

NF 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
NF REGISTRY
CHILDREN'S TUMOR FOUNDATION

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”.

Featuring
NF REGISTRY
CHILDREN'S TUMOR FOUNDATION

Registration

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

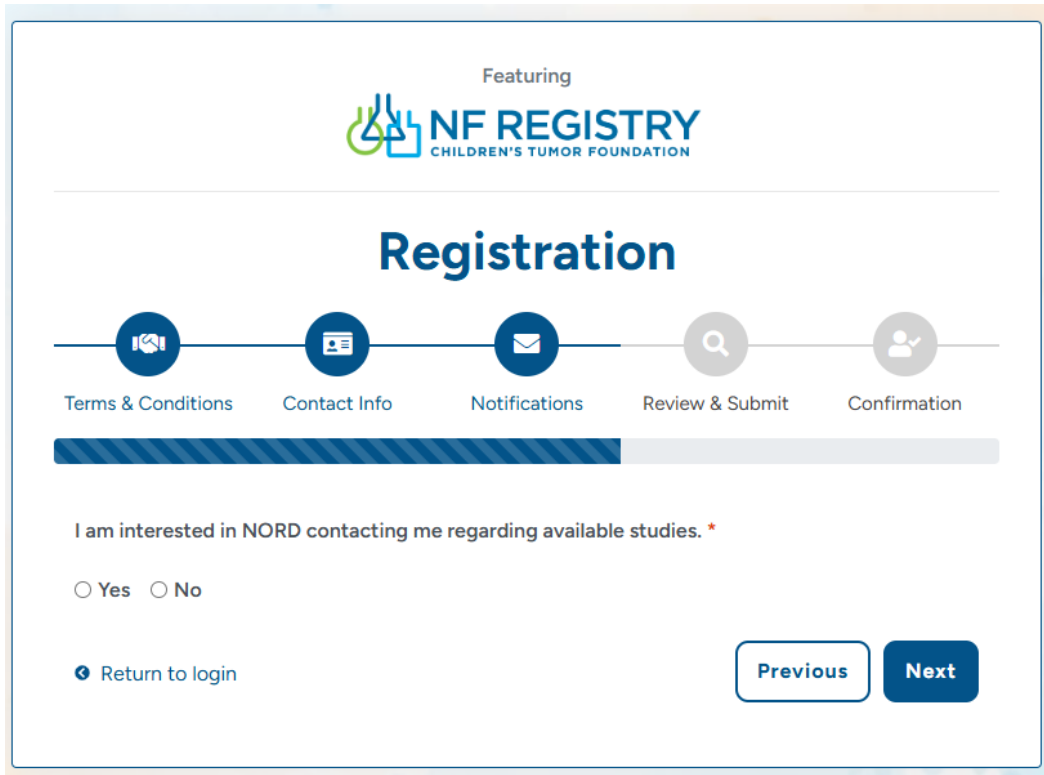
Country of Residence *

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”.



