

Nevus Owners Outcomes Registry (NOOR) 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
NOOR
NEVUS OWNERS OUTCOMES REGISTRY

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](#) and [Privacy Policy](#) and have read the [Consumer Health Data Privacy Notice](#). *

[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

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

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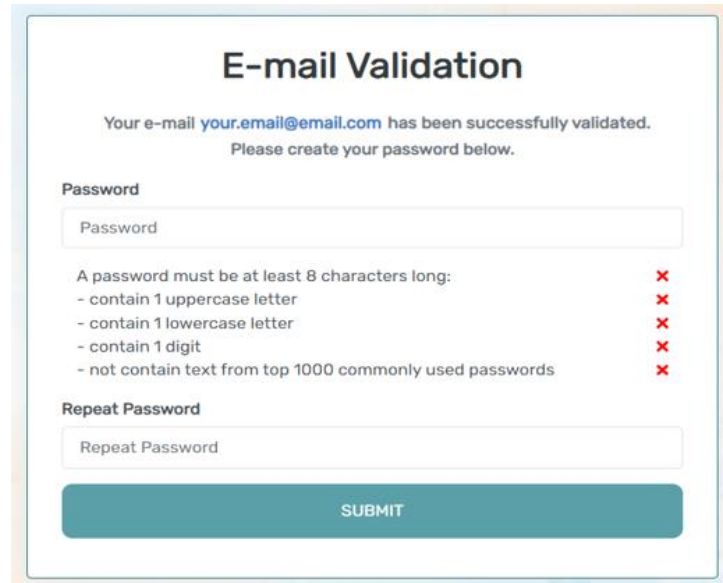
Registration

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

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

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

- 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

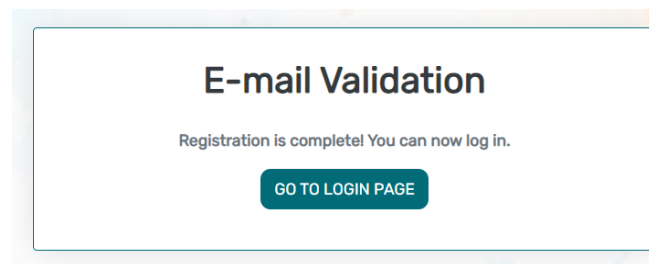
A password must be at least 8 characters long: ✗

- 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”.

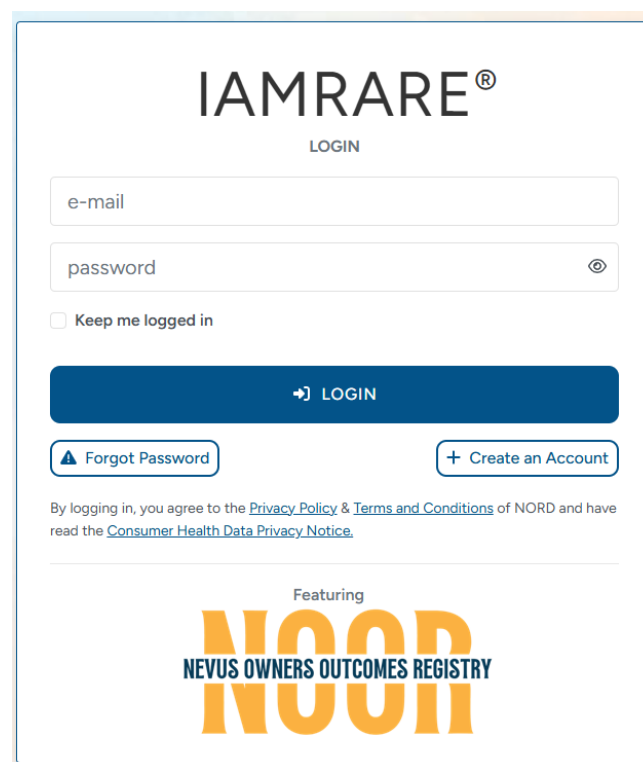


E-mail Validation

Registration is complete! You can now log in.

