



## Chondrosarcoma Patient Registry 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

**CS CHONDROSARCOMA FOUNDATION**

## Registration

Terms & Conditions   Contact Info   Notifications   Review & Submit   Confirmation

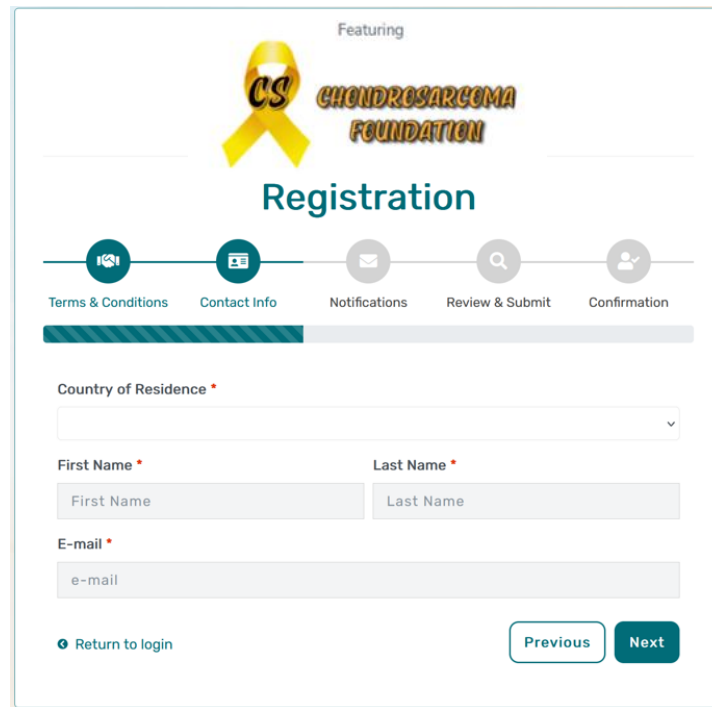
Below are links to the IAMRARE Terms of Use and Privacy Guidelines. The purpose of these documents is to outline your rights and responsibilities when using the platform. These documents include: 1) Standard policies for all studies on this platform, 2) A privacy statement that details how your data 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 & 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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## Registration

Terms & Conditions   Contact Info   Notifications   Review & Submit   Confirmation