Featuring

NF REGISTRY
CHILDREN'S TUMOR FOUNDATION

Registration

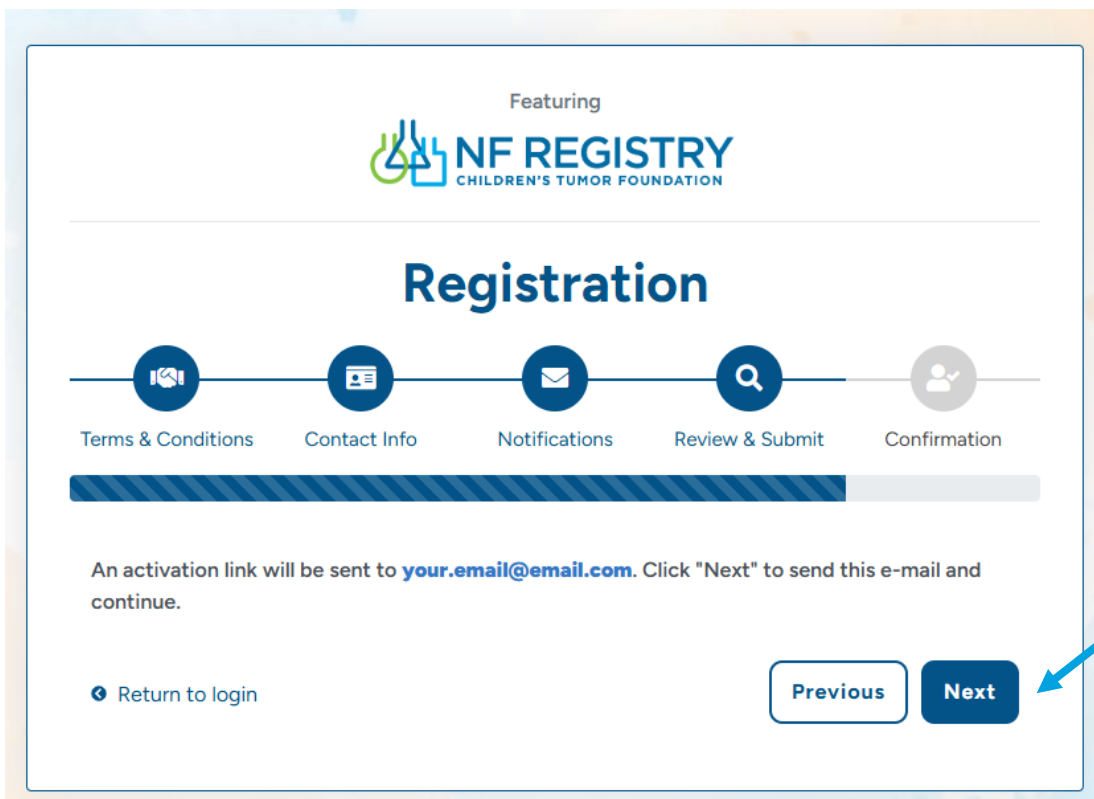
Terms & Conditions Contact Info Notifications Review & Submit Confirmation

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.



Featuring

NF REGISTRY
CHILDREN'S TUMOR FOUNDATION

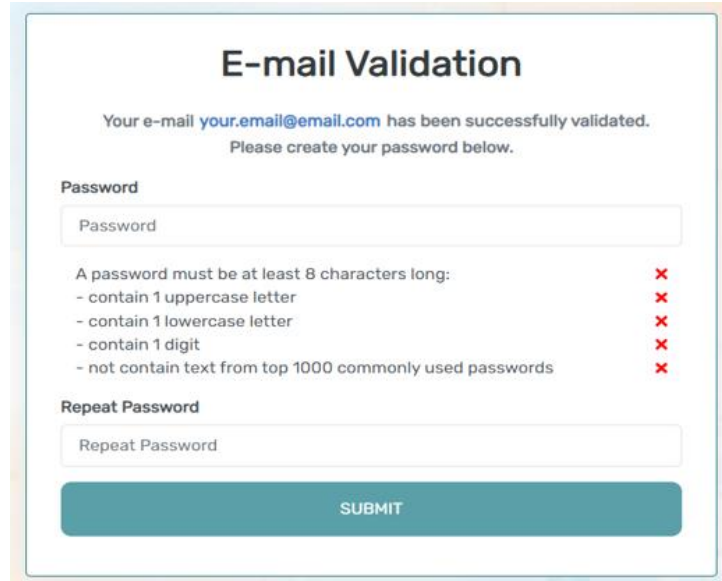
Registration

Terms & Conditions Contact Info Notifications Review & Submit Confirmation

An activation link will be sent to **your.email@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

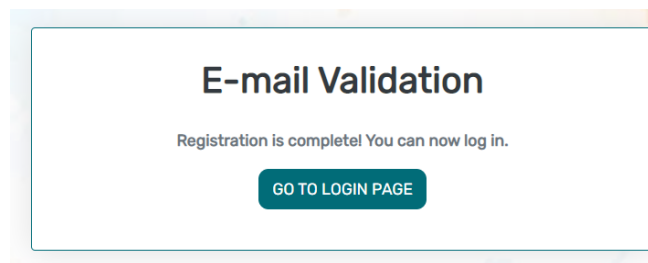
A password must be at least 8 characters long: ✘

- 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”.

