




SCN2A DRAGONFLY 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



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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SCN2A RELATED AUTISM & EPILEPSY
FAMILIESCN2A
FOUNDATION
WWW.SCN2A.ORG

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”.

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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

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An activation link will be sent to test@test.com. Click "Next" to send this e-mail and continue.

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- 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.

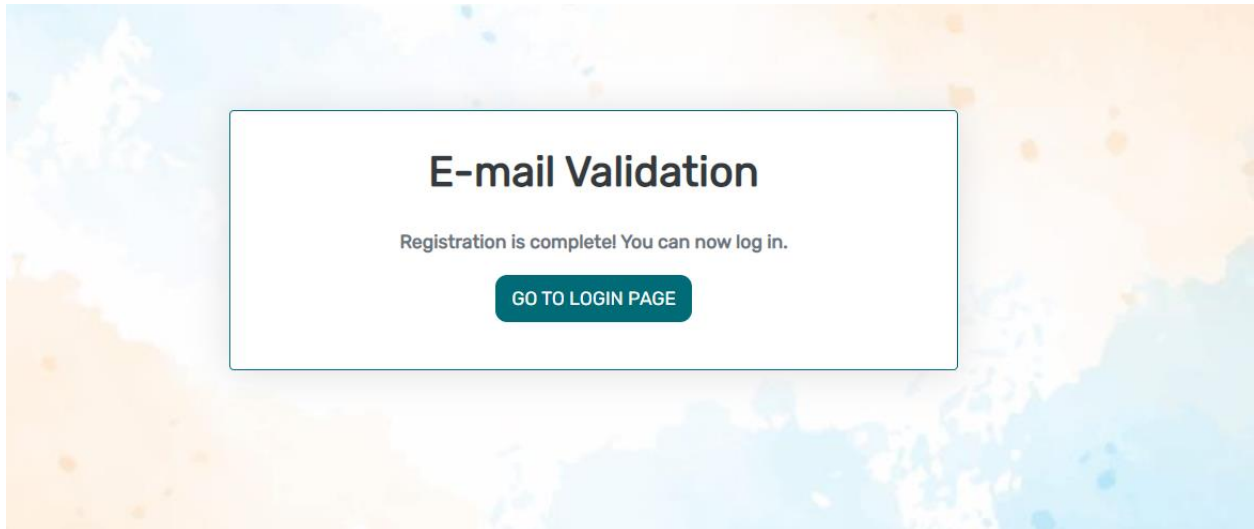
Password

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 ✗

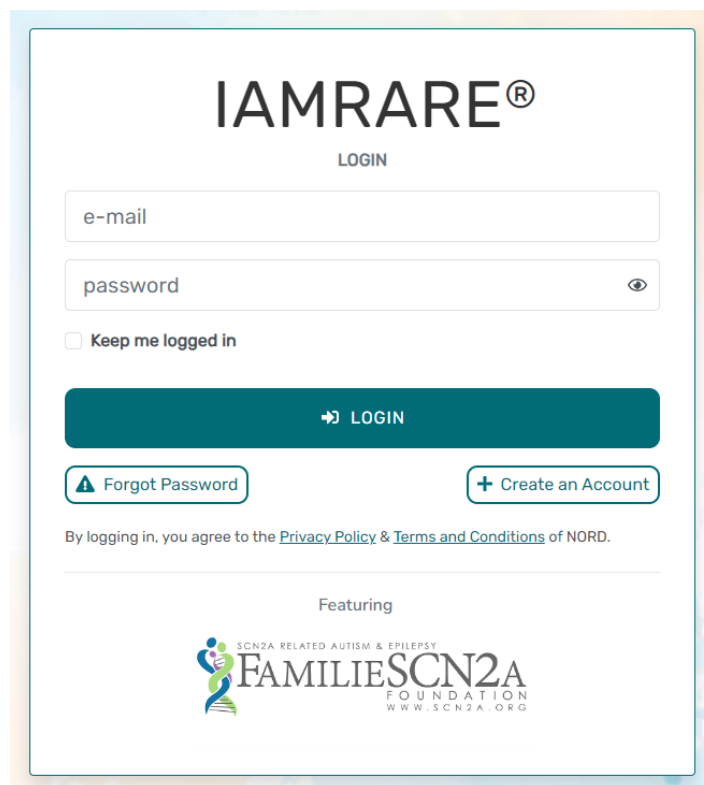
Repeat Password

[SUBMIT](#)