GO TO LOGIN PAGE

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



IAMRARE®

LOGIN



☐ Keep me logged in

→ LOGIN

 [Forgot Password](#) [+ Create an Account](#)

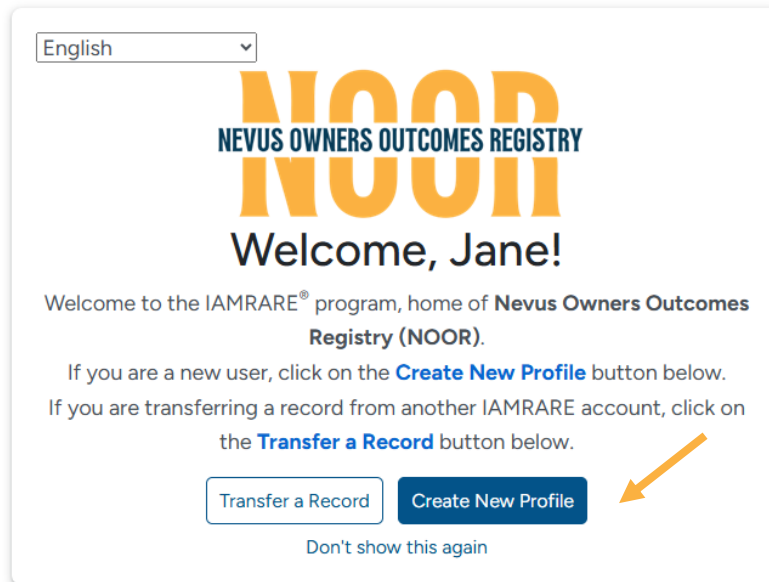
By logging in, you agree to the [Privacy Policy](#) & [Terms and Conditions](#) of NORD and have read the [Consumer Health Data Privacy Notice](#).

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NEVUS OWNERS OUTCOMES REGISTRY

Add a Participant

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



English

NOOR
NEVUS OWNERS OUTCOMES REGISTRY

Welcome, Jane!

Welcome to the IAMRARE® program, home of **Nevus Owners Outcomes Registry (NOOR)**.

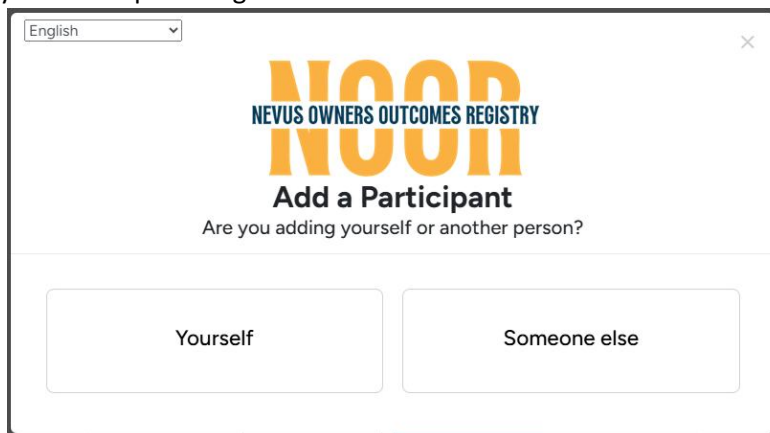
If you are a new user, click on the [Create New Profile](#) button below.

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.



English

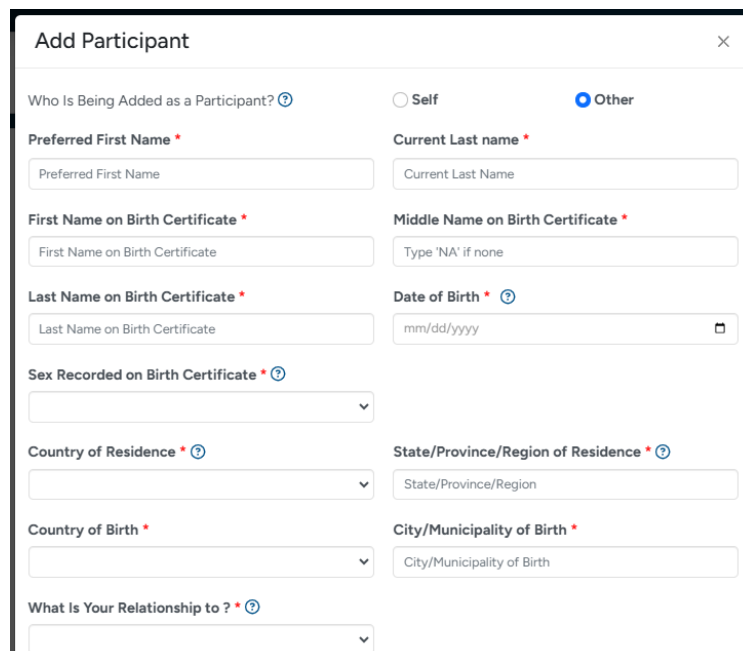
NOOR
NEVUS OWNERS OUTCOMES REGISTRY

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.”