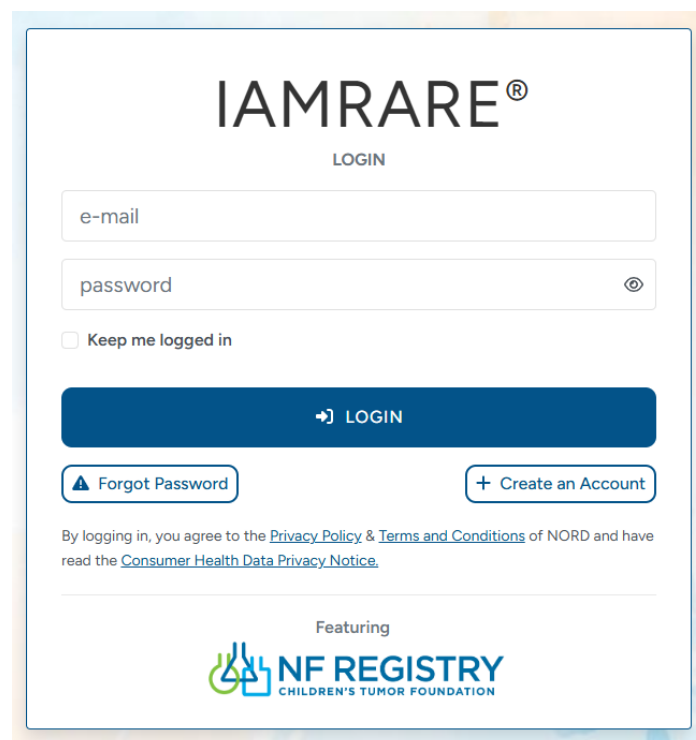


E-mail Validation

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

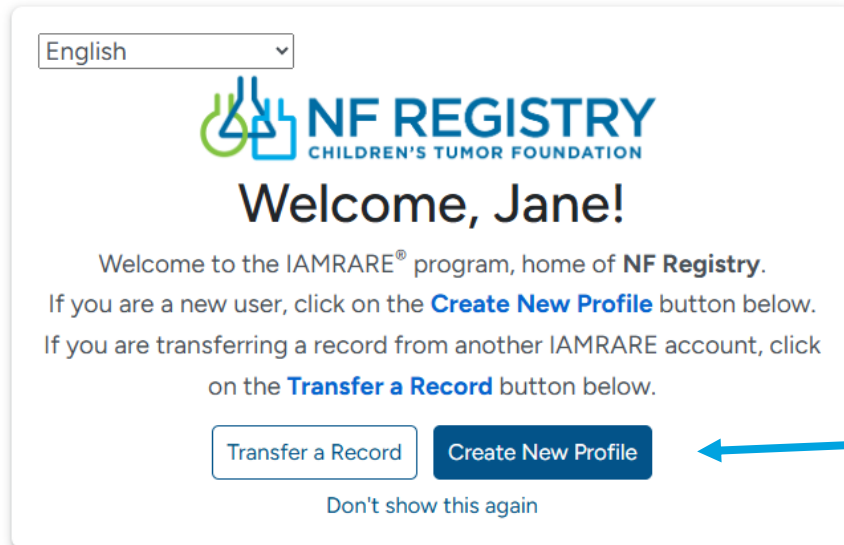
+ Create an Account

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

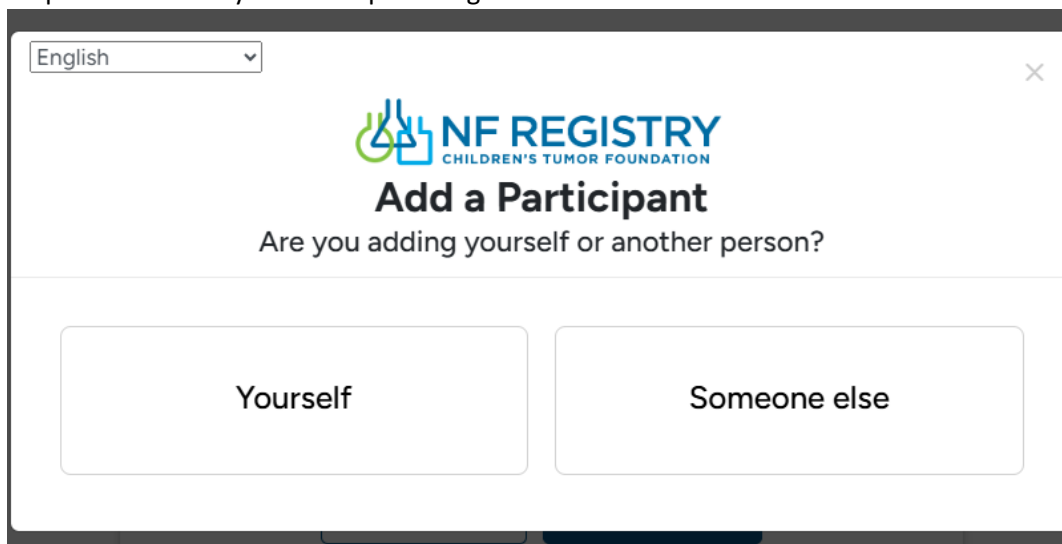
Featuring
 **NF REGISTRY**
CHILDREN'S TUMOR FOUNDATION

