




## SCN2A DRAGONFLY Registry 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 SCN2A-related disorder, select **Participant Account**.
  - If you are entering information for **someone else** who has an SCN2A-related disorder or you have an SCN2A-related disorder and are also entering information for yourself), select **Caregiver Account**.
  - If you are entering information for an SCN2A-related disorder patient who has passed away, select **Caregiver Account**.

Featuring



---

### 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”.

Featuring

SCN2A RELATED AUTISM & EPILEPSY  
**FAMILIE SCN2A**  
 FOUNDATION  
 WWW.SCN2A.ORG

## 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.

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

Featuring

SCN2A RELATED AUTISM & EPILEPSY  
**FAMILIE SCN2A**  
 FOUNDATION  
 WWW.SCN2A.ORG

## Caregiver Registration

Terms & Conditions   **Contact Info**   Notifications   Review & Submit   Confirmation

Country of Residence \*

First Name \*   Last Name \*

First Name   Last Name

E-mail \*

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”.

Featuring

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

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

Featuring

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

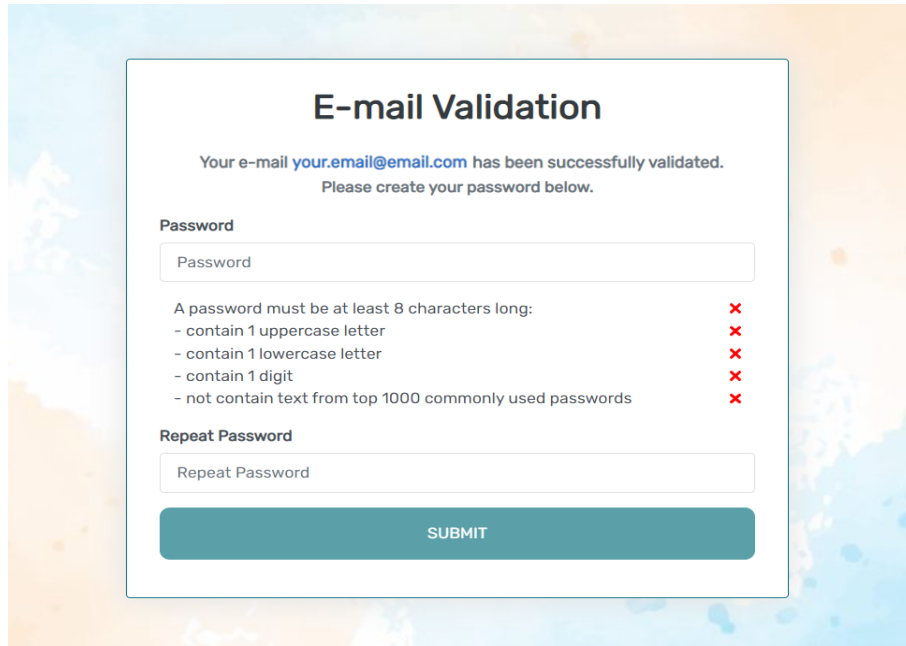
## Caregiver Registration

Terms & Conditions   Contact Info   Notifications   Review & Submit   Confirmation

An activation link will be sent to [youremail@email.com](mailto:youremail@email.com). Click "Next" to send this e-mail and continue.

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

- 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](mailto:your.email@email.com) has been successfully validated.  
Please create your password below.

