


Participant User Guide

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 a diagnosis of an SCN8A gene mutation select **Participant Account**.
 - If you are entering information for someone else who has an SCN8A gene mutation or you have an SCN8A gene mutation and are also entering information for yourself), select **Caregiver Account**.
 - If you are entering information for an SCN8A gene mutation patient who has passed away, select **Caregiver Account**.

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FOUNDATION
www.TheCuteSyndrome.com

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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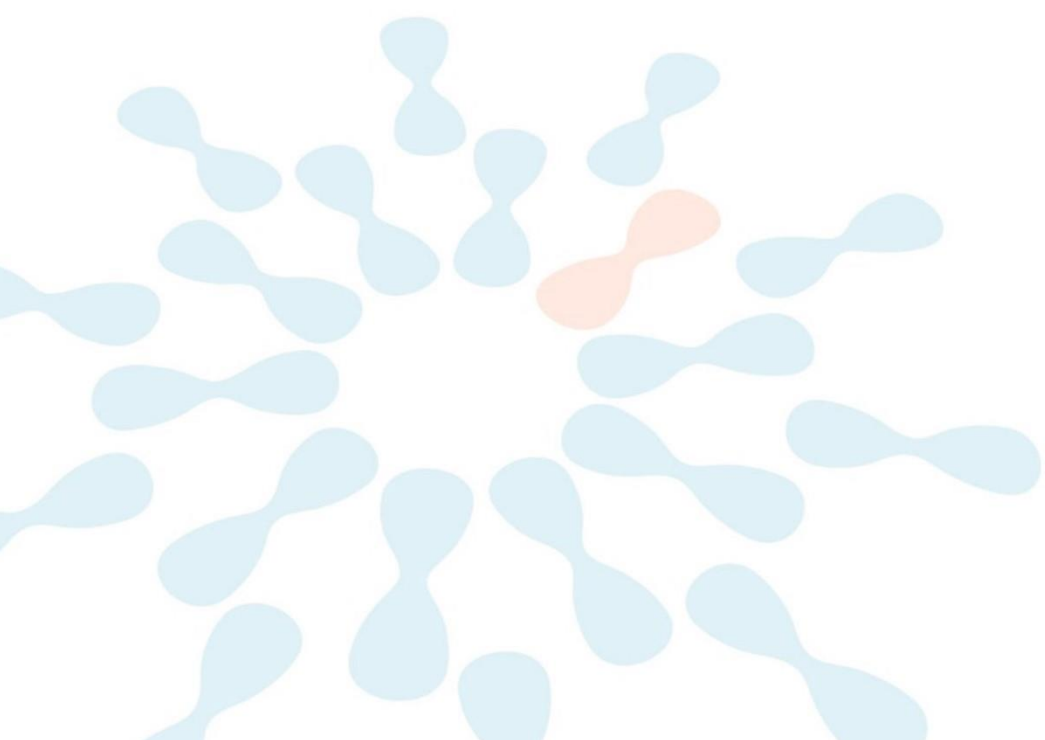
Caregiver Registration

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.

- 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”.

The screenshot shows a registration form for 'The Cute Syndrome Foundation'. At the top, there is a logo for 'SNA8 EPILEPSY' and the text 'Featuring The Cute Syndrome® FOUNDATION' with the website 'www.TheCuteSyndrome.com'. The main heading is 'Caregiver Registration'. Below this is a progress bar with five steps: 'Terms & Conditions', 'Contact Info', 'Notifications', 'Review & Submit', and 'Confirmation'. The 'Contact Info' step is currently active, indicated by a dark green bar under the progress bar. The form fields include: 'Country of Residence' (a dropdown menu), 'First Name' and 'Last Name' (two separate text input fields), and 'E-mail' (a text input field). At the bottom left, there is a 'Return to login' link. At the bottom right, there are two buttons: 'Previous' and 'Next', with 'Next' being highlighted in dark green.