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 ***

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."



NF REGISTRY
CHILDREN'S TUMOR FOUNDATION

Thank you for registering your first participant!
Would you like to consent to participate in NF 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.”

The screenshot shows the 'Consent to NF Registry' form for Jane Smith. The title is 'Consent Overview'. Below the title, it lists eligibility criteria for participants and legally authorized representatives. A section titled 'Please tell us about the Participant you would like to enroll in this study. *' contains two radio button options: 'They are a minor or an adult who is unable to contribute their own data. I am currently their caregiver.' and 'They were a patient with Neurofibromatosis type 1, NF2-related Schwannomatosis or Schwannomatosis and have since passed away. I participated in their medical care.' A blue 'Next' button is located at the bottom right, with a blue arrow pointing to it.

Consent to NF Registry

Jane Smith

Consent Overview

Those eligible to participate in our study include:

Participant: An individual diagnosed with Neurofibromatosis type 1, NF2-related Schwannomatosis or Schwannomatosis 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 Neurofibromatosis type 1, NF2 related Schwannomatosis or Schwannomatosis who is a minor (child under the age of 18) or an adult who is unable to contribute their own data. The Legally Authorized Representative must 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 Neurofibromatosis type 1, NF2-related Schwannomatosis or Schwannomatosis and have since passed away. I participated in their medical care.

Next

The screenshot shows the 'Consent to NF Registry' form for Jane Smith, specifically the 'Consent for a Person with a Legally Authorized Representative (Caregiver)' section. It includes contact information for the Principal Investigator (Kate Kelts), phone number (646-738-8567), and email (nregistry@ctf.org). The sponsor is listed as The Children's Tumor Foundation. A 'Key Information' section states that the user is invited to take part in a research study for people with Neurofibromatosis type 1, NF2-related schwannomatosis, or Schwannomatosis on behalf of the person in their care who is unable to consent. At the bottom, there are 'Previous' and 'Next' buttons, with a blue arrow pointing to the 'Next' button.

Consent to NF Registry

Jane Smith

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

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

Title: NF Registry

Principal Investigator: Kate Kelts, RN, BSN Director of Patient Education & Engagement

Phone: 646-738-8567

E-mail: nregistry@ctf.org

Sponsor: The Children's Tumor Foundation

Key Information

You are invited to take part in a research study for people with Neurofibromatosis type 1, NF2-related schwannomatosis, or Schwannomatosis (referred to collectively as NF from this point forward) on behalf of the person in your care who is not able to

Previous **Next**

Consent to NF Registry

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.

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 Rare Disease Patient 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 NF Registry have been answered to my satisfaction, and I understand the purpose of the

[Previous](#) [Next](#)