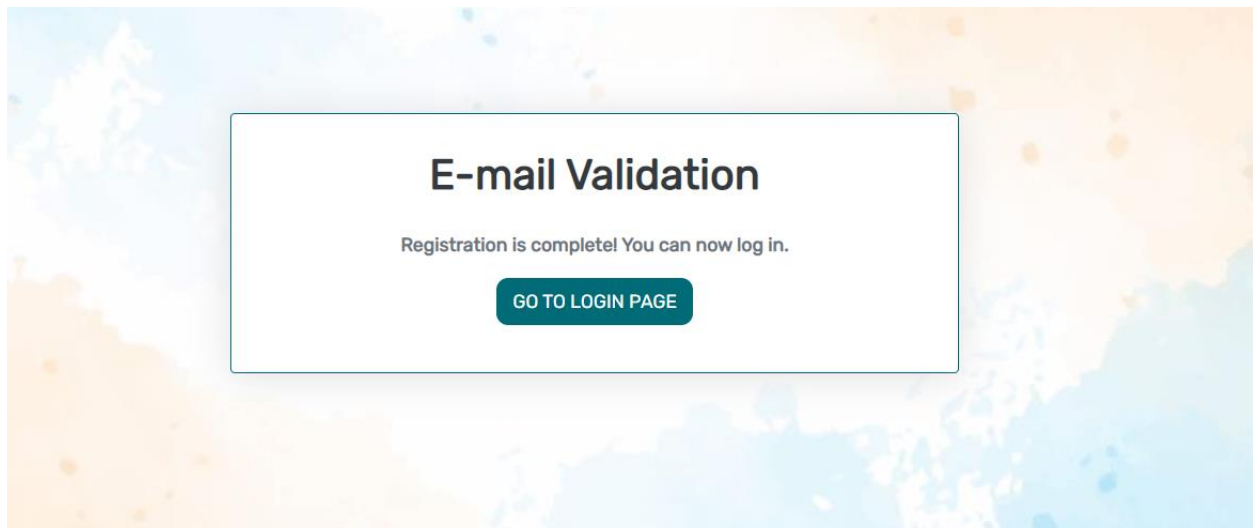
**Password**

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.

IAMRARE®  
LOGIN

e-mail

password

Keep me logged in

➔ LOGIN

⚠️ Forgot Password

+ Create an Account

By logging in, you agree to the [Privacy Policy](#) & [Terms and Conditions](#) of NORD.

Featuring

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

## Add a Participant

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

×

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

Welcome to the IAMRARE® program, home of **SCN2A DRAGONFLY Registry!**

Would you like to register a participant to join **SCN2A DRAGONFLY Registry?**

Not right now

Yes, register new participant

Don't show this again

- Step 2: Fill out the Participant's information.

Add Participant ✕

**Acknowledgement\***

By checking this box, you acknowledge that information collected on this platform will only be used for research purposes by NORD and in ways that will not reveal who you are. Federal or state laws may require us to show information to university or government officials (or sponsors) who are responsible for monitoring the safety of any studies running on this platform. You will not be identified in any publications.

**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 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.”

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

Thank you for registering your first participant!  
Would you like to consent to participate in **SCN2A DRAGONFLY Registry?**

- 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.

Next

## 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](mailto: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.

Previous

Next

## 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



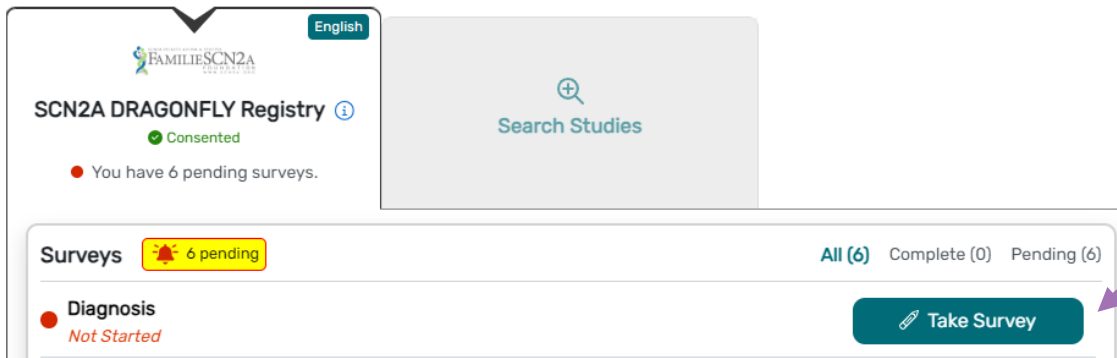
Select Opt-Ins for this study

- 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

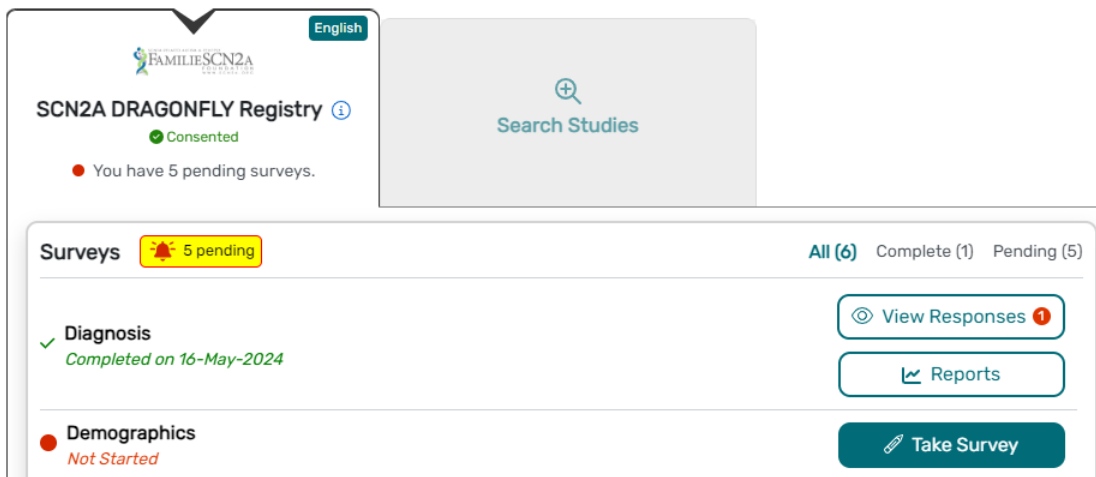


- Step 4: Once you've reviewed your consent, click "Close". You will then have access to start taking surveys.