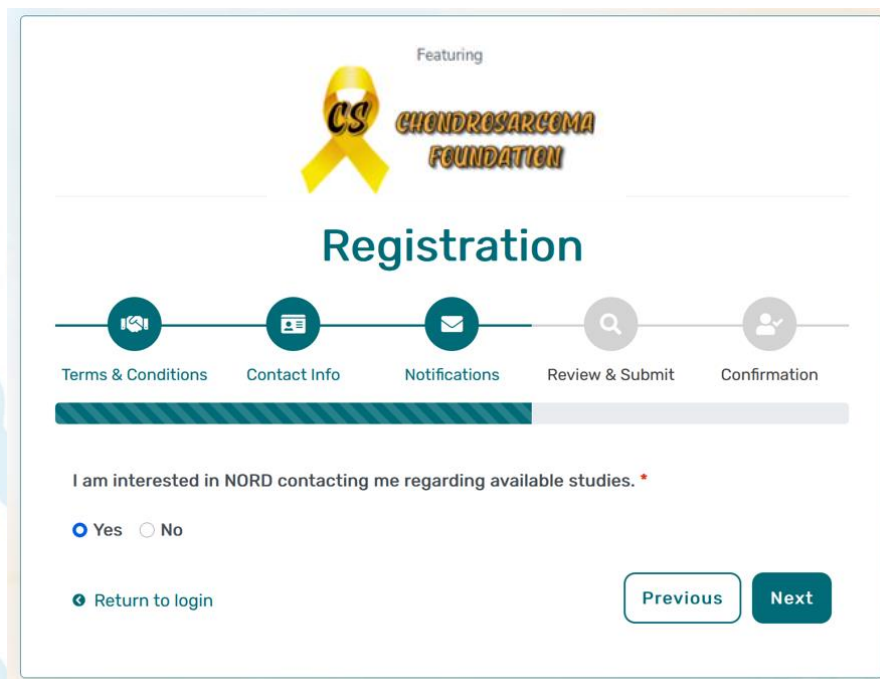
Country of Residence \*

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

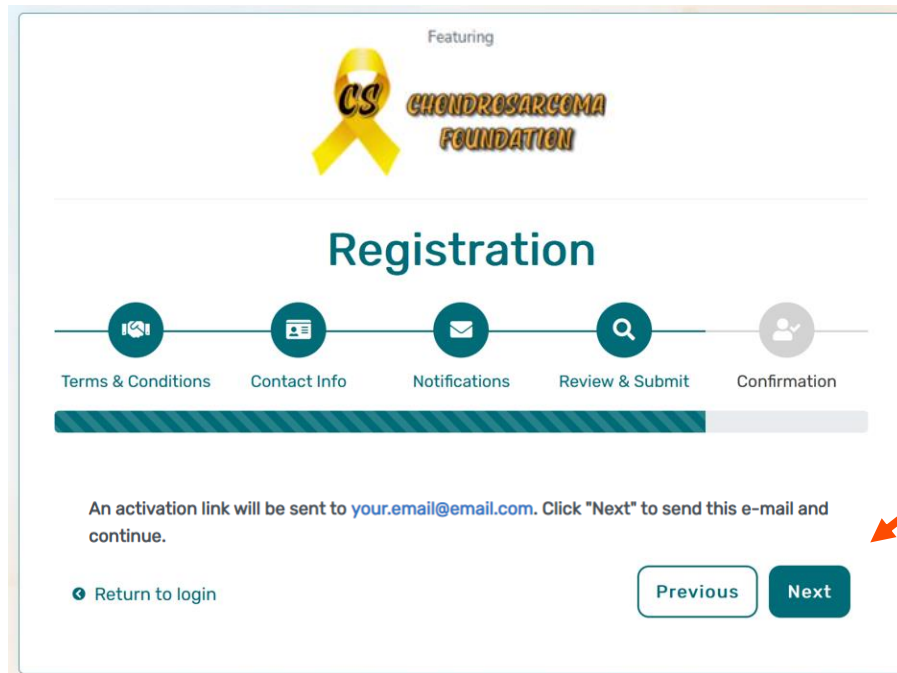
Terms & Conditions   Contact Info   Notifications   Review & Submit   Confirmation

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.



Featuring

**CS CHONDROSARCOMA FOUNDATION**

## Registration

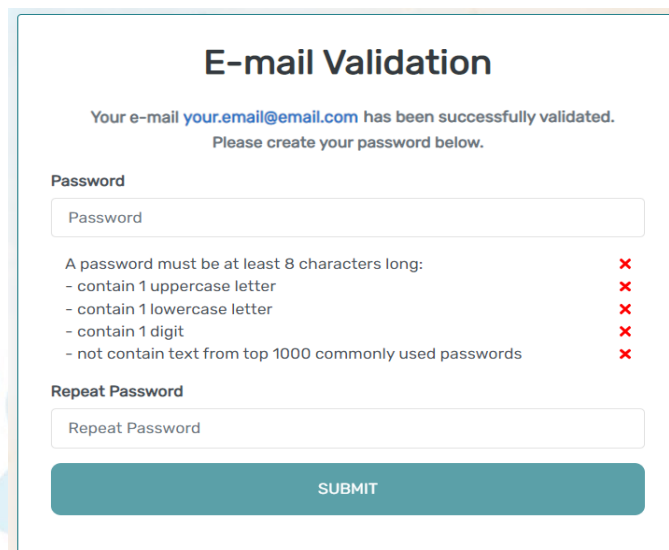
Terms & Conditions   Contact Info   Notifications   Review & Submit   Confirmation

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

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

An orange arrow points to the "Next" button.

