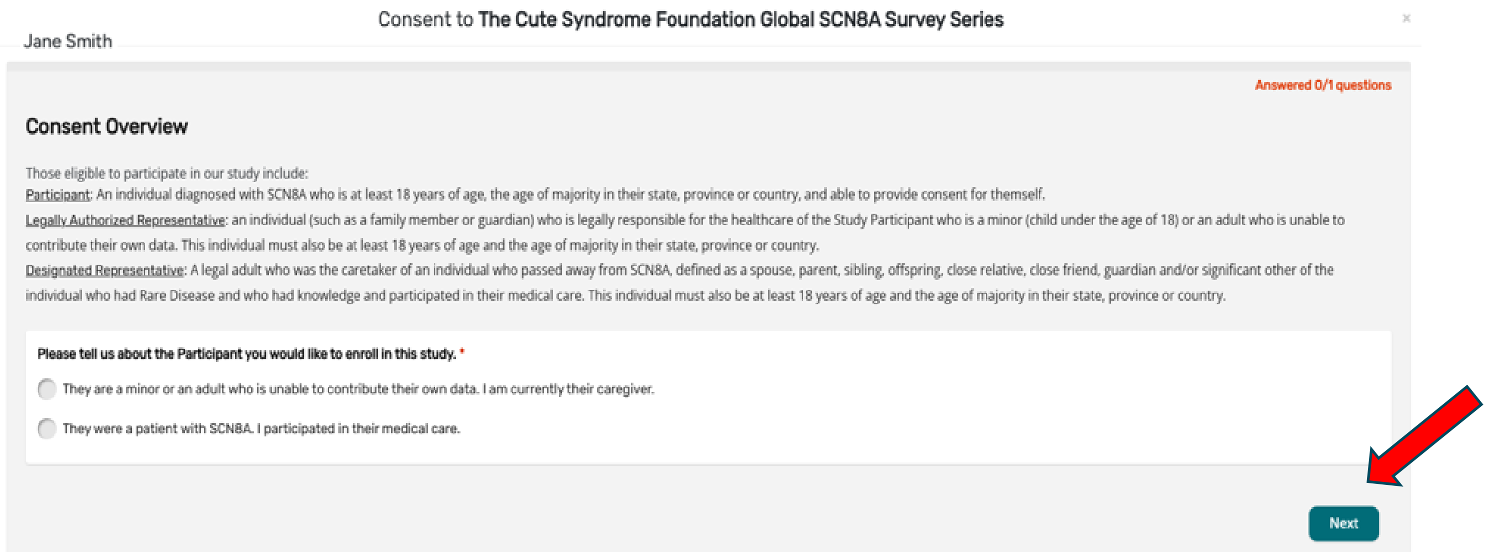
Preferred First Name *	**Current Last name** *
Preferred First Name	Current Last Name
First Name on Birth Certificate *	**Middle Name on Birth Certificate** *
First Name on Birth Certificate	Type 'NA' if none
Last Name on Birth Certificate *	**Date of Birth** * ?
Last Name on Birth Certificate	mm/dd/yyyy
Sex Recorded on Birth Certificate * ?	
Sex Recorded on Birth Certificate	
Country of Residence * ?	**State/Province/Region of Residence** * ?
Choose country	Type 'NA' if none
Country of Birth *	**City/Municipality of Birth** *
Choose country of birth	City/Municipality of Birth
What Is Your Relationship to ? * ?	
Choose relationship	

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.”


Consent to **The Cute Syndrome Foundation Global SCN8A Survey Series**

Jane Smith

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 themself.