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Caregiver Registration

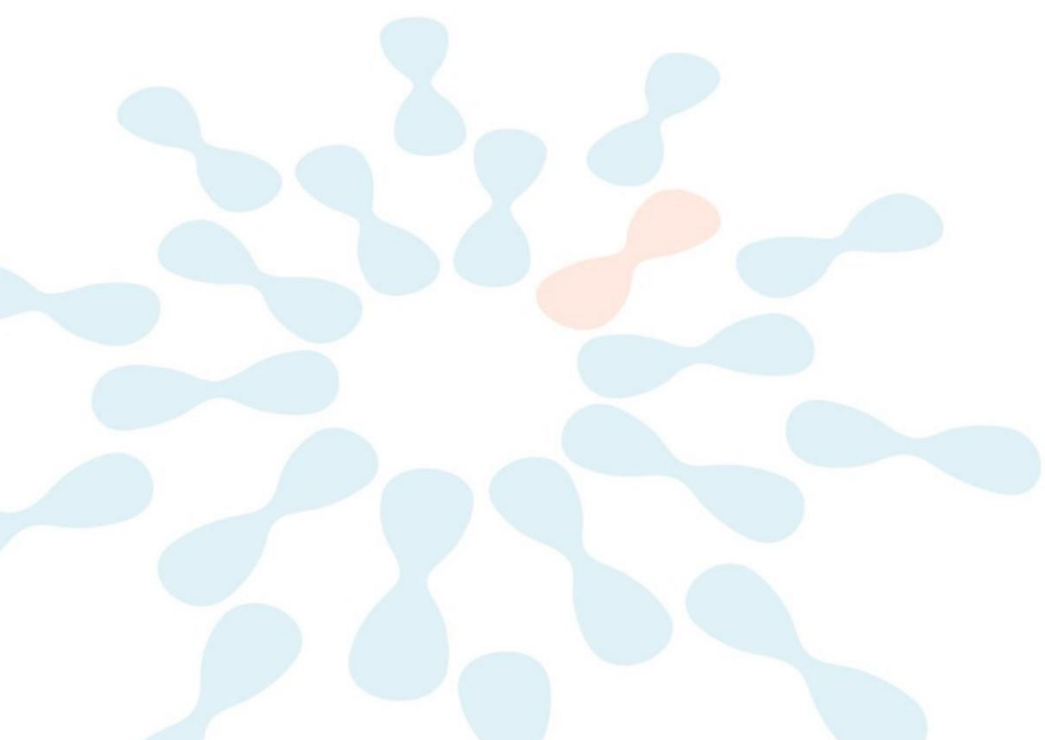
Terms & Conditions Contact Info Notifications Review & Submit Confirmation

Country of Residence *

First Name * Last Name *

E-mail *

Return to login Previous Next



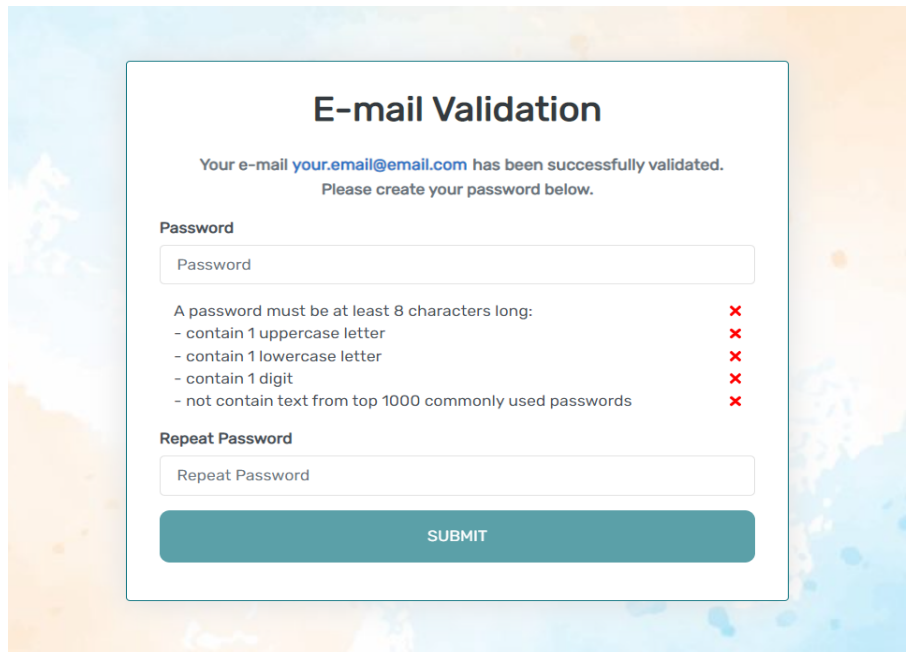
- Step 4: Select whether you are interested in being contacted by NORD regarding available studies. When you are finished with this page, click “Next”.