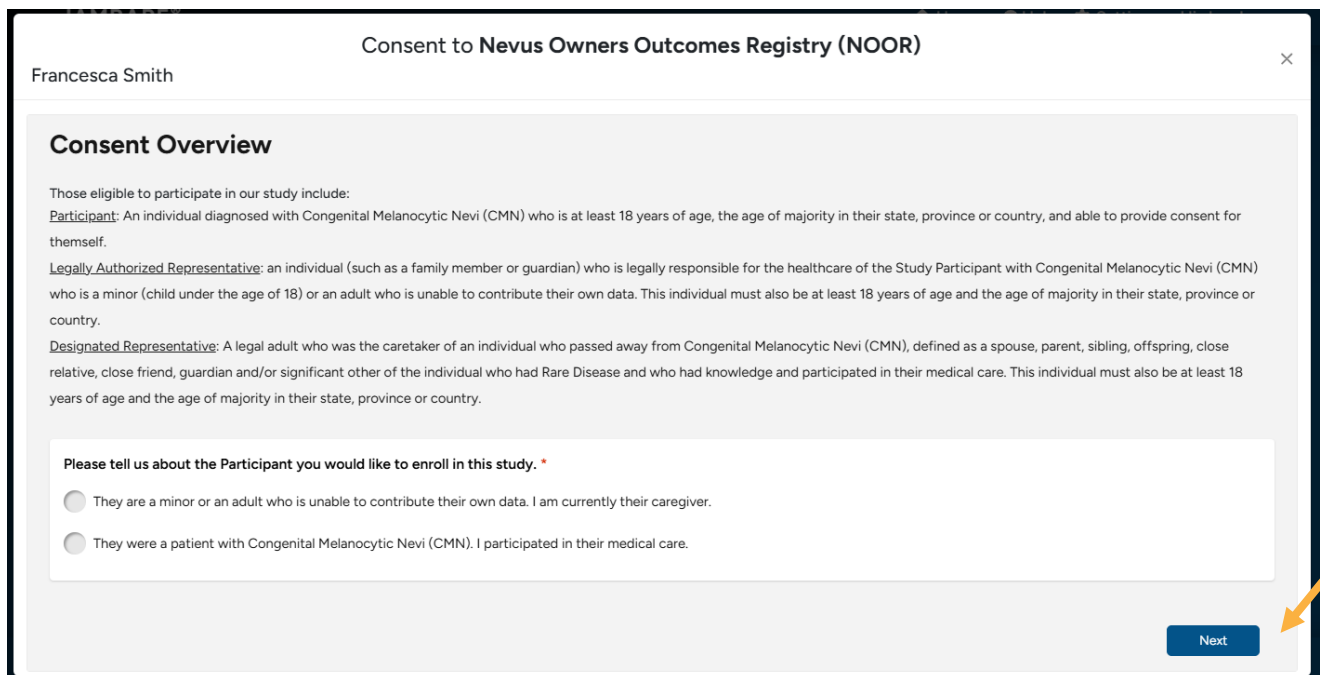


NOOR
NEVUS OWNERS OUTCOMES REGISTRY

Thank you for registering your first participant!
Would you like to consent to participate in Nevus Owners Outcomes Registry (NOOR)?

Not right now 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 Nevus Owners Outcomes Registry (NOOR)

Francesca Smith

Consent Overview

Those eligible to participate in our study include:

Participant: An individual diagnosed with Congenital Melanocytic Nevus (CMN) 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 with Congenital Melanocytic Nevus (CMN) 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 Congenital Melanocytic Nevus (CMN), 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 Congenital Melanocytic Nevus (CMN). I participated in their medical care.

Next

Consent to Nevus Owners Outcomes Registry (NOOR)

Francesca Smith

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

Consent to Participate in the Nevus Owners Outcomes Registry (NOOR) and to Allow Your Data to be Shared for Future Research

Title: Nevus Owners Outcomes Registry (NOOR)

Principal Investigator: Margaret Mangold, MD

Phone: (501) 500-1932

E-mail: noor@nevus.org

Sponsor: Nevus Outreach, Inc.