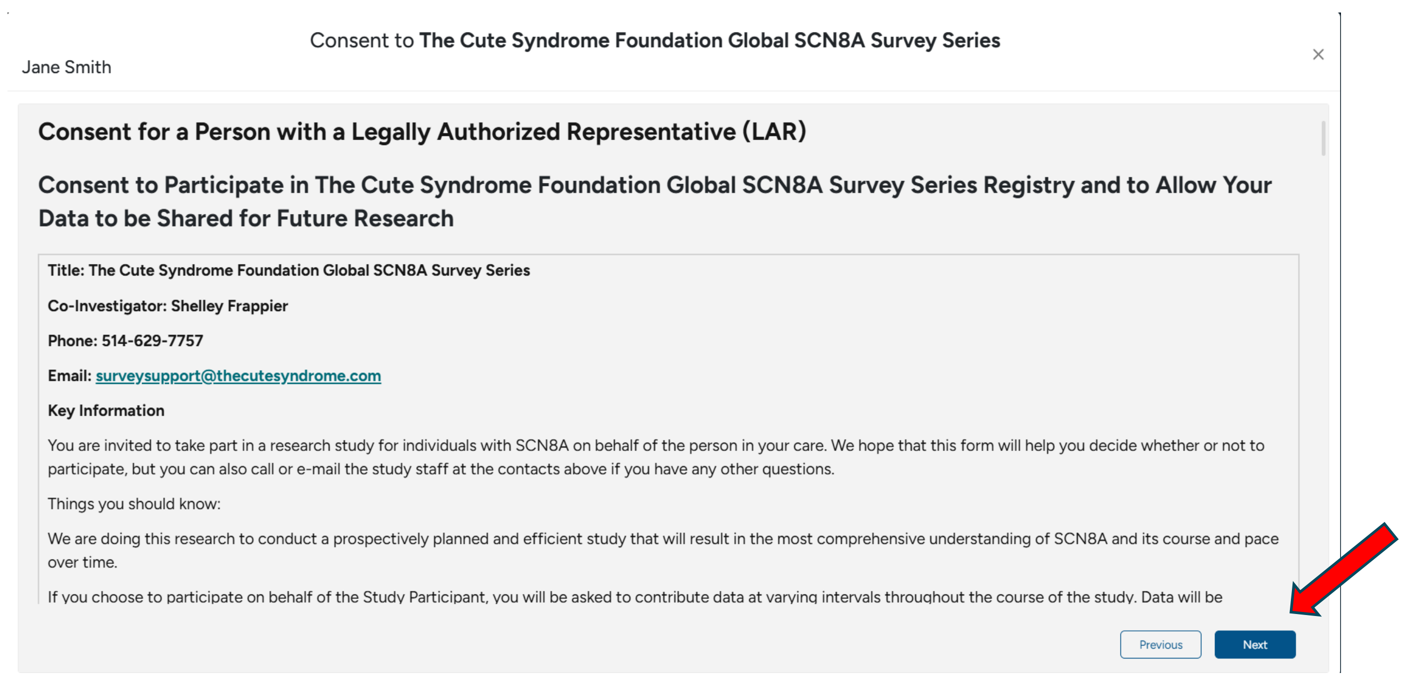
Legally Authorized Representative: an individual (such as a family member or guardian) who is legally responsible for the healthcare of the Study Participant who is a minor (child under the age of 18) or an adult who is unable to contribute their own data. This individual must also be at least 18 years 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