The screenshot shows the 'Caregiver Registration' form for The Cute Syndrome Foundation. At the top, the logo for SNA Epilepsy is displayed alongside the text 'Featuring The Cute Syndrome FOUNDATION' and the website 'www.TheCuteSyndrome.com'. Below the logo is a progress bar with five steps: 'Terms & Conditions', 'Contact Info', 'Notifications', 'Review & Submit', and 'Confirmation'. The 'Review & Submit' step is currently active, indicated by a dark teal bar under the progress bar. The main content area contains the text 'I am interested in NORD contacting me regarding available studies. *' followed by two radio buttons: 'Yes' (which is selected) and 'No'. At the bottom left, there is a link 'Return to login'. At the bottom right, there are two buttons: 'Previous' and 'Next'.

- Step 5: Select “Next” so that an activation link is sent to your e-mail to complete registration.

This screenshot shows the same 'Caregiver Registration' form, but now the 'Confirmation' step is active, as shown by the dark teal bar under the progress bar. The main content area contains the text 'An activation link will be sent to your.email@email.com. Click "Next" to send this e-mail and continue.' followed by a text input field. At the bottom left, there is a link 'Return to login'. At the bottom right, there are two buttons: 'Previous' and 'Next'. An orange arrow points to the 'Next' button.

- 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](#) has been successfully validated.
Please create your password below.

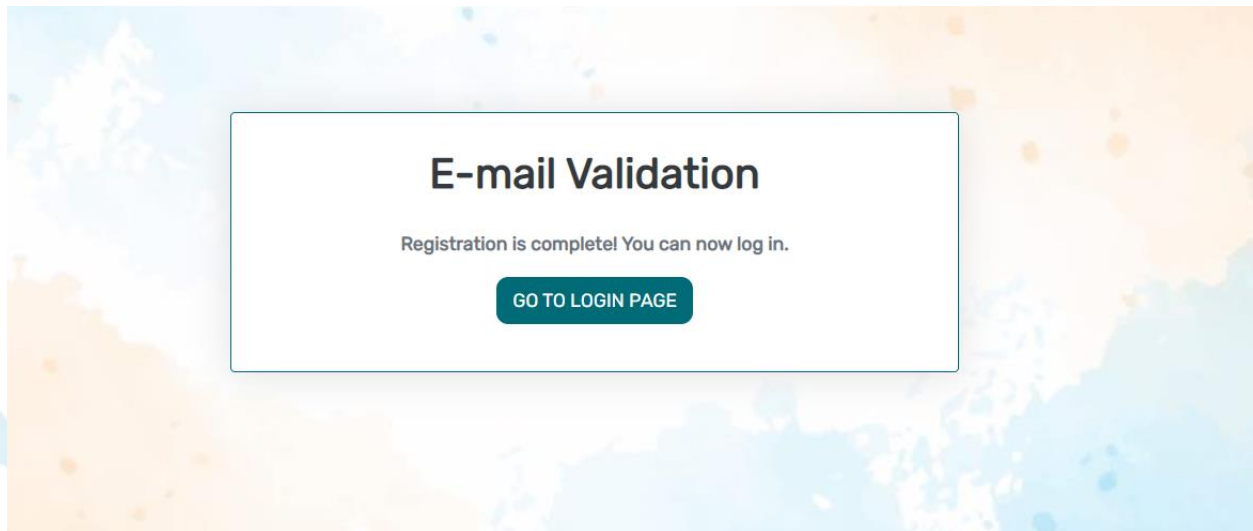
Password

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”.

