



Genetic Cardiomyopathy Awareness Consortium


Brought to you by DCM Foundation 

The Genetic Cardiomyopathy Registry (GCR) 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 or suspicious family history of cardiomyopathy, select **Participant Account**.
 - If you are entering information for **someone else** who has a diagnosis or suspicious family history of cardiomyopathy, select **Caregiver Account**. If you would like to add information about multiple individuals (e.g., you and your child), select **Caregiver Account**.

Featuring



Genetic Cardiomyopathy
Awareness Consortium

Brought to you by DCM Foundation 

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
Genetic Cardiomyopathy
Awareness Consortium
Brought to you by DCM Foundation

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
Genetic Cardiomyopathy
Awareness Consortium
Brought to you by DCM Foundation

Caregiver Registration

Terms & Conditions Contact Info Notifications Review & Submit Confirmation

Country of Residence *

First Name * Last Name *

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
Genetic Cardiomyopathy
Awareness Consortium
Brought to you by DCM Foundation

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
Genetic Cardiomyopathy
Awareness Consortium
Brought to you by DCM Foundation

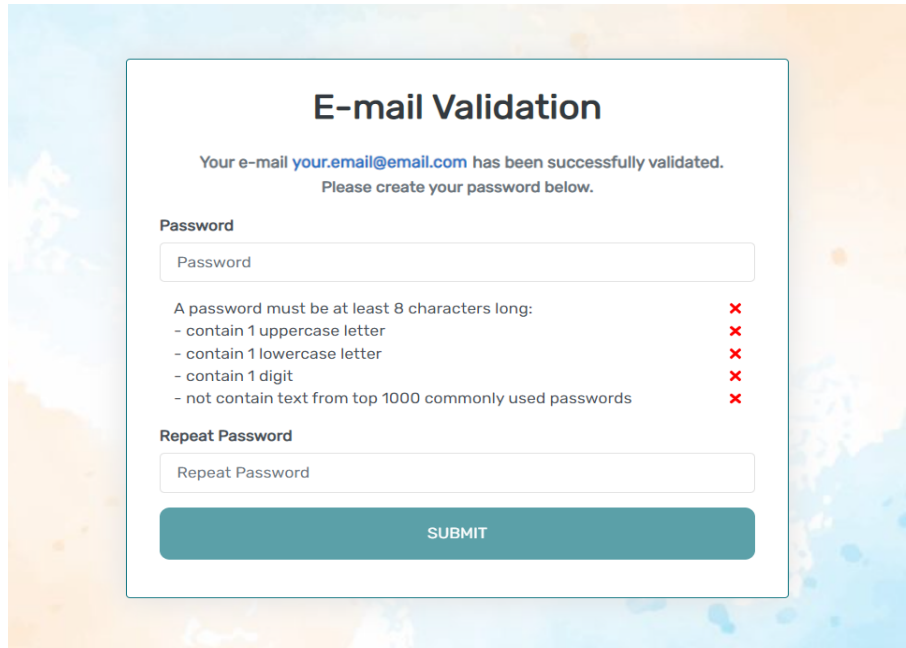
Caregiver Registration

Terms & Conditions Contact Info Notifications Review & Submit Confirmation

An activation link will be sent to 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 has been successfully validated.
Please create your password below.