Consent to **The Cute Syndrome Foundation Global SCN8A Survey Series**

Jane Smith

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

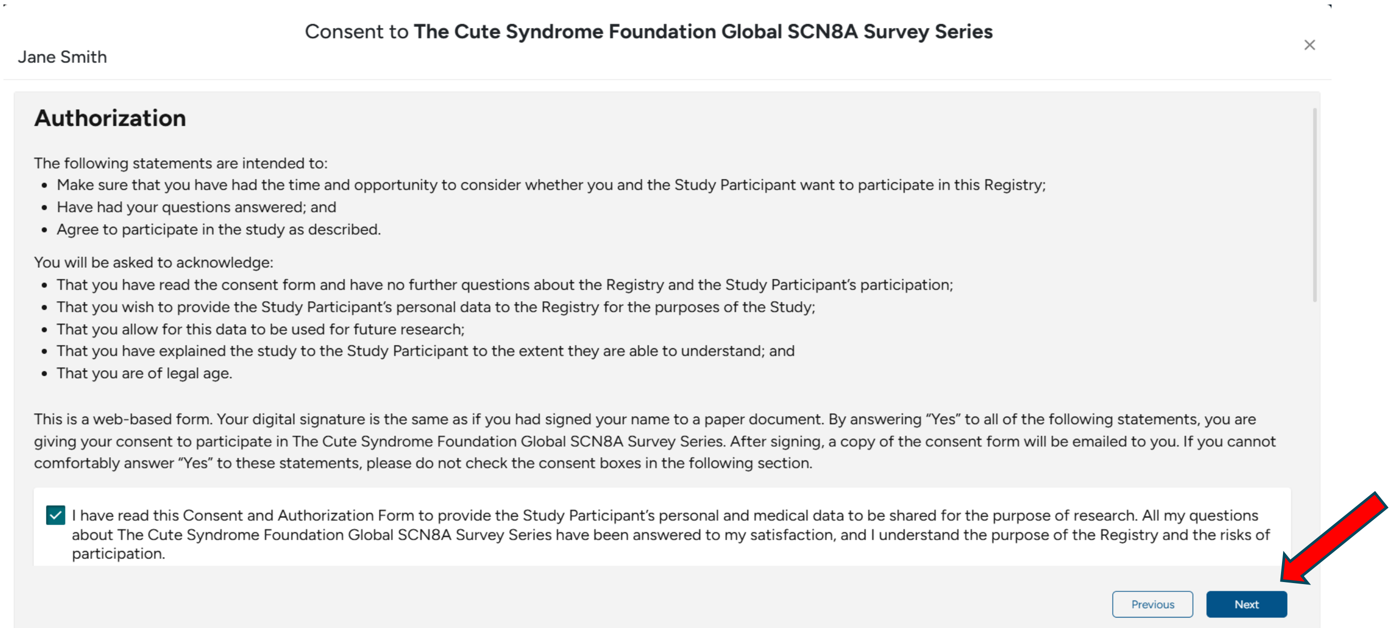
You are invited to take part in a research study for individuals with SCN8A on behalf of the person in your care. We hope that this form will help you decide whether or not to participate, but you can also call or e-mail the study staff at the contacts above if you have any other questions.

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

Previous Next



Consent to **The Cute Syndrome Foundation Global SCN8A Survey Series**

Jane 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:

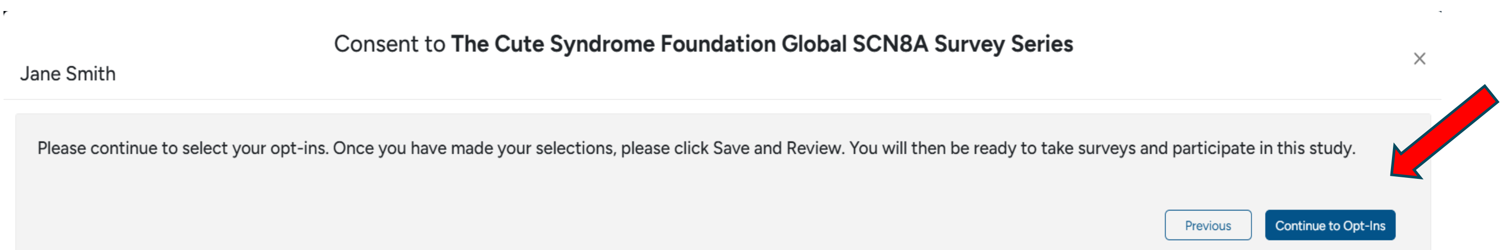
- That you have read the consent form and have no further questions about the Registry and the Study Participant's participation;
- That you wish to provide the Study Participant's personal data to the Registry for the purposes of the Study;
- That you allow for this data to be used for future research;
- 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 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.