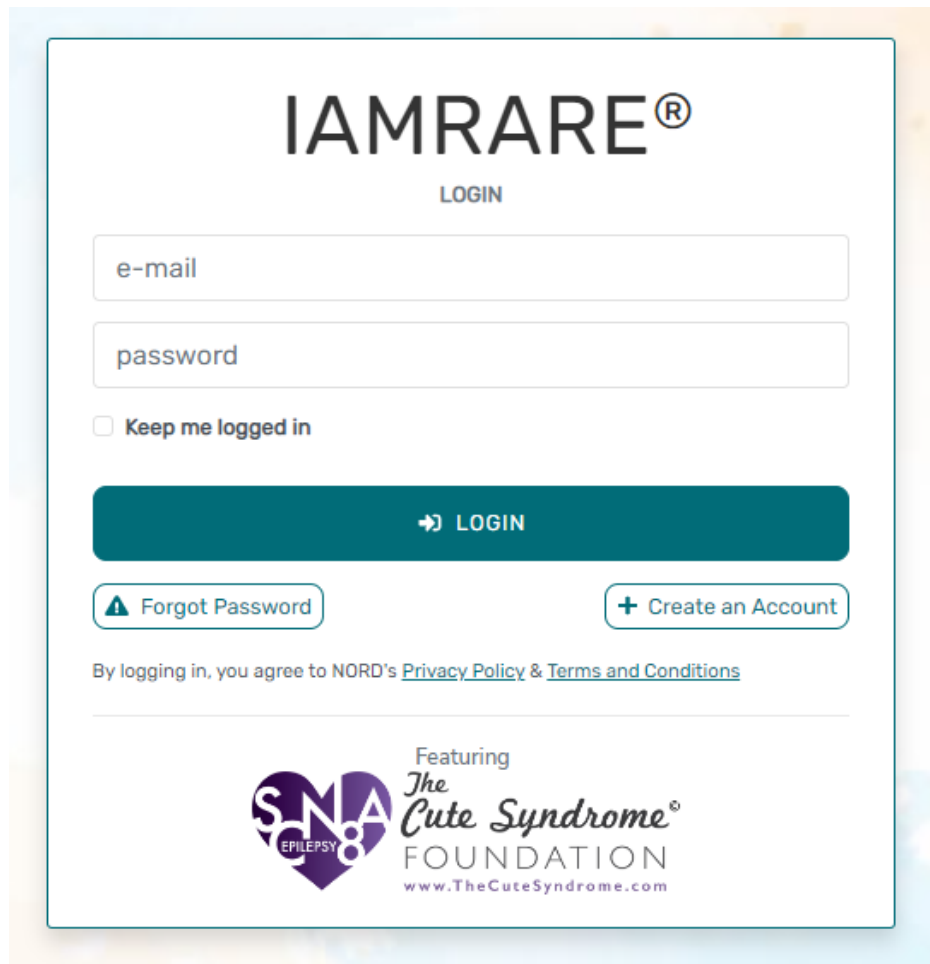


E-mail Validation

Registration is complete! You can now log in.