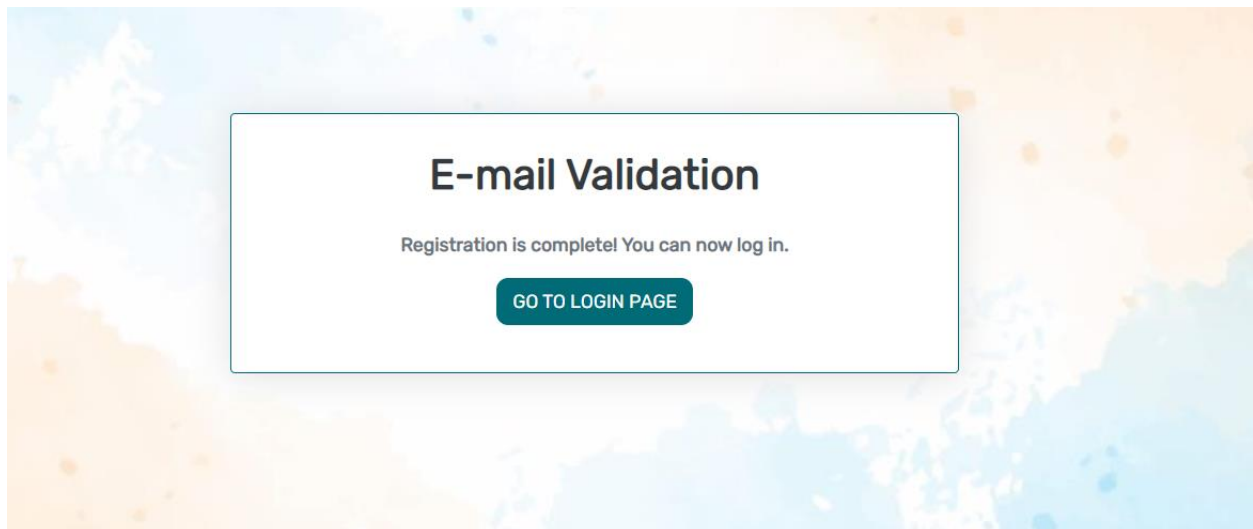
Password

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”.

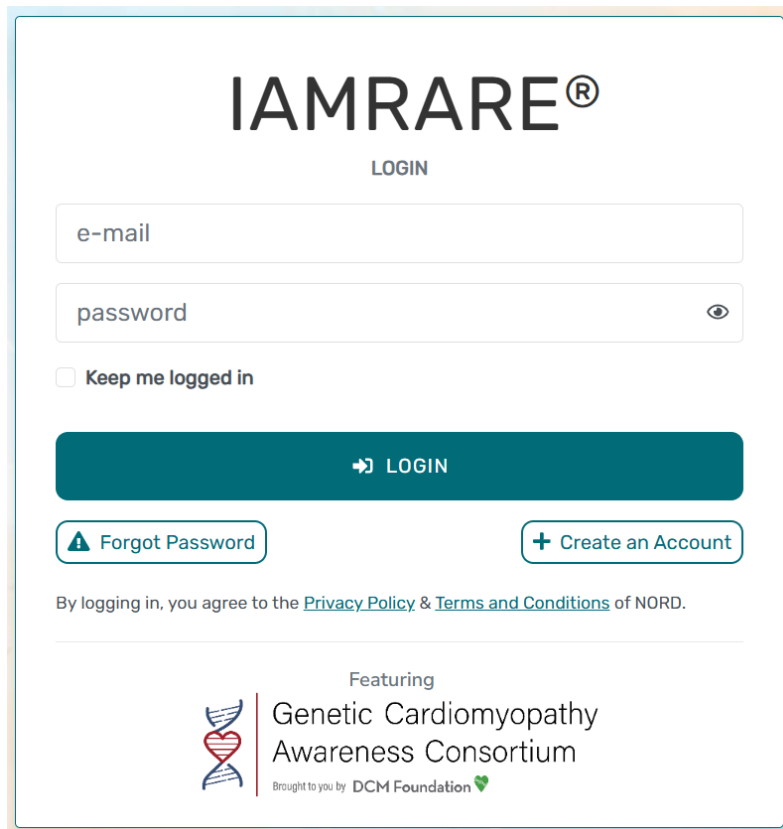


E-mail Validation

Registration is complete! You can now log in.

GO TO LOGIN PAGE

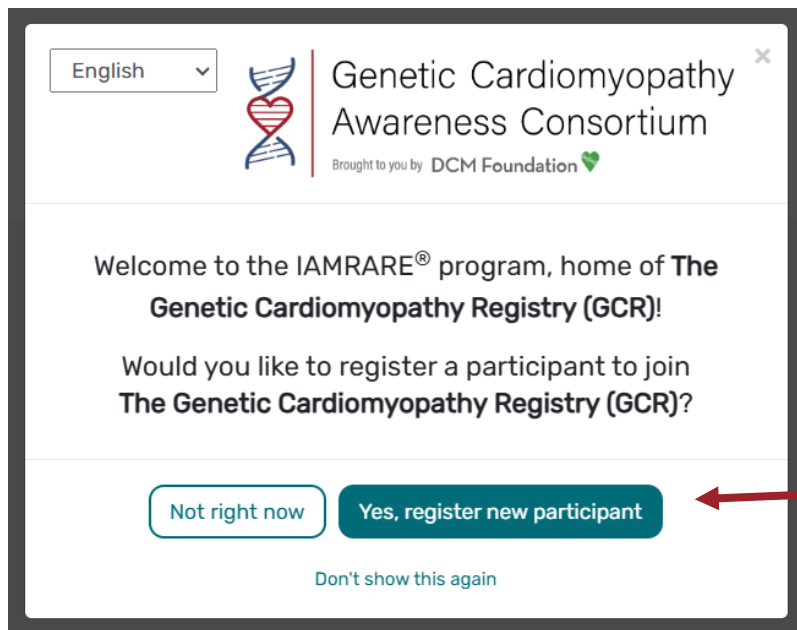
- Step 8: Log in using your new e-mail and password.