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



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

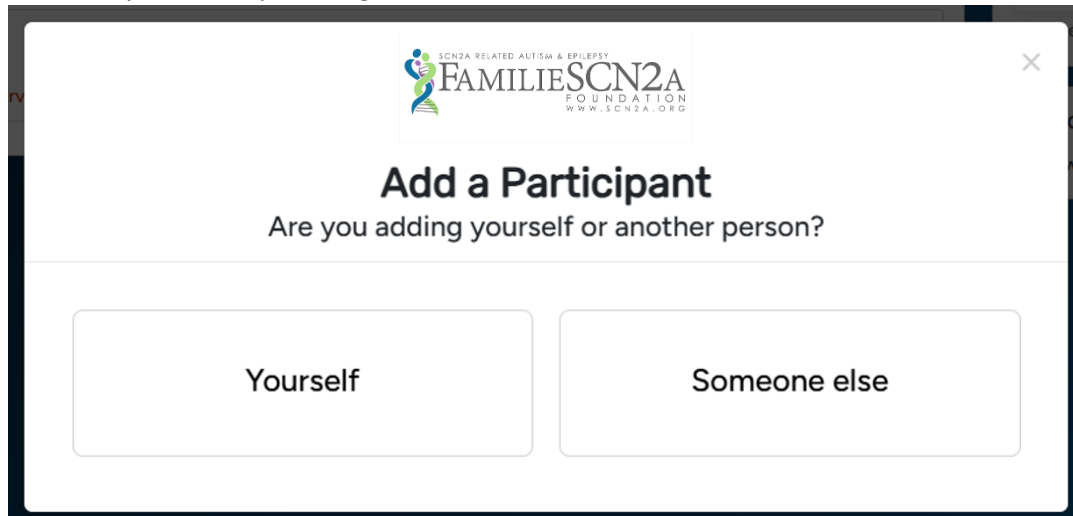


Add a Participant

- 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.

The 'Add Participant' form contains the following fields and options:

- Who Is Being Added as a Participant? Self Other
- Preferred First Name * (text input)
- Current Last name * (text input)
- First Name on Birth Certificate * (text input)
- Middle Name on Birth Certificate * (text input, placeholder: Type 'NA' if none)
- Last Name on Birth Certificate * (text input)
- Date of Birth * (calendar icon, placeholder: mm/dd/yyyy)
- Sex Recorded on Birth Certificate * (dropdown menu)
- Country of Residence * (dropdown menu)
- State/Province/Region of Residence * (text input, placeholder: State/Province/Region)
- Country of Birth * (dropdown menu)
- City/Municipality of Birth * (text input, placeholder: City/Municipality of Birth)
- What Is Your Relationship to ? * (dropdown menu)

Consent to the Study

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

The consent dialog box features the logo for the SCN2A Related Autism & Epilepsy FamilieSCN2A Foundation (www.scn2a.org). The text reads: "Thank you for registering your first participant! Would you like to consent to participate in SCN2A DRAGONFLY Registry?" At the bottom, there are two buttons: "Not right now" and "Yes, complete consent for this participant." A purple arrow points to the "Yes" button.

- 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 SCN2A DRAGONFLY Registry

Consent Overview

Those eligible to participate in our study include:

Participant: An individual diagnosed with an SCN2A-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 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 an SCN2A-related disorder, defined as a spouse, parent, sibling, offspring, close relative, close friend, guardian and/or significant other of the individual and who had knowledge of 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 an SCN2A-related disorder. I participated in their medical care.