GO TO LOGIN PAGE

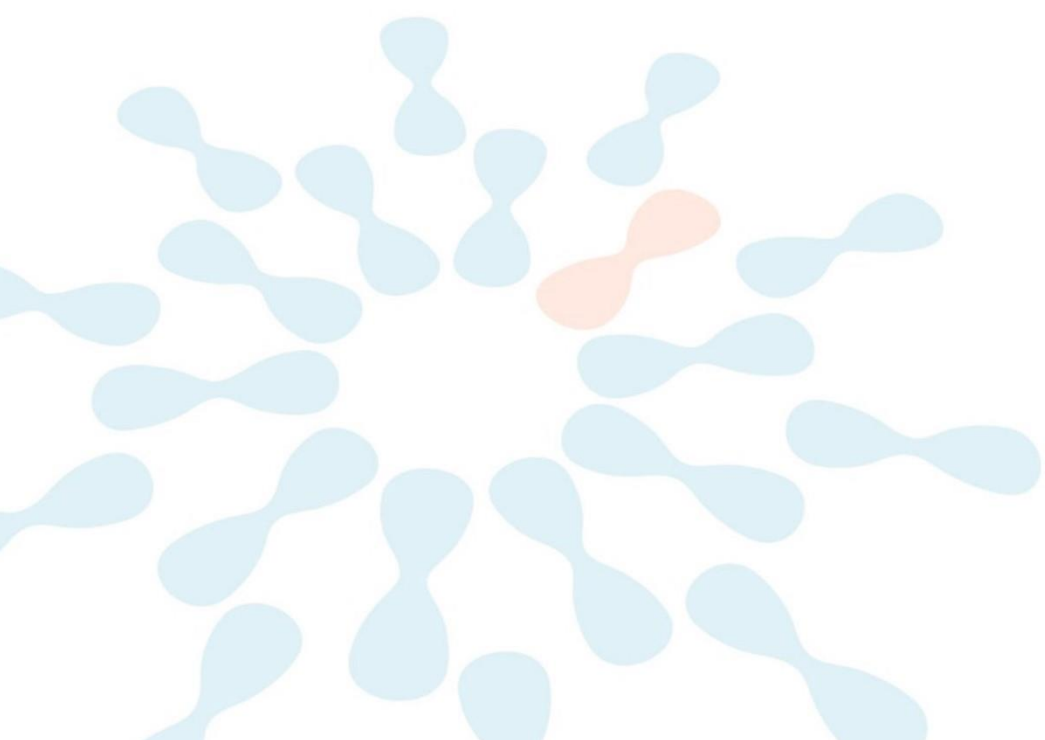
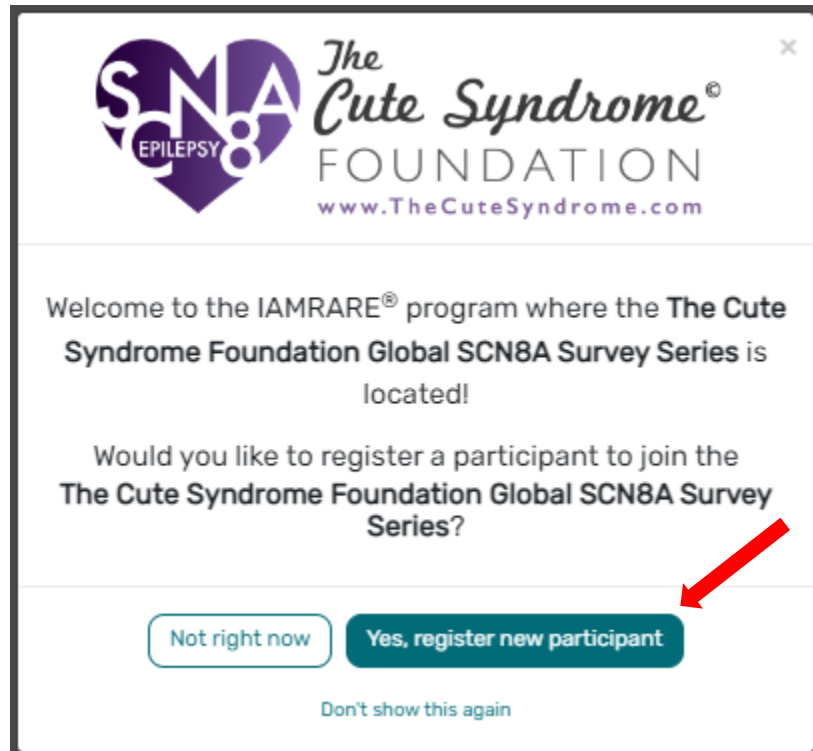
- Step 8: Log in using your new e-mail and password.