Previous | Next

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



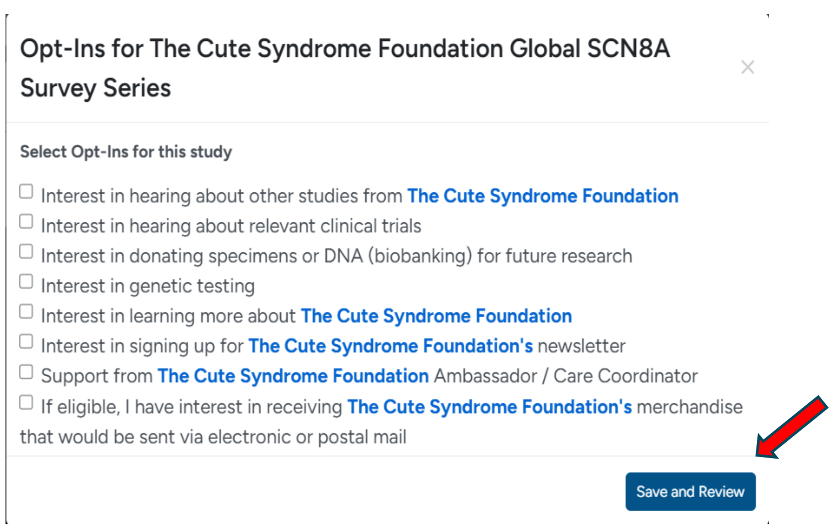
Consent to **The Cute Syndrome Foundation Global SCN8A Survey Series**

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 The Cute Syndrome Foundation Global SCN8A Survey Series

Select Opt-Ins for this study

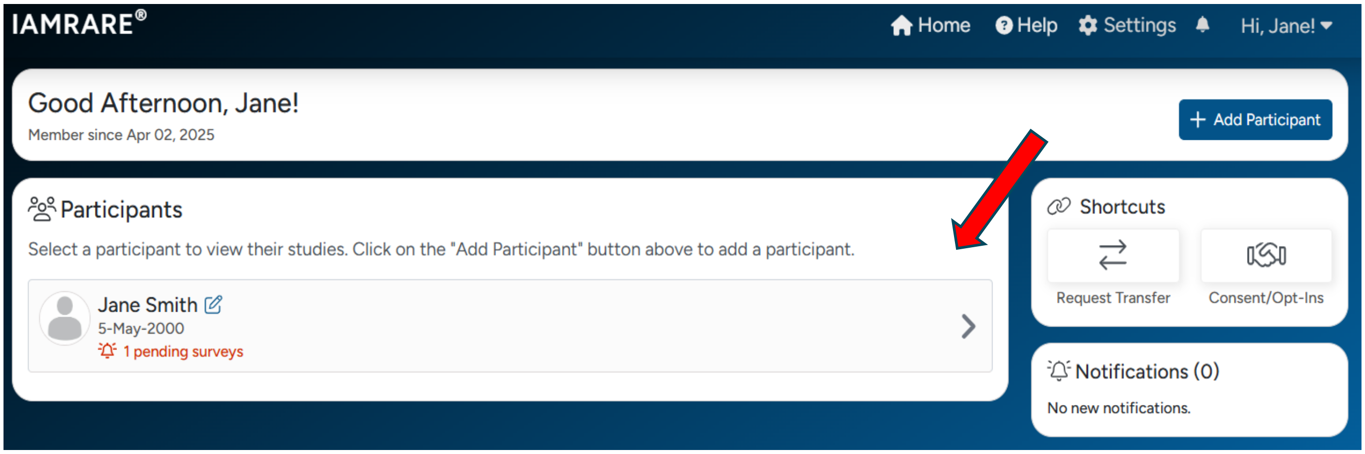
☐ Interest in hearing about other studies from **The Cute Syndrome Foundation**
☐ Interest in hearing about relevant clinical trials
☐ Interest in donating specimens or DNA (biobanking) for future research
☐ Interest in genetic testing
☐ Interest in learning more about **The Cute Syndrome Foundation**
☐ 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