Key Information

You are invited to take part in a research study for people with Congenital Melanocytic Nevi (CMN) on behalf of the person in your care who is not able or no longer able to provide their own consent. Your role is called Legally Authorized Representative (LAR). This form will help you decide if you want to participate. You can contact the study staff above if you have any other questions. Their phone numbers and emails are listed above.

Things you should know:

Previous

Next

Consent to Nevus Owners Outcomes Registry (NOOR)

Francesca Smith

Authorization

The following statements are intended to:

- Make sure that you have had the time and opportunity to consider whether you want to participate in this registry;
- Have had your questions answered; and
- Agree to participate in the study as described.

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 NOOR 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 NOOR 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 NOOR 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 Nevus Owners Outcomes Registry (NOOR)

Francesca 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 Nevus Owners Outcomes Registry (NOOR)

Select Opt-Ins for this study

- ☐ Interest in hearing about other studies from **Nevus Outreach**
- ☐ 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 **Nevus Outreach**
- ☐ Interest in signing up for a **Nevus Outreach** newsletter
- ☐ Support from **Nevus Outreach** Ambassador / Care Coordinator
- ☐ If eligible, I have interest in receiving **Nevus Outreach** merchandise that would be sent via electronic or postal mail
- ☐ Support from other Patient Advocacy Groups
- ☐ Interest in learning about upcoming events such as webinars and conferences

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 “Take Survey” for an available survey.

[Back to the study list](#)

Francesca Smith [Edit](#)
2-Jan-2013

Nevus Owners Outcomes Registry (NOOR)

Surveys 1 pending

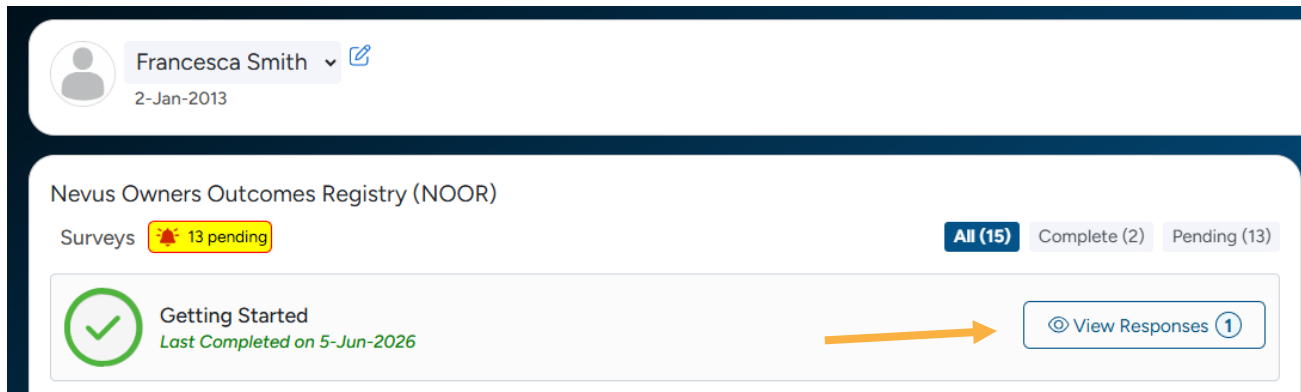
All (1) Complete (0) Pending (1)