The image shows a login page for IAMRARE. At the top, the text "IAMRARE®" is displayed in a large, bold, sans-serif font, with "LOGIN" centered below it in a smaller font. There are two input fields: the first is labeled "e-mail" and the second is labeled "password". Below these fields is a checkbox labeled "Keep me logged in". A prominent teal button with a right-pointing arrow and the text "LOGIN" is centered below the checkbox. At the bottom of the form area, there are two buttons: "Forgot Password" with a warning triangle icon and "Create an Account" with a plus sign icon. Below the buttons, a line of text states: "By logging in, you agree to NORD's [Privacy Policy](#) & [Terms and Conditions](#)". At the bottom of the page, there is a logo for "SCNA EPILEPSY" (a purple heart shape with the letters S, C, N, A and the word EPILEPSY) and the text "Featuring The Cute Syndrome® FOUNDATION" with the website "www.TheCuteSyndrome.com". The background of the page is white with a light blue decorative pattern of abstract shapes at the bottom.

Add a Participant

- Step 1: To start, click Yes, register new participant.



- Step 2: 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 ? * ⓘ

Profile Image
 OR
No image selected

Consent to the Study

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

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Thank you for registering your first participant!

Would you like to consent to participate in the **The Cute Syndrome Foundation Global SCN8A Survey Series?**

- Step 2: Scroll down and read through the consent form thoroughly. Once you finish reading, 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 “Continue to Opt-Ins.”

Consent to The Cute Syndrome Foundation Global SCN8A Survey Series

related concerns or complaints with someone who is not part of this registry team, you may contact North Star Review Board Board at 877-473-8439 (toll free) or info@northstarreviewboard.org. Review and approval of this Registry by North Star Review Board is not an endorsement of this registry or its outcome. Contact the DSM at:

- You have questions, concerns, or complaints that are not being answered by the research team.
- You are not getting answers from the research team.
- You cannot reach the research team.
- You want to talk to someone else about the research.
- You have questions about your rights as a research subject.

Do not sign this form unless you have had a chance to ask questions and have received satisfactory answers to all of your questions

Authorization

I have read (or someone has read to me) this Consent and Authorization Form to provide data for future research purposes and have decided to donate the Study Participant's data to The Cute Syndrome Foundation Global SCN8A Survey Series. The general purposes of registry participation, details of my and the Study Participant's involvement and possible hazards and inconveniences have been explained to my satisfaction. I understand that I will receive an electronic copy of this consent authorization form.

Because of the way data is collected and saved, to participate in this study, the participant or person agreeing must be willing to agree to permitting data to be shared as described. If you cannot agree to this, please do not participate in the study.

Please reference the following sections of the consent form for details on how data collected in this study will be used.

- How the Study Participant's Data gets into the registry
- How the Study Participant's Data is stored and used for future research.
- Confidentiality
- Voluntary Participation and Withdrawal
- Privacy Rights

I give permission on behalf of the Study Participant to provide research data to The Cute Syndrome Foundation Global SCN8A Survey Series only for the purposes described above. The Study Participant's data will be used as described in the consent form.

I give permission on behalf of the Study Participant to provide my research data that has been pseudonymized to The Cute Syndrome Foundation Global SCN8A Survey Series for future research within recognized ethical standards for scientific research.

I wish to be contacted on behalf of the Study Participant about future research studies that may be of interest.

[Continue to Opt-Ins](#)

- Step 3: Select your opt-ins, then click Save and Review.