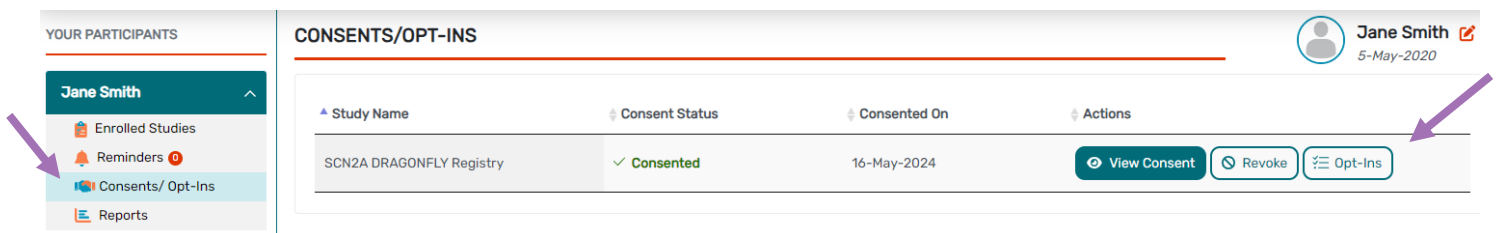
### View Responses and Reports

- 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.



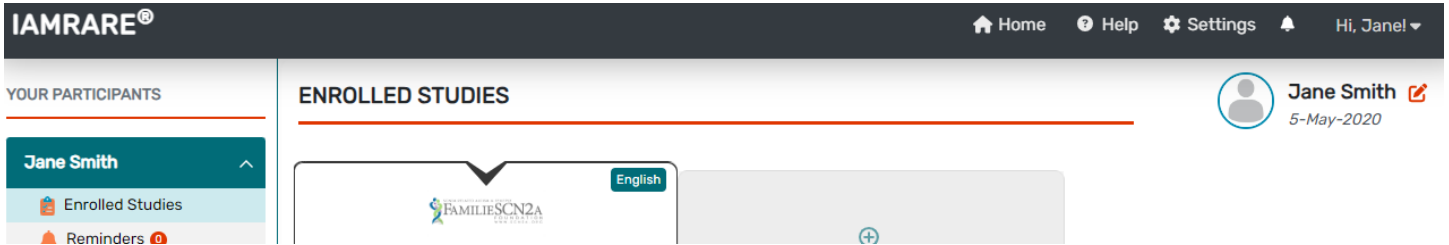
### View Consent and Opt-Ins

- Step 1: Once you have consented to the study, you are able to view your consent at any time. 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".