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

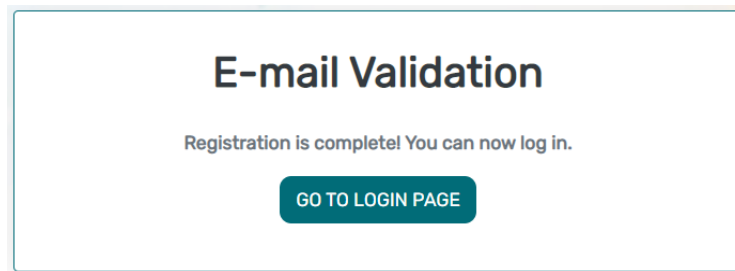
**Password**

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 ×

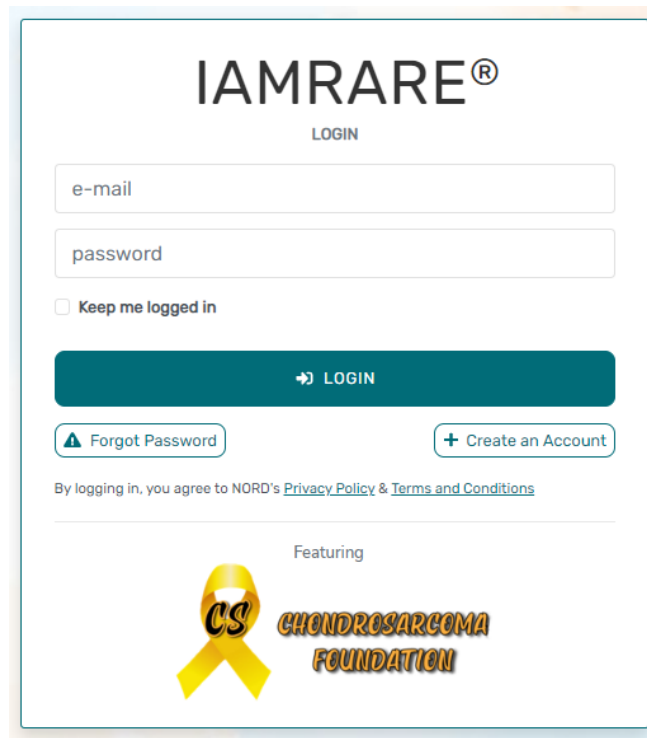
**Repeat Password**

[SUBMIT](#)

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

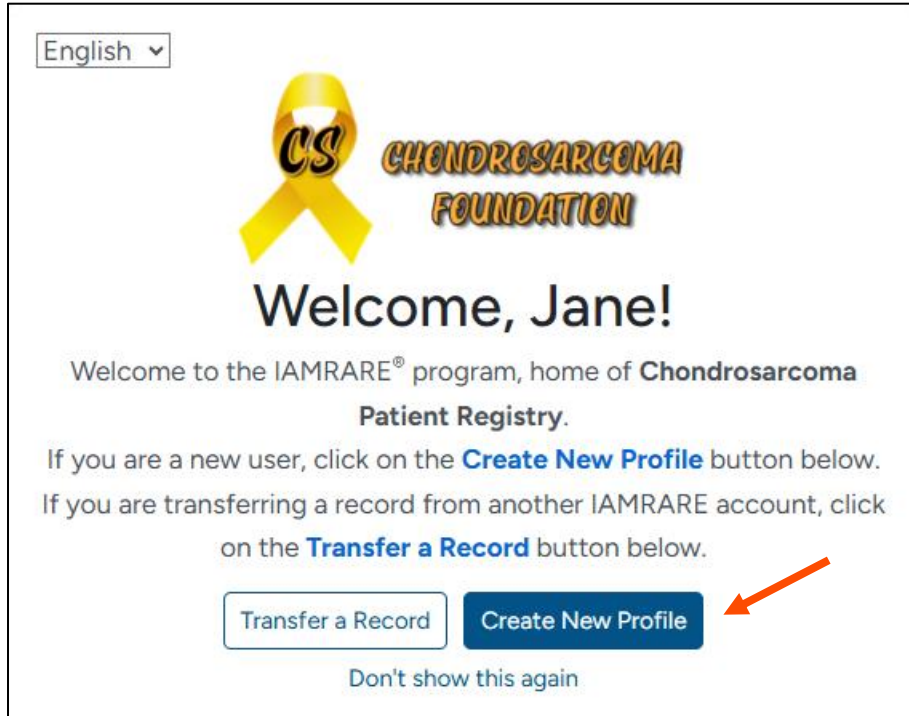


- Step 7: Log in using your new e-mail and password.