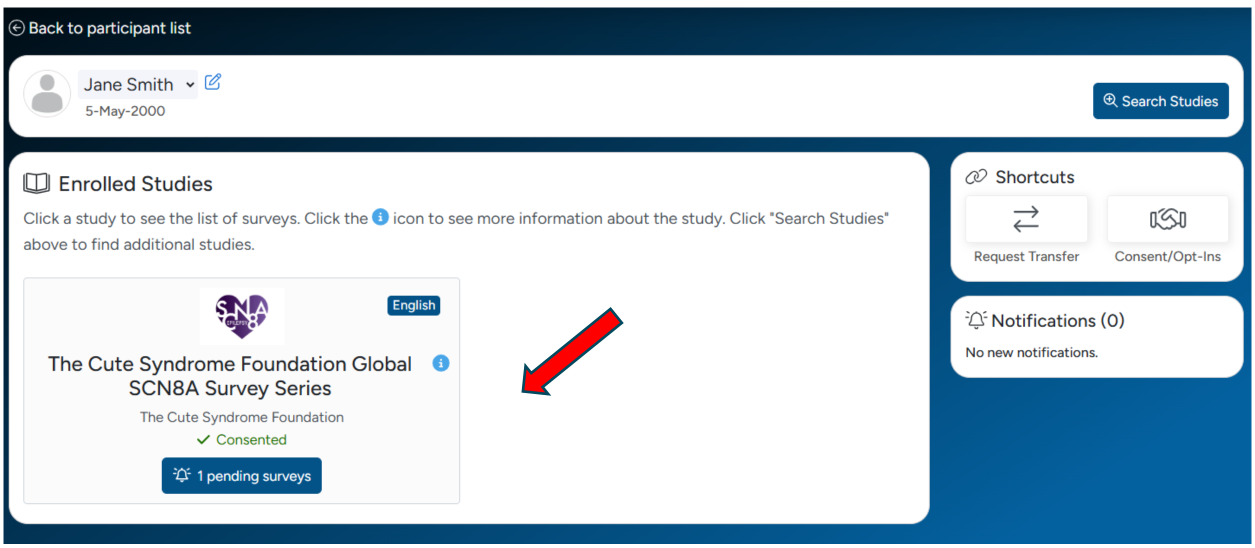
- Step 5: Once you've reviewed your consent, click "Close". You will then have access to start taking surveys.

Taking Surveys

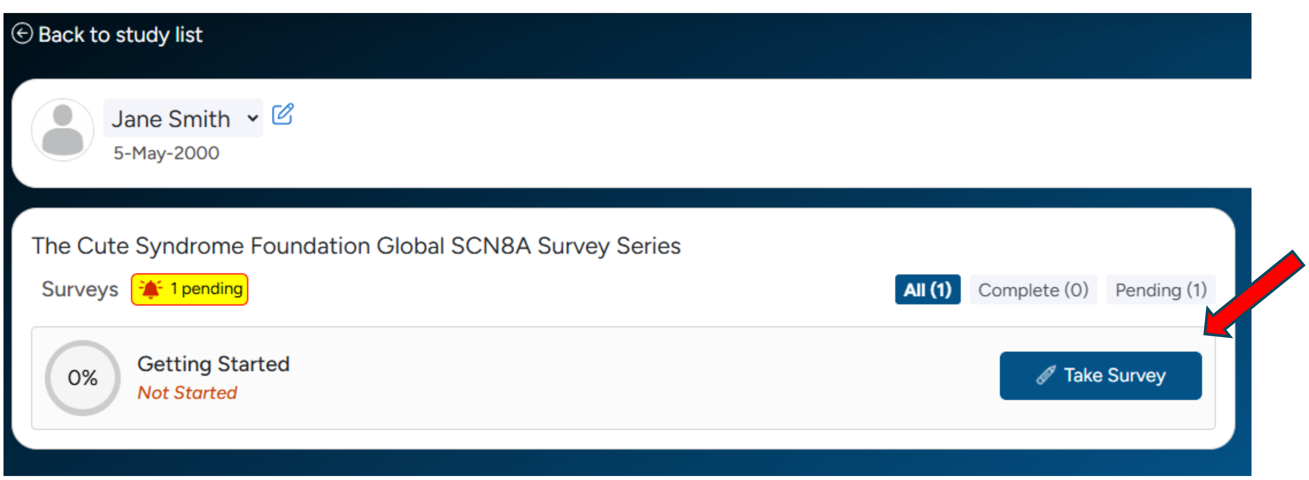
- Step 1: Click on your Participant.