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

Consent to NF Registry

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 NF Registry

Select Opt-Ins for this study

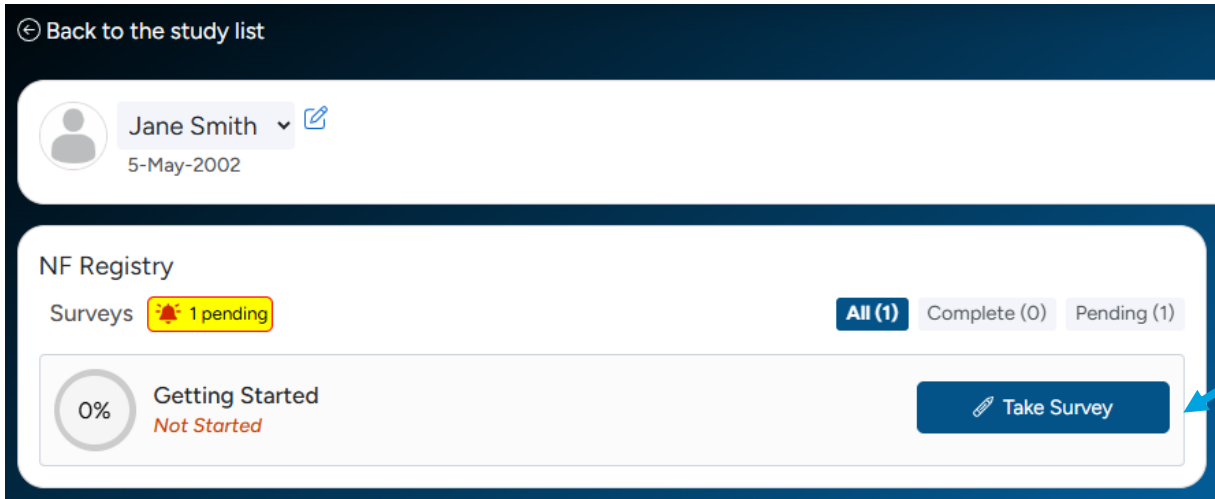
- Interest in hearing about other studies from [The Children's Tumor Foundation](#)
- Interest in hearing about relevant clinical trials
- Interest in donating specimens or DNA (biobanking) for future research
- Interest in genetic testing
- Interest in signing up for a [The Children's Tumor Foundation](#) newsletter
- If eligible, I have interest in receiving [The Children's Tumor Foundation](#) merchandise that would be sent via electronic or postal mail
- Interest in learning about upcoming events such as webinars and conferences
- Interest in hearing from approved industry partners about relevant market research. Market research means answering questions or sharing your opinions to help companies better understand patient experiences, needs, and preferences. This information may be used to improve research studies, treatments, or care in the future.

[Cancel](#) [Save Changes](#)

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

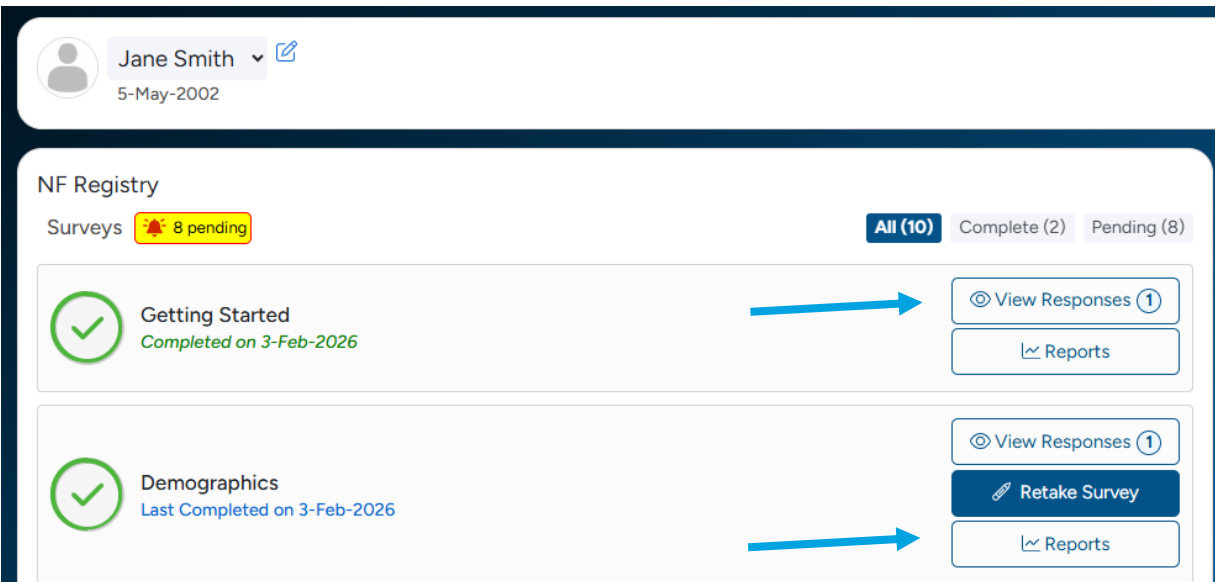
Taking Surveys

- Step 1: Click "Take Survey" for an available survey.