## Add a Participant

- Step 1: To start, click Create new profile.



English ▾



# Welcome, Jane!

Welcome to the IAMRARE® program, home of **Chondrosarcoma Patient Registry**.

If you are a new user, click on the **Create New Profile** button below.

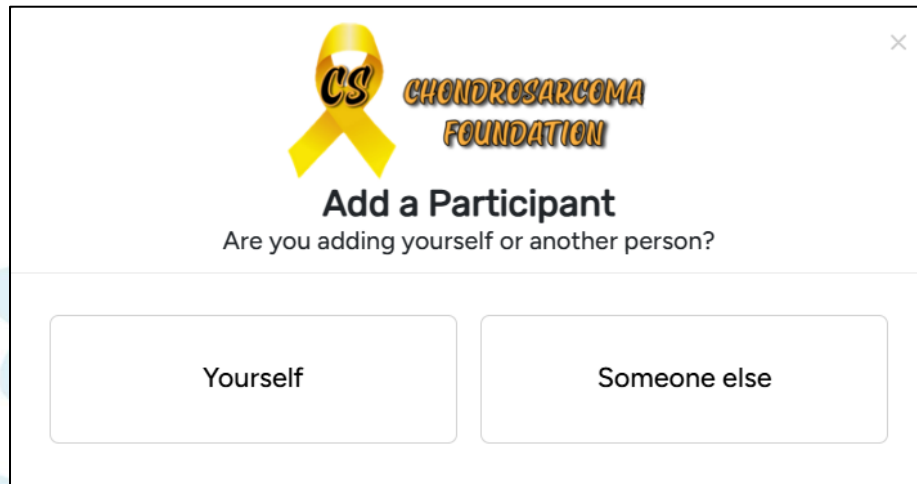
If you are transferring a record from another IAMRARE account, click on the **Transfer a Record** button below.


[Transfer a Record](#) [Create New Profile](#)

[Don't show this again](#)

An orange arrow points to the 'Create New Profile' button.

- Step 2: Select who you will be providing information about.





## Add a Participant

Are you adding yourself or another person?

[Yourself](#) [Someone else](#)

- Step 3: Fill out the Participant's information.

**Add Participant** [X]

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 \*** ⓘ  [Calendar Icon]

**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.”

 [X]

Thank you for registering your first participant!

Would you like to proceed to the next step to complete a consent to participate in the.

**Chondrosarcoma Patient Registry**

- Step 2: Scroll down and read through the consent form thoroughly. Once you finish reading, click the “Next” button.

Jane Smith

Consent to Chondrosarcoma Patient Registry

### Consent Overview

Those eligible to participate in our study include:

**Participant:** An individual diagnosed with chondrosarcoma 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 chondrosarcoma, defined as a spouse, parent, sibling, offspring, close relative, close friend, guardian and/or significant other of the individual who had chondrosarcoma 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.

Next

Jane Smith

Consent to Chondrosarcoma Patient Registry

### About the Participant

1. Is the Participant living? \*

☐ Yes

☐ No

Previous Next

Jane Smith

Consent to Chondrosarcoma Patient Registry

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

#### Consent to Participate in the Chondrosarcoma Patient Registry and to Allow Data to be Shared for Future Research

Title: Chondrosarcoma Patient Registry

Principal Investigator: Jeffrey T. Kramer, M.S.

Phone: 301-352-3042 / 301-404-7100

Email: [info@csfshayna.org](mailto:info@csfshayna.org)

Sponsor: Chondrosarcoma CS Foundation, Inc.

#### Key Information

You are invited to take part in a research study for individuals with chondrosarcoma 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 gain a better understanding of chondrosarcoma and its course and pace over time.