- Step 2: Click on the appropriate study.

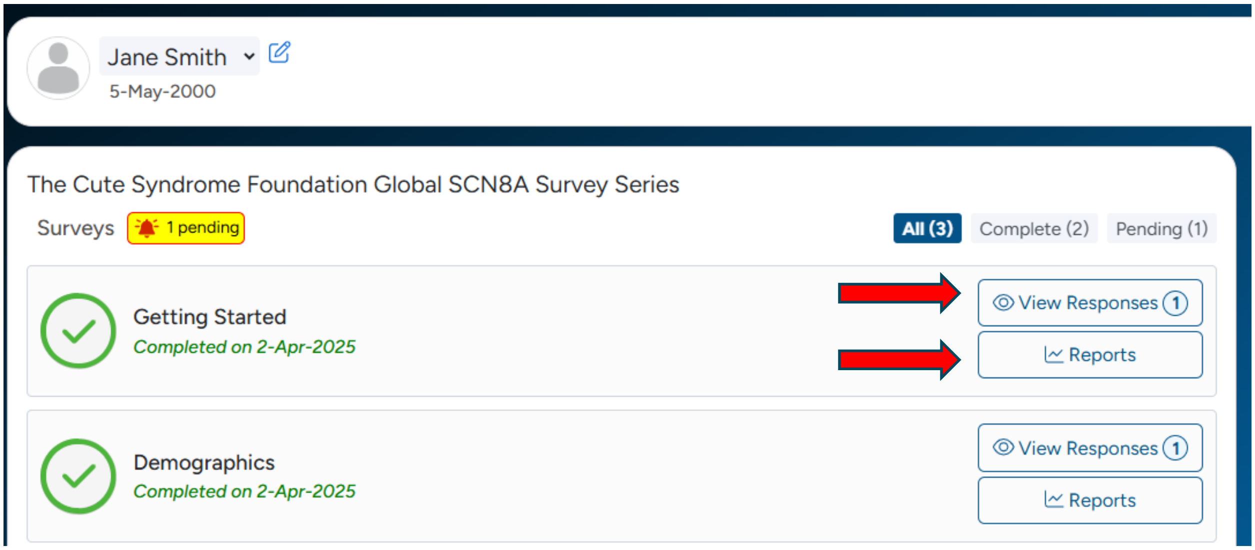


- Step 3: Click “Take Survey” for an available survey.