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Consent to SCN2A DRAGONFLY Registry

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

Consent to Participate in the SCN2A Dragonfly Registry and to Allow Data to be Shared for Future Research

Title: SCN2A Dragonfly Registry

Principal Investigator: Brad Bryan, PhD MBA, Team for Accelerating Science and Clinical Outcomes, The SCN2A Foundation

Phone: 915-244-5303

E-mail: brad.bryan@scn2a.org

Sponsor: FamilieSCN2A Foundation

Key Information

You are invited to take part in a research study for individuals with SCN2A-related conditions 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 build a list, or registry, of people with SCN2A-related conditions. SCN2A-related conditions are genetic disorders that affect how the brain works. In the registry, people and their families can choose to share details about their medical history, symptoms, and treatments. This information is collected and organized in a safe and private way. Scientists and researchers can access the registry to learn more about these conditions, find patterns, and understand how they affect people's lives. When people join the registry, they help scientists gather more knowledge about SCN2A-related disorders (SRD). This may lead to better treatments and maybe even cures in the future. Researchers may contact the SCN2A Registry to share information about new studies and tests. Registry Staff will let the Study Participants know about these research opportunities. Overall, the research registry for people with SCN2A-related disorders is an important tool that brings together information from many people. It helps scientists learn more about these conditions and work towards improving the lives of those who are affected.

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Consent to SCN2A DRAGONFLY Registry

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 SCN2A Registry on behalf of the Study Participant. 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 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 SCN2A Registry have been answered to my satisfaction, and I understand the purpose of the registry and the risks of participation.

I wish to provide the Study Participant's research data to the SCN2A Registry for the purposes described above under Study Aims.

Previous

Next

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

Consent to SCN2A DRAGONFLY Registry

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 SCN2A DRAGONFLY Registry

Select Opt-Ins for this study

- Interest in hearing about other studies from [FamilieSCN2A 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 [FamilieSCN2A Foundation](#)
- Interest in signing up for a [FamilieSCN2A Foundation](#) newsletter
- Support from [FamilieSCN2A Foundation](#) Ambassador / Care Coordinator
- If eligible, I have interest in receiving [FamilieSCN2A Foundation](#) merchandise that would be sent via electronic or postal mail
- Interest in hearing about family conferences and events run by [FamilieSCN2A Foundation](#)
- Support from other Patient Advocacy Groups
- For US Residents: If eligible, I would like to receive a thank you token that would be sent via electronic or postal mail.
- Interest in hearing about news and other studies from [FamilieSCN2A Foundation](#).
- Interest in learning about upcoming events such as webinars and conferences
- Interest in learning more about [SCN2A-related disorders](#) educational programs and resources from [FamilieSCN2A Foundation](#)
- I agree to be contacted by [FamilieSCN2A Foundation](#) regarding their initiatives.
- If eligible, I would like to receive [SCN2A-related disorders](#) awareness tokens 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 for a user named Jane. At the top, there's a navigation bar with 'Home', 'Help', 'Settings', and 'Hi, Jane!'. Below that, a greeting says 'Good Morning, Jane!' with a '+ Add Participant' button. The main section is titled 'Participants' and contains a list of participants. The first participant is Jane Smith, with a date of birth '5-May-2000' and '7 pending surveys'. A purple arrow points to the right arrow icon next to her name. To the right of the list are two shortcut buttons: 'Request Transfer' and 'Consent/Opt-Ins'. Below that is a 'Notifications (0)' section showing 'No new notifications.'

- Step 2: Click on the appropriate study.

This screenshot shows the 'Enrolled Studies' section for Jane Smith. It features a dropdown menu for her name and a list of studies. The first study is 'SCN2A DRAGONFLY Registry' by the 'FamilleSCN2A Foundation'. It shows a status of 'Consented' and a button for '1 pending surveys'. A purple arrow points to this button. The interface also includes a 'Back to participant list' link at the top and instructions on how to interact with the study cards.