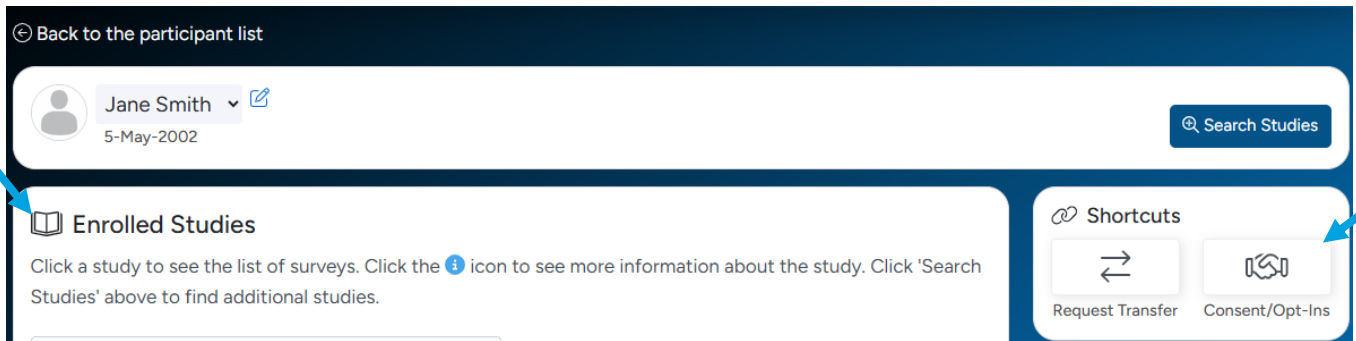
View Responses and Reports

- 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.



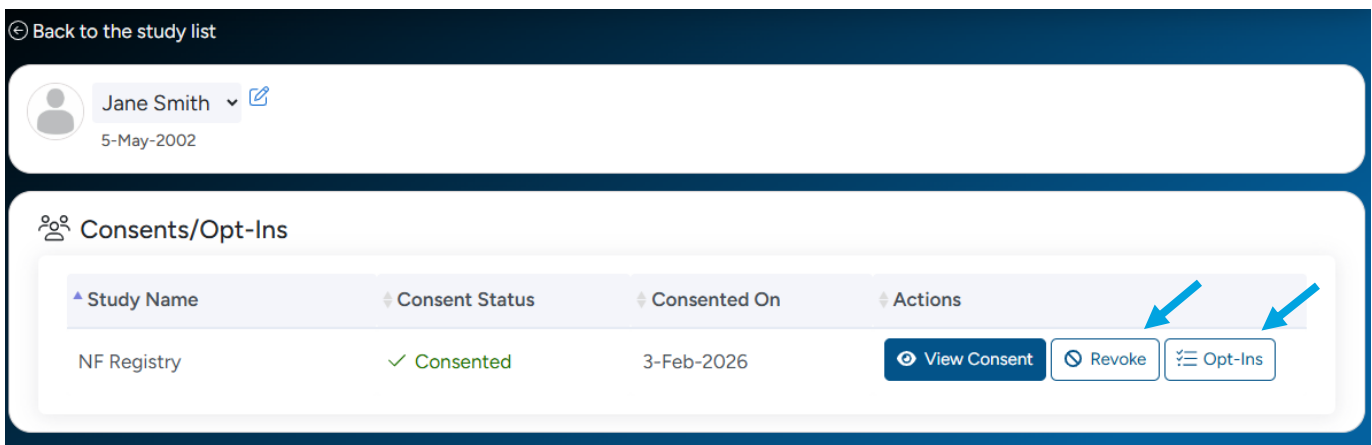
View Consent and Opt-Ins

- 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.



The screenshot shows the 'Enrolled Studies' page for Jane Smith (5-May-2002). At the top left is a 'Back to the participant list' link. Below it is a user profile card with Jane Smith's name and a search icon. A 'Search Studies' button is on the right. The main content area has a blue arrow pointing to the 'Enrolled Studies' header. Below the header is a brief instruction: 'Click a study to see the list of surveys. Click the ⓘ icon to see more information about the study. Click 'Search Studies' above to find additional studies.' To the right is a 'Shortcuts' section with two buttons: 'Request Transfer' and 'Consent/Opt-Ins', with a blue arrow pointing to the latter.