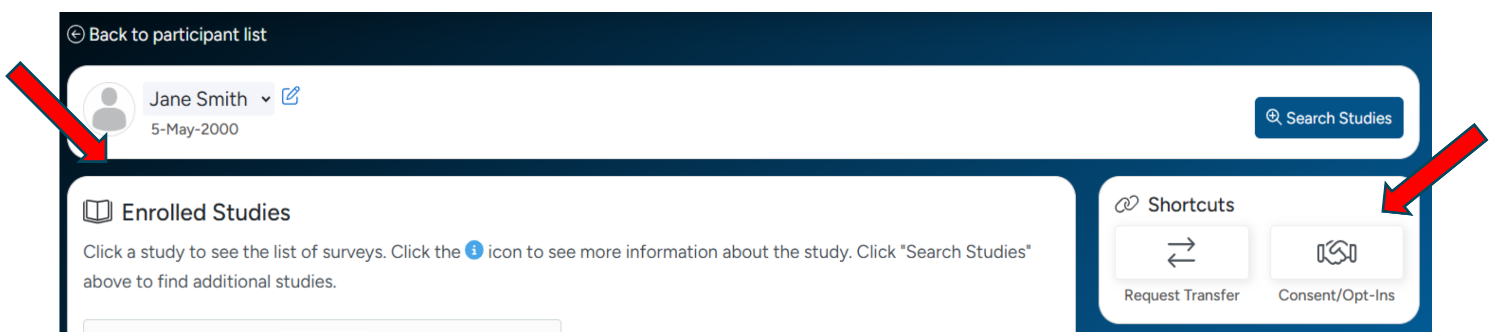
View Responses and Reports

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

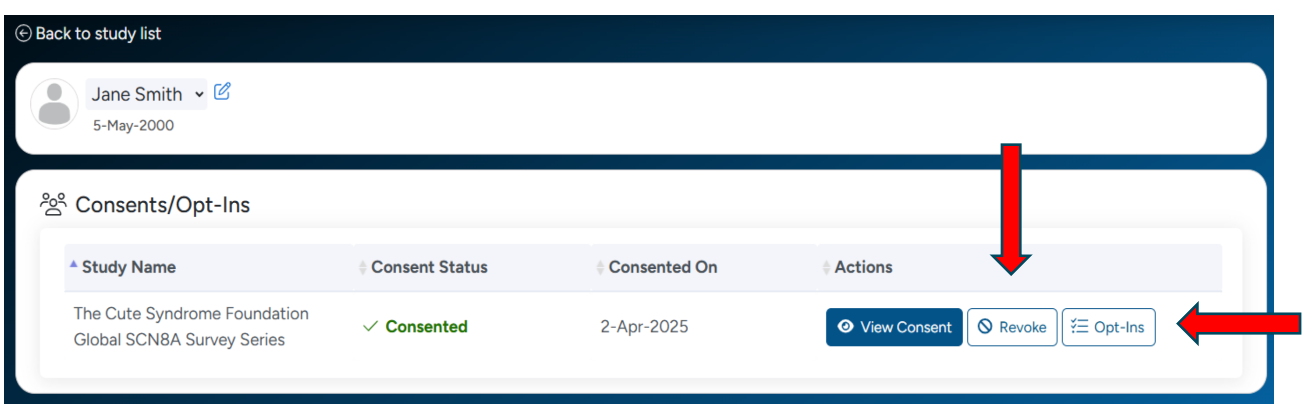


View Consent and Opt-Ins

- 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.



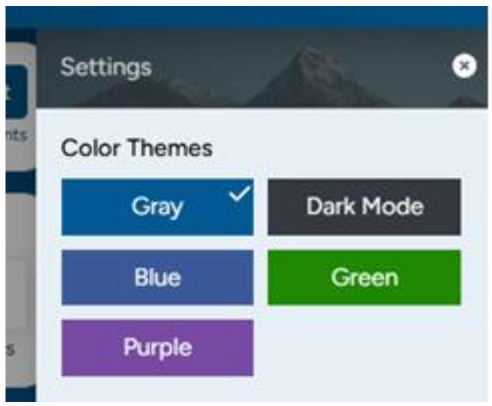
- Step 2: You may revoke your consent at any time by clicking "Revoke". You may also edit your Opt-Ins by clicking "Opt-Ins".



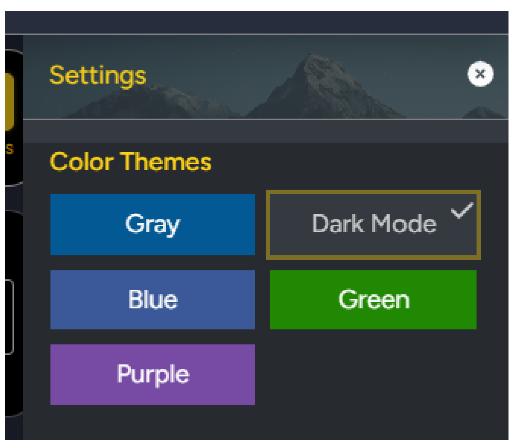
Dark Mode Settings

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

- Step 2: Select Dark Mode.