If you choose to participate on behalf of the study Participant in your care, you will be asked to complete surveys about their journey with chondrosarcoma. You will enter their information into online surveys at least once a year. We will ask questions about the participant, their symptoms and treatments. This will take approximately 60 minutes.

You may feel uncomfortable answering some of the questions. There is a risk to the Study Participant's privacy if the data is disclosed or misused. However, the registry is designed to make the chance of this happening very small.

Participating in our study may not help the Study Participant directly, but your time and information may help others with chondrosarcoma in the future. There are no direct benefits for you or the Study Participant by participating in the study.

It is up to you whether to participate in this study, and you can stop at any time. Please take time to read this entire form and ask questions before deciding whether to take part in this research project on behalf of the

Previous Next



- Step 3: Once you click “Next” and 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.”

Jane Smith

Consent to Chondrosarcoma Patient 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 Chondrosarcoma 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 Chondrosarcoma Patient 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 Chondrosarcoma Patient Registry for the purposes described above under Study Aims.

☐ I wish to provide the Study Participant's research data to the Chondrosarcoma Patient Registry for future research within recognized ethical standards for scientific research, as described under How We Use Your Data.

Previous Next

- Step 4: Once you click “Next” and reach the Thank You page, click “Continue to Opt-Ins”.

Jane Smith

Consent to Chondrosarcoma Patient Registry

### Thank You

You have completed the consent. You are now ready to take surveys and participate within the study. Thank you.

Previous Continue to Opt-Ins

- Step 5: 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 Chondrosarcoma Patient Registry

### Select Opt-Ins for this study

☐ Interest in hearing about other studies from Chondrosarcoma CS Foundation, Inc.

☐ 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 Chondrosarcoma CS Foundation, Inc.

Save and Review

- Step 6: 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 user interface. At the top, there's a navigation bar with 'Home', 'Help', 'Settings', and a user greeting 'Hi, Jane!'. Below this, a welcome message 'Good Afternoon, Jane!' is displayed along with 'Member since Mar 28, 2025' and an 'Add Participant' button. The main section is titled 'Participants' and includes instructions: 'Select a participant to view their studies. Click on the "Add Participant" button above to add a participant.' A list of participants shows 'Jane Smith' (5-May-2000) with '1 pending surveys'. An orange arrow points to a chevron icon on the right of Jane Smith's entry. To the right of the participants list are 'Shortcuts' for 'Request Transfer' and 'Consent/Opt-Ins', and a 'Notifications (0)' section stating 'No new notifications.'

- Step 2: Click on the appropriate study.

This screenshot shows the 'Enrolled Studies' page. At the top, there's a 'Back to participant list' link and a dropdown for 'Jane Smith' (5-May-2000) with a 'Search Studies' button. The 'Enrolled Studies' section contains instructions: '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.' A study card for 'Chondrosarcoma Patient Registry' is shown, featuring a yellow ribbon logo, the text 'Chondrosarcoma CS Foundation, Inc.', a 'Consented' status, and '1 pending surveys'. An orange arrow points to the study card. To the right are 'Shortcuts' for 'Request Transfer' and 'Consent/Opt-Ins', and a 'Notifications (0)' section stating 'No new notifications.'

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

This screenshot shows the survey page for the 'Chondrosarcoma Patient Registry'. At the top, there's a 'Back to study list' link and a dropdown for 'Jane Smith' (5-May-2000). The study title 'Chondrosarcoma Patient Registry' is followed by 'Surveys' and a '1 pending' indicator. A filter bar shows 'All (1)', 'Complete (0)', and 'Pending (1)'. Below this, a progress indicator shows '0% Getting Started' with the status 'Not Started'. An orange arrow points to the 'Take Survey' button in the bottom right corner.

## 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.

The screenshot shows the user profile for Jane Smith (5-May-2000) at the top. Below, the 'Chondrosarcoma Patient Registry' section displays 'Surveys' with a status of '15 pending'. A card titled 'Getting Started' indicates it was 'Completed on 28-Mar-2025'. To the right of this card are two buttons: 'View Responses (1)' and 'Reports', both highlighted with orange arrows.