0% **Getting Started**
Not Started

Take Survey

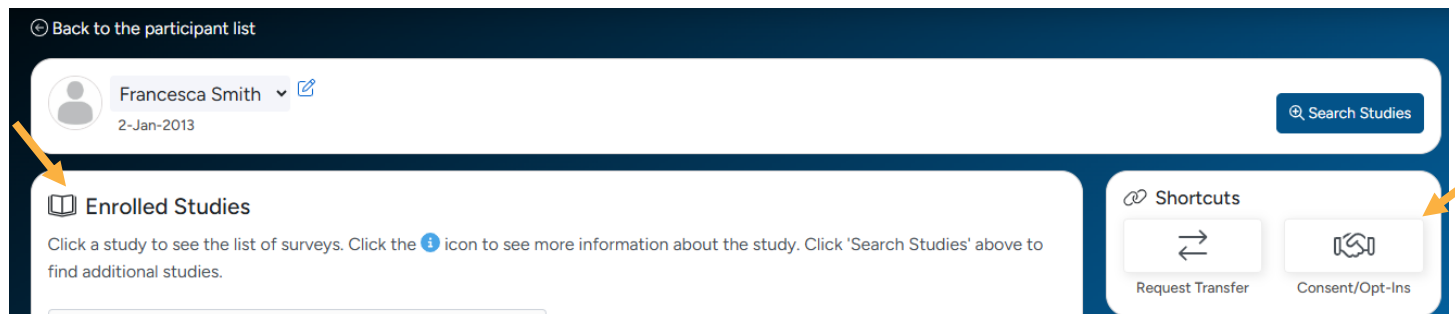
View Responses

- 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.

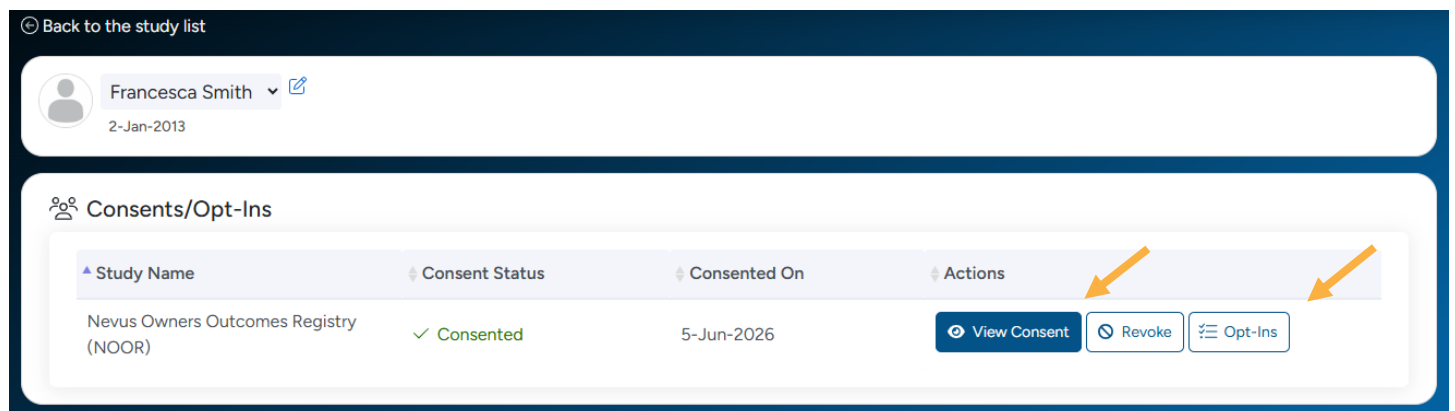


View Consent and Opt-Ins

- 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”.

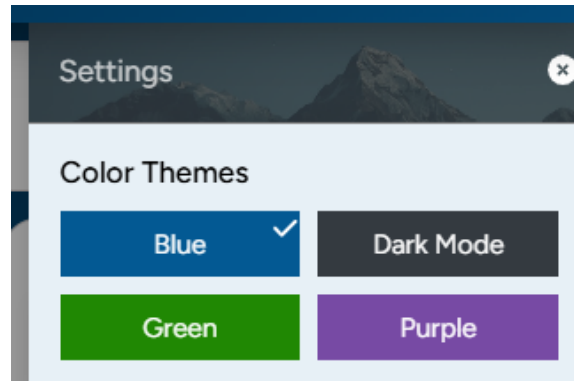


Dark Mode Settings

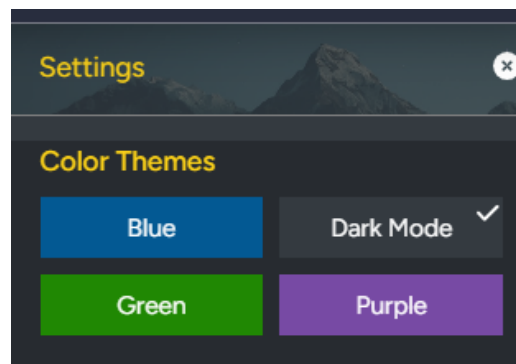
- Step 1: You can view the platform in Dark Mode. First, click Settings.



- Step 2: Select Dark Mode.