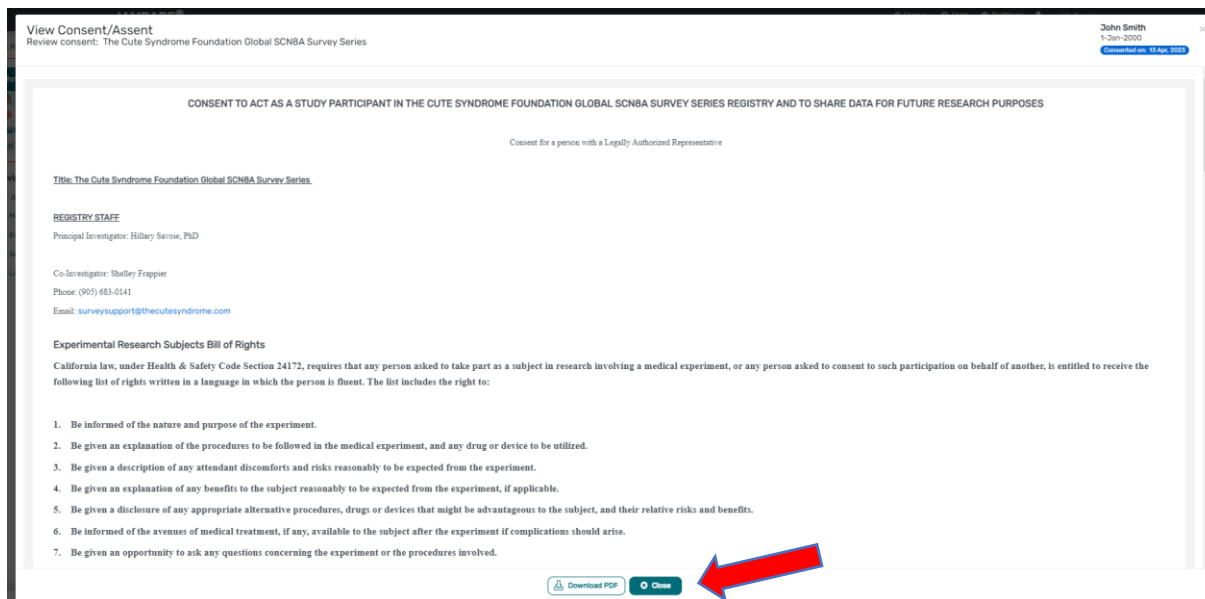
Opt-Ins for The Cute Syndrome Foundation Global SCN8A Survey Series

Select Opt-Ins for this study

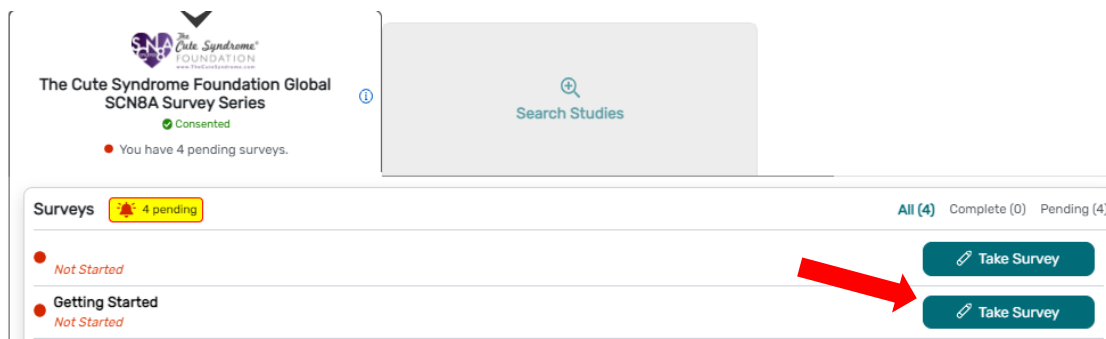
- Interest in hearing about clinical trials you may be eligible for
- Interest in donating specimens or DNA (biobanking) for future research

[Save and Review](#)

- Step 4: Download a copy of your consent, or click Close to continue.




- Step 5: You now have access to start taking surveys.



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.

ENROLLED STUDIES



Global SCN8A Survey Series ⓘ

Consented

You have 7 pending surveys.

[Search Studies](#)

Surveys 🔔 7 pending

Getting Started
Completed on 27-Jan-2023

Demographics
Not Started

All (8) Complete (1) Pending (7)

[View Responses](#) 1

[Reports](#)

[Take Survey](#)