## 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. At the top, there's a 'Back to participant list' link and a user profile for Jane Smith. A 'Search Studies' button is also present. Below the header, the 'Enrolled Studies' section provides instructions on how to view study details. To the right, a 'Shortcuts' panel contains two buttons: 'Request Transfer' and 'Consent/Opt-Ins'. An orange arrow points to the 'Consent/Opt-Ins' button.

- 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. It features a table with the following columns: Study Name, Consent Status, Consented On, and Actions. The table contains one entry for 'Chondrosarcoma Patient Registry' with a 'Consented' status and a date of '28-Mar-2025'. The 'Actions' column for this entry includes three buttons: 'View Consent', 'Revoke', and 'Opt-Ins'. Two orange arrows point to the 'Revoke' and 'Opt-Ins' buttons.

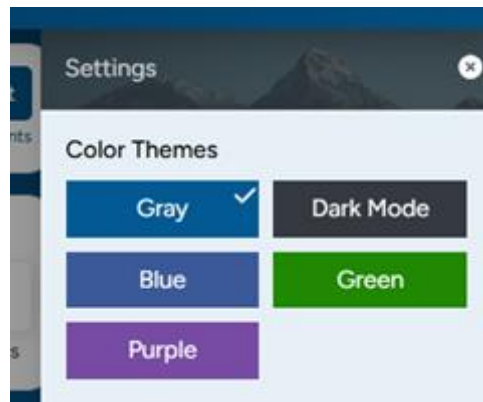
Study Name	Consent Status	Consented On	Actions
Chondrosarcoma Patient Registry	✓ Consented	28-Mar-2025	<a href="#">View Consent</a> <a href="#">Revoke</a> <a href="#">Opt-Ins</a>

## Dark Mode Settings

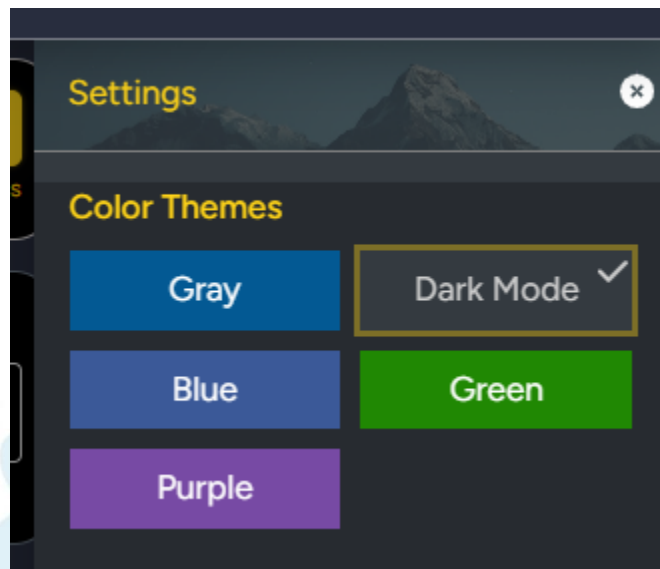
- Step 1: You can view the platform in Dark Mode. First, click Settings.



- Step 2: Select Dark Mode.



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

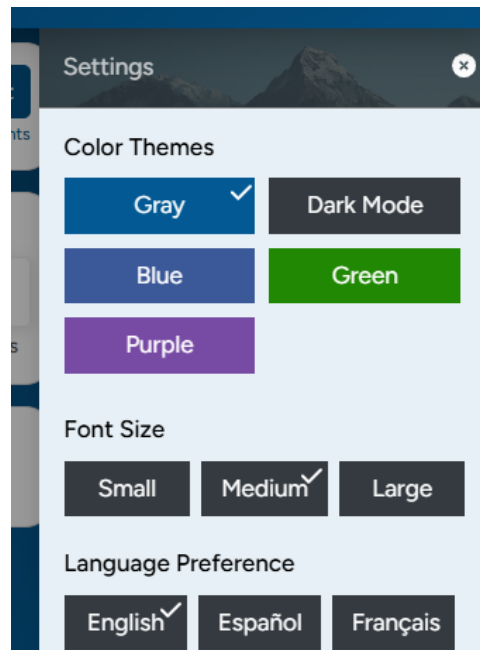


## Display Settings

- 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 (chondrosarcoma.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.