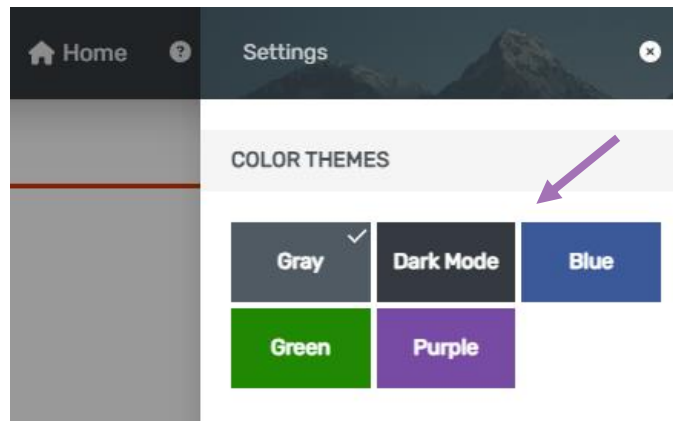


## Dark Mode Settings

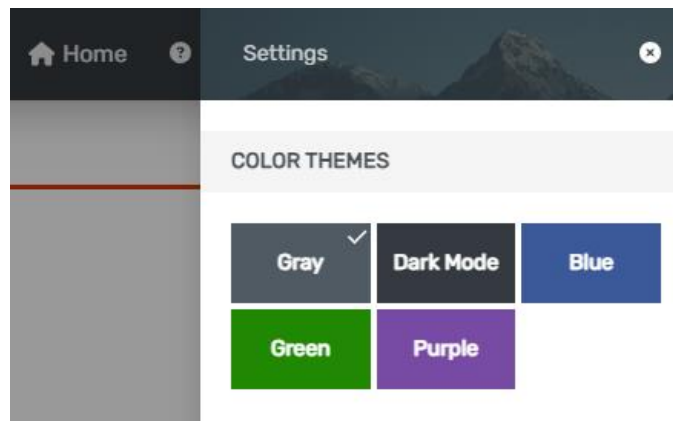
- Step 1: You can view the platform in Dark Mode. First, click Settings.



- Step 2: Select Dark Mode.

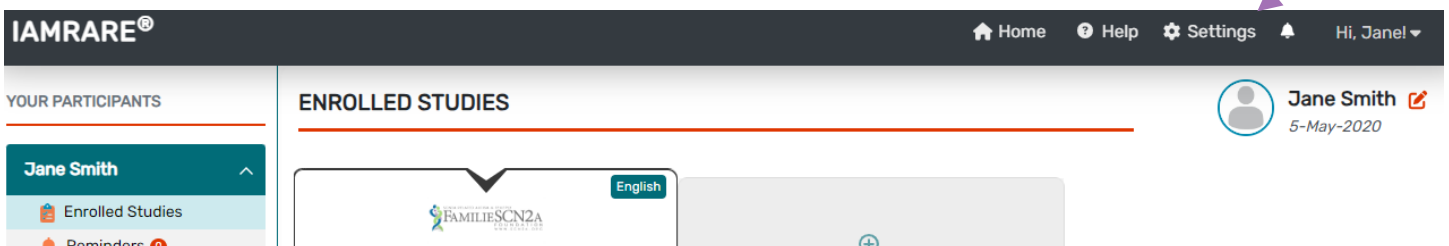


- Step 3: Exit the Settings menu, and your selection will be saved.

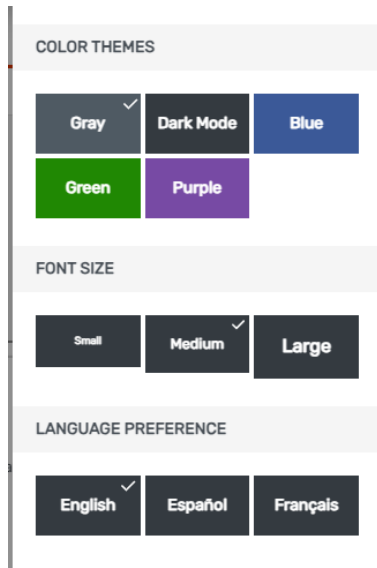


## Display Settings

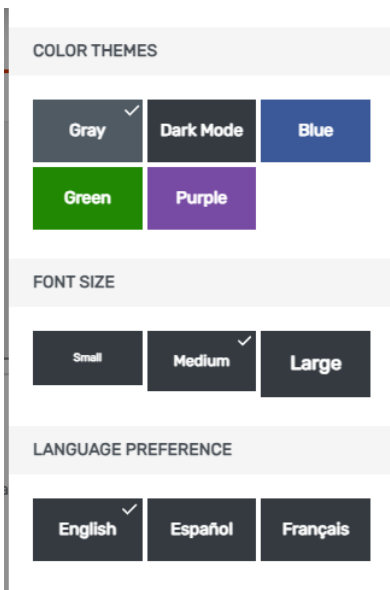
- Step 1: You can change the platform display settings. First, click Settings.