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

This screenshot shows the details for the 'SCN2A DRAGONFLY Registry' survey. It displays a progress indicator of '0%' and 'Not Started'. There is a 'Take Survey' button. Above the button, it shows 'All (1)' surveys, with 'Complete (0)' and 'Pending (1)'. A purple arrow points to the 'Take Survey' button. The interface also includes a 'Back to study list' link at the top and a dropdown menu for Jane Smith's name.

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.

Back to study list

Jane Smith 5-May-2000

SCN2A DRAGONFLY Registry

Surveys 8 pending **All (10)** Complete (2) Pending (8)

Diagnosis *Completed on 27-Mar-2025* View Responses (1) Reports

Demographics *Completed on 27-Mar-2025* View Responses (1) Reports

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

Back to participant list

Jane Smith 5-May-2000

Search Studies
Learn about searching for studies

Enrolled Studies
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.

Shortcuts
Request Transfer Consent/Opt-Ins

Back to study list

Jane Smith 5-May-2000

Consents/Opt-Ins

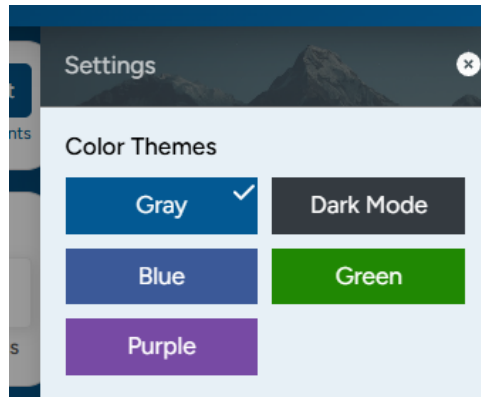
Study Name	Consent Status	Consented On	Actions
SCN2A DRAGONFLY Registry	Consented	6-Mar-2024	<a>View Consent <a>Revoke <a>Opt-Ins

Dark Mode Settings

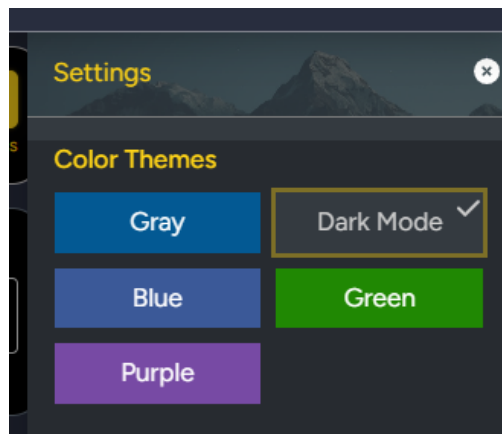
- Step 1: You can view the platform in Dark Mode. First, click Settings.



- Step 2: Select Dark Mode.