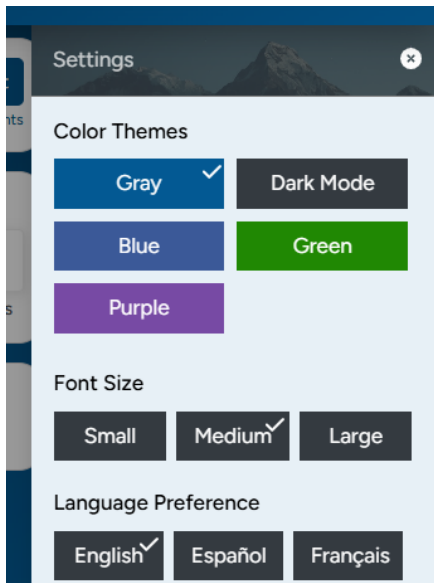
- Step 3: Exit the Settings menu, and your selection will be saved.



Display Settings

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

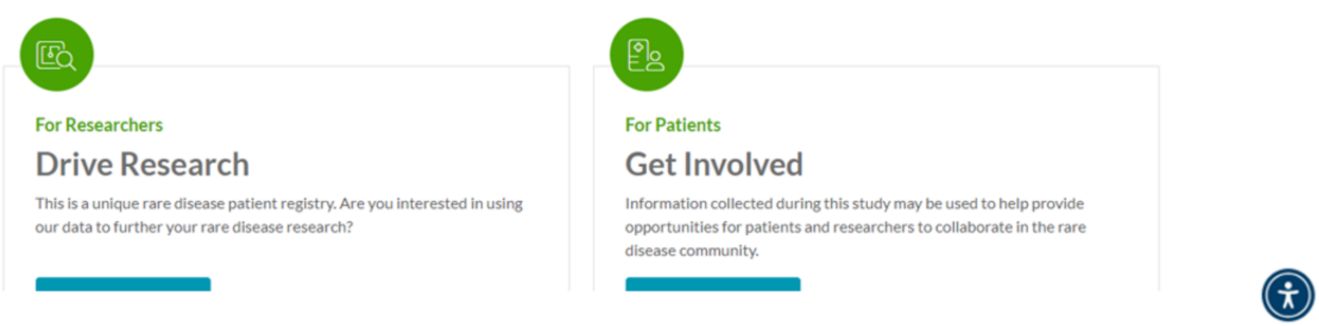
- Step 2: Select a color theme, a font size, or language preference.

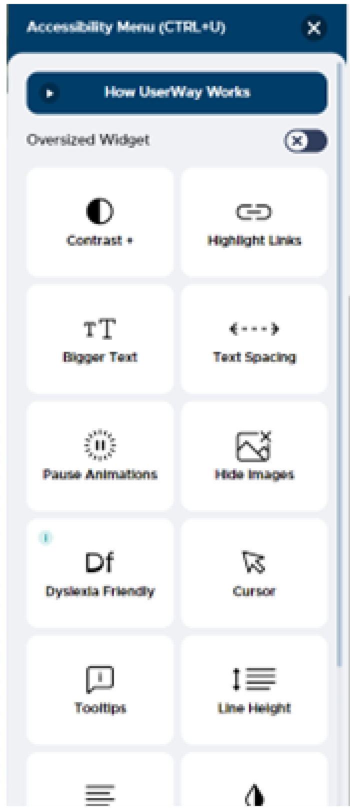


- Step 3: Exit the Settings menu, and your selection will be saved.

Microsite Visibility

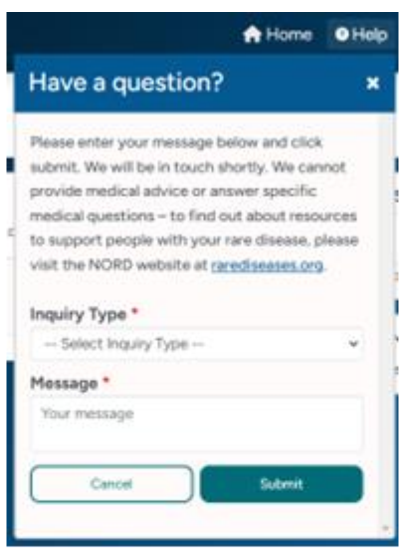
- Step 1: You can change how you view the microsite (Tcsfsurveys.iamrare.org) using an Accessibility menu. Click the icon of a person at the bottom of the screen. You are able to change the settings such as the contrast, text sizing, and text spacing.





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.