For Patients

### Get Involved

Information collected during this study may be used to help provide opportunities for patients and researchers to collaborate in the rare disease community.

[LEARN MORE](#)

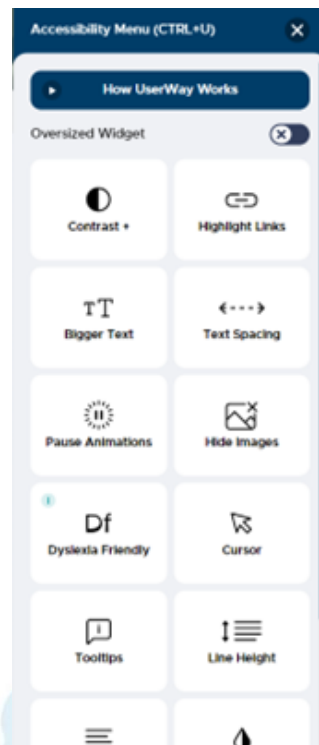



For Researchers

### Drive Research

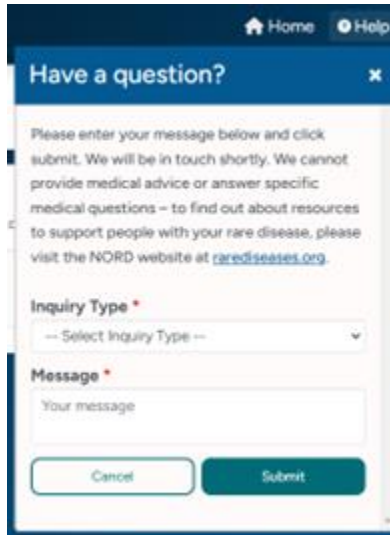
This is a unique rare disease patient registry. Are you interested in using our data to further your rare disease research?

[LEARN MORE](#)



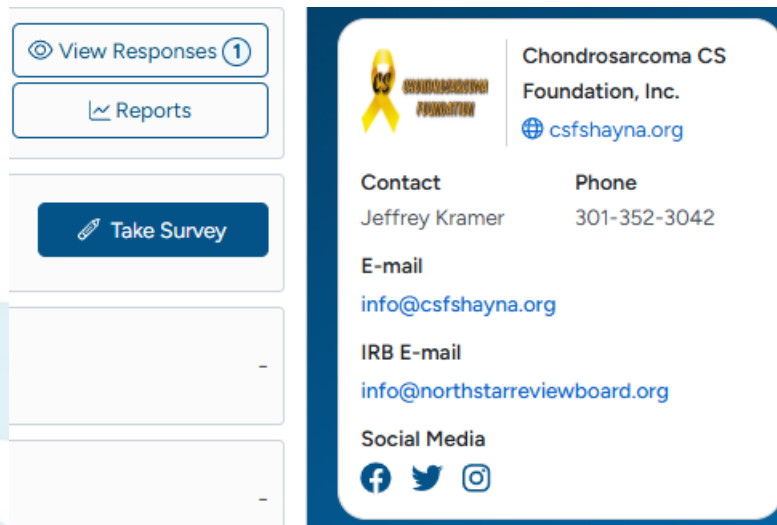
## Need Assistance?

- 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 app interface with a blue header bar containing 'Home' and 'Help' icons. Below the header is a modal titled 'Have a question?' with a close button (X). The modal contains a text area for a message, a dropdown menu for 'Inquiry Type' with the placeholder '-- Select Inquiry Type --', and a 'Message' field with the placeholder 'Your message'. At the bottom are 'Cancel' and 'Submit' buttons.

- 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 mobile app interface with a blue header bar. Below the header is a modal titled 'Have a question?' with a close button (X). The modal contains a text area for a message, a dropdown menu for 'Inquiry Type' with the placeholder '-- Select Inquiry Type --', and a 'Message' field with the placeholder 'Your message'. At the bottom are 'Cancel' and 'Submit' buttons.