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

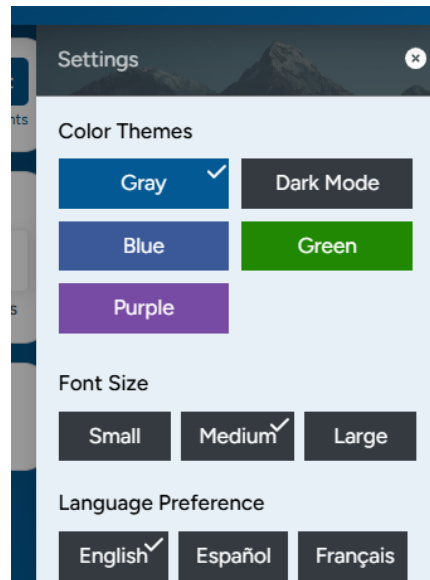


Display Settings

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



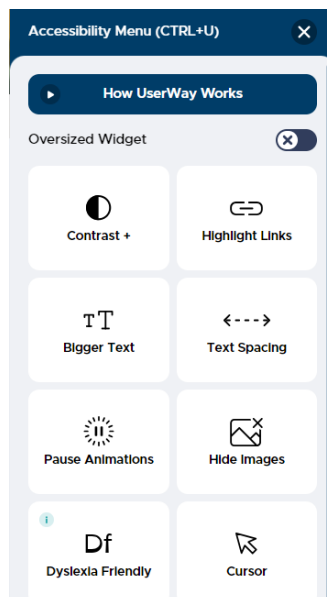
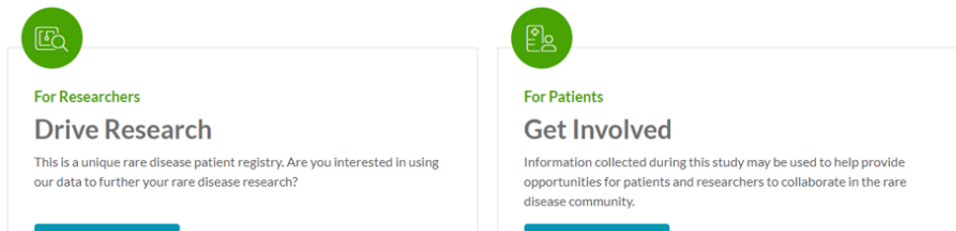
- Step 2: Select a color theme, a font size, or language preference.



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

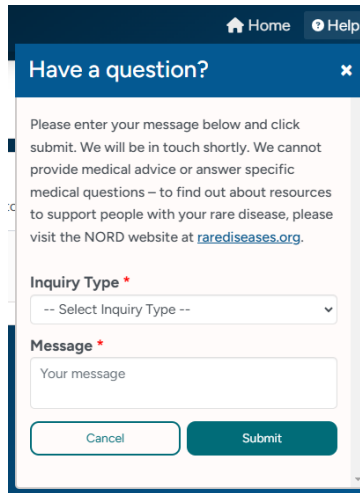
Microsite Visibility

- Step 1: You can change how you view the microsite (scn2a.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.



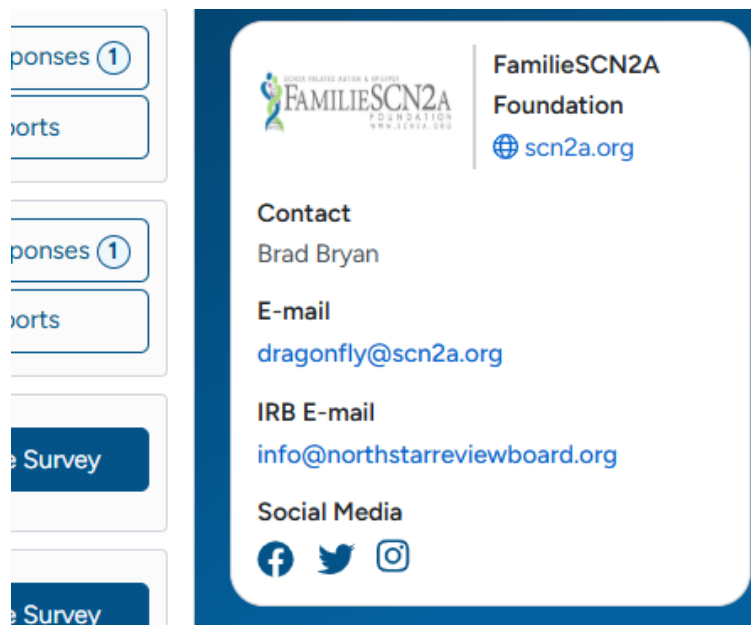
Need Assistance?

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



The screenshot shows a mobile application interface with a 'Home' button and a 'Help' button. A modal window titled 'Have a question?' is open. The modal contains the following 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 the text is a dropdown menu for 'Inquiry Type' with the placeholder text '-- Select Inquiry Type --'. Underneath is a text input field labeled 'Message' with the placeholder text 'Your message'. At the bottom of the modal 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 screenshot shows a contact information card for the FamilieSCN2A Foundation. The card is titled 'FamilieSCN2A Foundation' and includes the website scn2a.org. The contact information is as follows:

- Contact:** Brad Bryan
- E-mail:** dragonfly@scn2a.org
- IRB E-mail:** info@northstarreviewboard.org
- Social Media:** Facebook, Twitter, and Instagram icons.