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

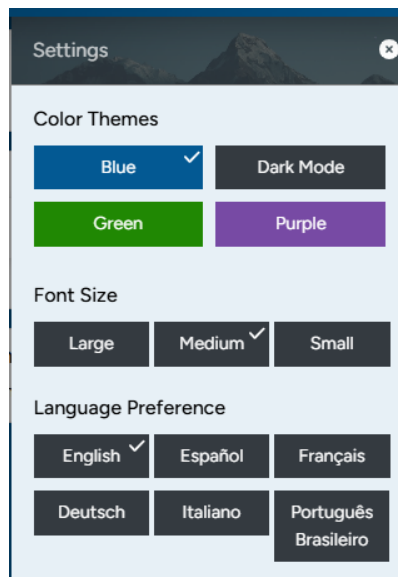


Display Settings

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



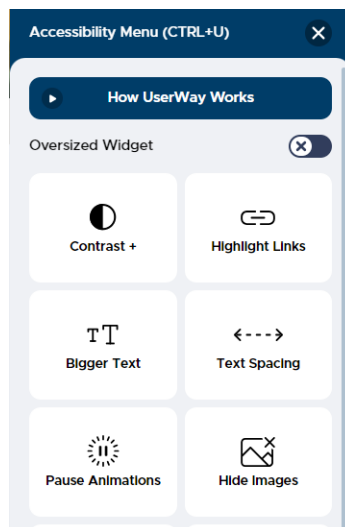
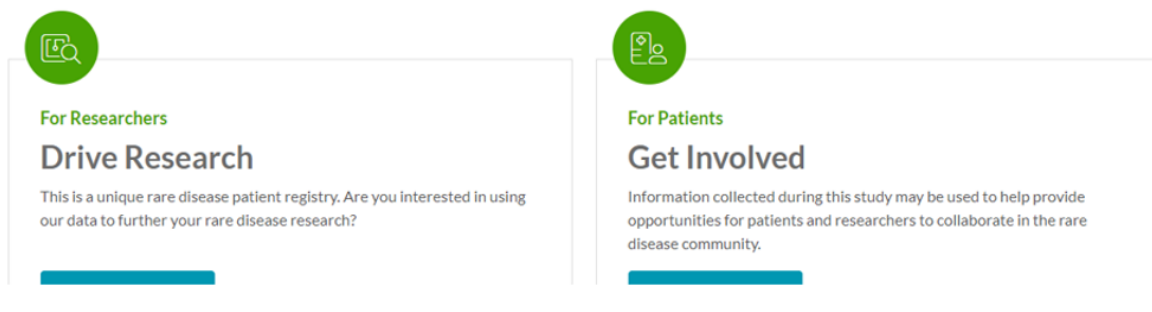
- Step 2: Select a color theme, a font size, or language preference.



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

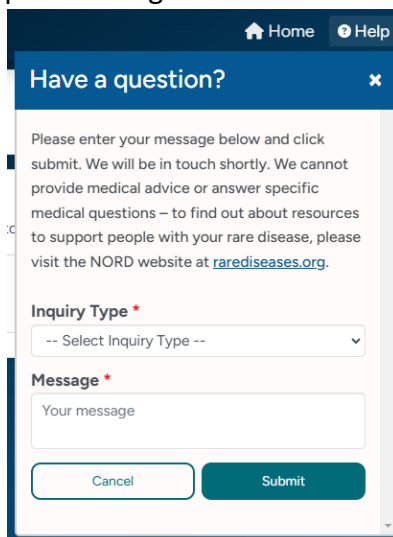
Microsite Visibility

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



The screenshot shows a mobile application interface with a dark blue header containing 'Home' and 'Help' icons. A modal window titled 'Have a question?' is open. It contains a text area for a message, a dropdown menu for 'Inquiry Type' with the placeholder '-- Select Inquiry Type --', and a 'Submit' button. A 'Cancel' button is also present at the bottom.

- 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 image shows a contact information card for Nevus Outreach. It features the organization's logo, which consists of the word 'nevus' in a stylized font with colorful dots above it, and 'OUTREACH' in a smaller font below. To the right of the logo is the text 'Nevus Outreach' and the website 'nevus.org' with a globe icon. Below this, the card lists contact details: 'Contact' (Margaret Mangold), 'Phone' (870-266-6554), 'E-mail' (noor@nevus.org), and 'IRB E-mail' (info@northstarreviewboard.org). At the bottom, it says 'Social Media' and includes icons for Facebook, X, and Instagram.