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

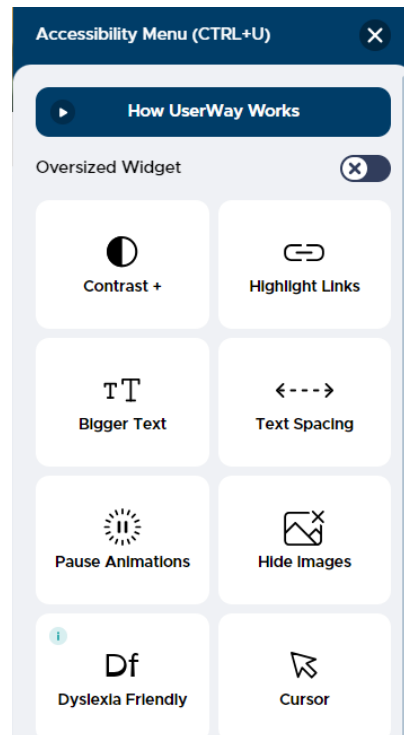
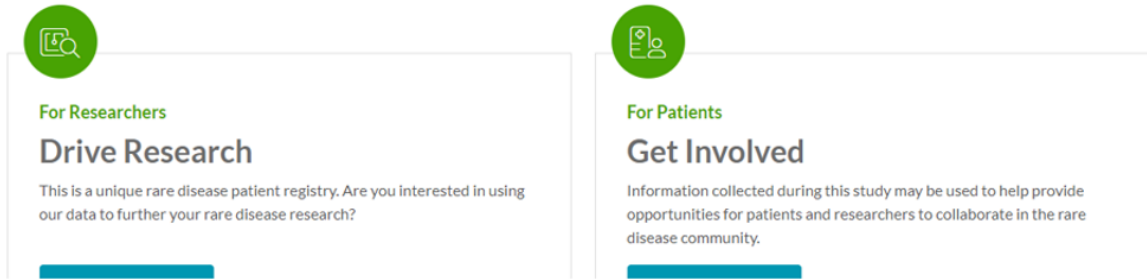


- Step 3: Exit the Settings menu, and your selection will be saved.



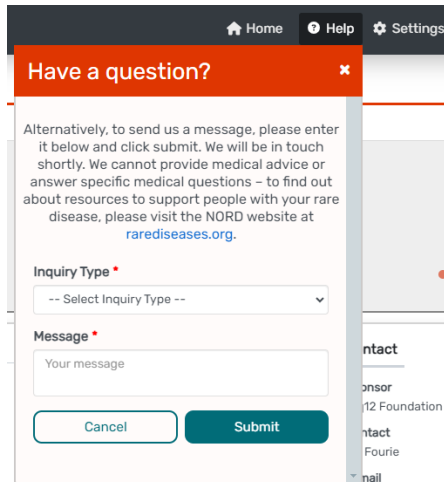
## Microsite Visibility

- 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.



Home Help Settings

### Have a question?

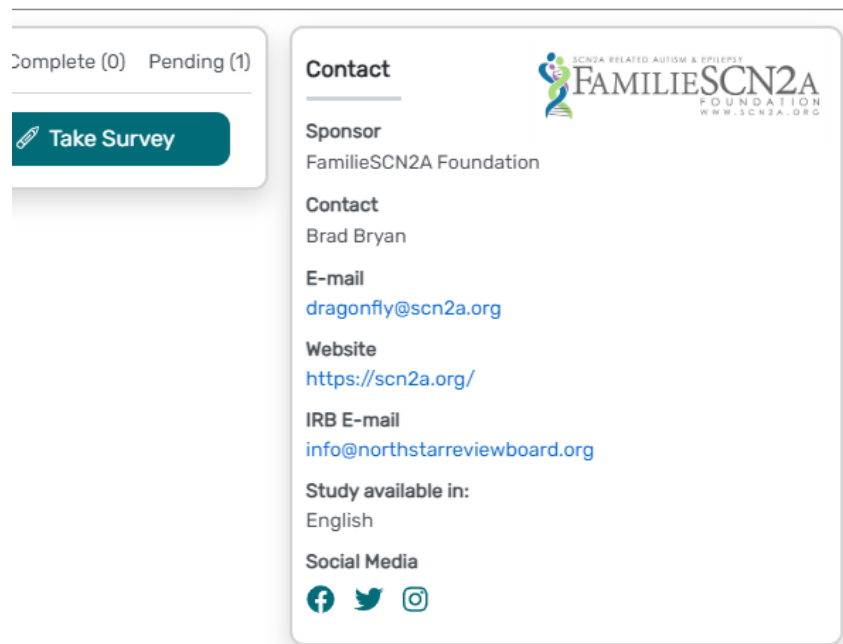
Alternatively, to send us a message, please enter it below and click submit. We will be in touch shortly. We cannot provide medical advice or answer specific medical questions – to find out about resources to support people with your rare disease, please visit the NORD website at [rarediseases.org](http://rarediseases.org).

**Inquiry Type \***  
-- Select Inquiry Type --

**Message \***  
Your message

Cancel 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.



Complete (0) Pending (1)

Take Survey

### Contact



**Sponsor**  
FamilieSCN2A Foundation

**Contact**  
Brad Bryan

**E-mail**  
[dragonfly@scn2a.org](mailto:dragonfly@scn2a.org)

**Website**  
<https://scn2a.org/>

**IRB E-mail**  
[info@northstarreviewboard.org](mailto:info@northstarreviewboard.org)

**Study available in:**  
English

**Social Media**  