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



The screenshot shows the 'Consents/Opt-Ins' page for Jane Smith (5-May-2002). At the top left is a 'Back to the study list' link. Below it is a user profile card with Jane Smith's name and a search icon. The main content area has a blue arrow pointing to the 'Consents/Opt-Ins' header. Below the header is a table with the following columns: Study Name, Consent Status, Consented On, and Actions. The table contains one row for 'NF Registry' with a 'Consented' status and a date of '3-Feb-2026'. The Actions column contains three buttons: 'View Consent', 'Revoke', and 'Opt-Ins', with blue arrows pointing to the 'Revoke' and 'Opt-Ins' buttons.

Study Name	Consent Status	Consented On	Actions
NF Registry	✓ Consented	3-Feb-2026	View Consent Revoke Opt-Ins

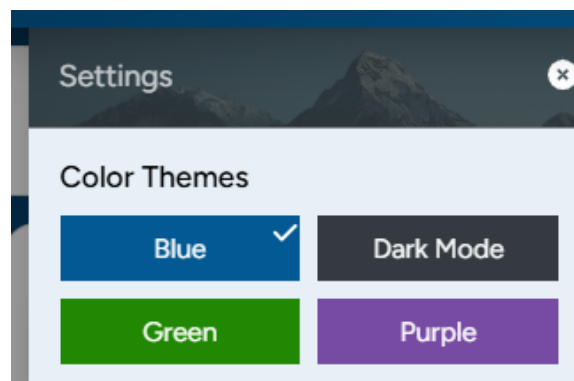
Dark Mode Settings

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



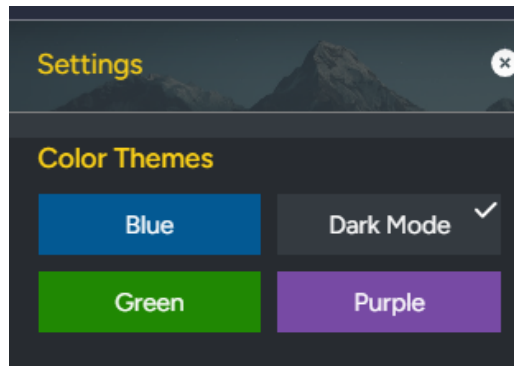
The screenshot shows the IAMRARE user profile page. At the top left is the IAMRARE logo. At the top right are navigation links: Home, Help, Settings, and Hi, Jane! Below the logo is a greeting: 'Good Afternoon, Jane!' and 'Member since Jan 21, 2026'. On the right is a '+ Add Participant' button. Below the greeting are two sections: 'Participants' and 'Shortcuts'.

- Step 2: Select Dark Mode.



The screenshot shows the 'Settings' dialog box with a close button (X) in the top right corner. Under the 'Color Themes' section, there are four buttons: 'Blue' (selected with a checkmark), 'Dark Mode', 'Green', and 'Purple'.

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

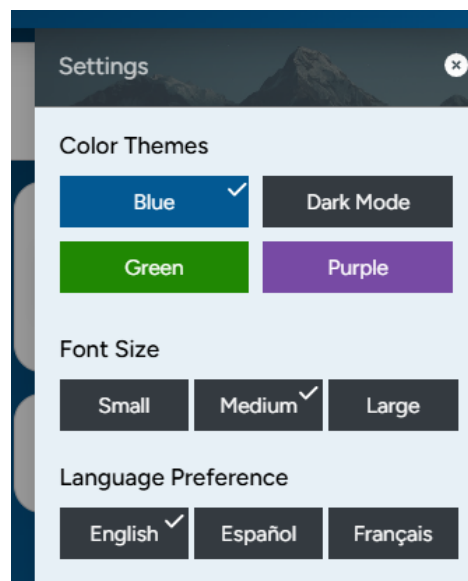


Display Settings

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



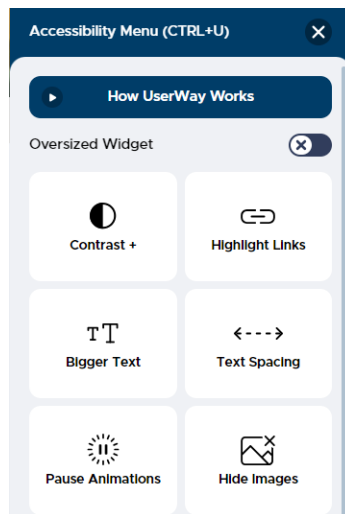
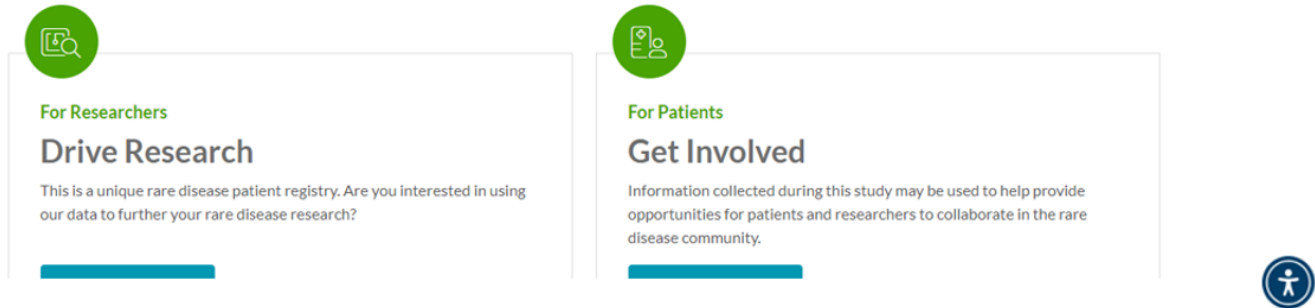
- Step 2: Select a color theme, a font size, or language preference.



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

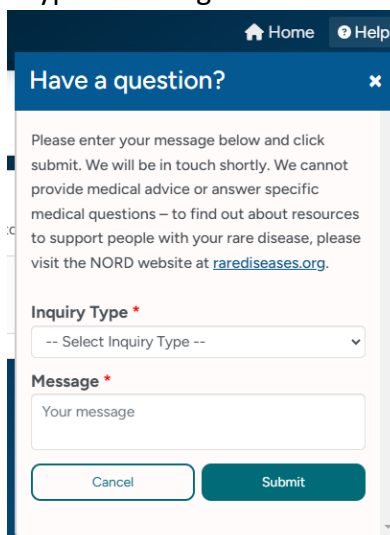
Microsite Visibility

- 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.



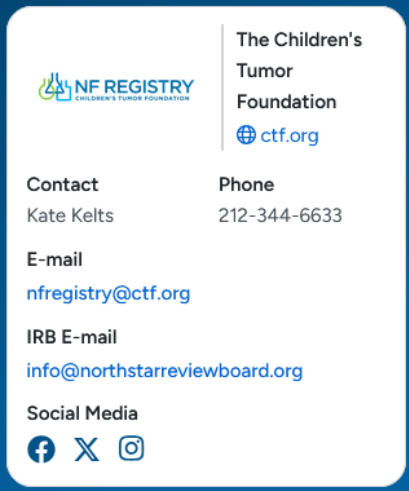
Need Assistance?

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



- 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 with a blue border. On the left side, there is a logo for 'NF REGISTRY' with 'CHILDREN'S TUMOR FOUNDATION' written below it. On the right side, the text reads 'The Children's Tumor Foundation' followed by a globe icon and the website 'ctf.org'. Below this, there are two columns of contact information: 'Contact' with 'Kate Kelts' and 'Phone' with '212-344-6633'. Underneath, there is an 'E-mail' section with the address 'nregistry@ctf.org' and an 'IRB E-mail' section with 'info@northstarreviewboard.org'. At the bottom, there is a 'Social Media' section with icons for Facebook, X, and Instagram.

NF REGISTRY
CHILDREN'S TUMOR FOUNDATION

The Children's
Tumor
Foundation
ctf.org

Contact
Kate Kelts

Phone
212-344-6633

E-mail
nregistry@ctf.org

IRB E-mail
info@northstarreviewboard.org

Social Media
[f](#) [X](#) [@](#)