The image shows the IAMRARE login page. At the top, the logo 'IAMRARE®' is displayed in a large, bold, black font. Below the logo, the word 'LOGIN' is centered in a smaller, black font. There are two input fields: the first is labeled 'e-mail' and the second is labeled 'password' with an eye icon to its right. Below the password field is a checkbox labeled 'Keep me logged in'. A large, dark teal button with a white arrow icon and the text 'LOGIN' is positioned below the input fields. To the left of this button is a smaller button with a warning icon and the text 'Forgot Password', and to the right is a button with a plus icon and the text 'Create an Account'. Below these buttons, a line of text reads: 'By logging in, you agree to the [Privacy Policy](#) & [Terms and Conditions](#) of NORD.' At the bottom of the page, there is a logo for the Genetic Cardiomyopathy Awareness Consortium, which includes a stylized DNA double helix and a heart. To the right of the logo, the text reads 'Featuring Genetic Cardiomyopathy Awareness Consortium' and 'Brought to you by DCM Foundation' with a small green heart icon.

Add a Participant

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



The image shows a dialog box with a dark border. At the top left, there is a dropdown menu set to 'English'. To the right of the dropdown is the logo for the Genetic Cardiomyopathy Awareness Consortium, which includes a stylized DNA double helix and a heart. Below the logo, the text reads 'Brought to you by DCM Foundation' with a small green heart icon. The main text of the dialog box reads: 'Welcome to the IAMRARE® program, home of **The Genetic Cardiomyopathy Registry (GCR)**!' followed by 'Would you like to register a participant to join **The Genetic Cardiomyopathy Registry (GCR)**?'. At the bottom, there are two buttons: 'Not right now' and 'Yes, register new participant'. A red arrow points to the 'Yes, register new participant' button. Below the buttons, there is a link that says '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 *

Preferred First Name *

Current Last Name *

Current Last Name *

First Name on Birth Certificate *

First Name on Birth Certificate *

Middle Name on Birth Certificate *

Type 'NA' if none

Last Name on Birth Certificate *

Last Name on Birth Certificate *

Date of Birth *

Date of Birth *

Sex Recorded on Birth Certificate * ⓘ

Female

Country of Residence *

United States

State/Province of Residence *

State/Province/Region

Country of Birth *

United States


City/Municipality of Birth *

Hillville


What Is Your Relationship to ? *

Consent to the Study

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



Genetic Cardiomyopathy
Awareness Consortium

Brought to you by DCM Foundation 

Thank you for registering your first participant!

Would you like to consent to participate in **The Genetic Cardiomyopathy Registry (GCR)**?



- 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 **The Genetic Cardiomyopathy Registry (GCR)**

Consent Overview

Those eligible to participate in our study include:

Participant: An individual diagnosed with genetic cardiomyopathy, or a suspicious family history of cardiomyopathy, 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.

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 genetic cardiomyopathy and have since passed away. I participated in their medical care.

Next



Consent to **The Genetic Cardiomyopathy Registry (GCR)**

Answered 1/5 questions

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

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

Title: Genetic Cardiomyopathy Registry

Principal Investigator: Kathy Crispell, MD, FACC

E-mail: patientquestions@geneticcardiomyopathy.org

Sponsor: DCM Foundation


Key Information

You are invited to take part in a research study for individuals with genetic cardiomyopathy, or a suspicious family history of cardiomyopathy, 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 identify significant numbers of people with genetic subtypes of cardiomyopathies. More research is needed to better understand how specific variants/mutations cause disease, and to develop specific gene-based therapies and other therapies. Adequate numbers of people with specific genetic variants/mutations are needed for meaningful research.

Previous **Next**



Consent to The Genetic Cardiomyopathy Registry (GCR)

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 Genetic Cardiomyopathy 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 acknowledge that I am at least 18 years of age and am able to provide consent on behalf of the Study Participant (person in my care). I have read this

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

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

Consent to The Genetic Cardiomyopathy Registry (GCR)

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".

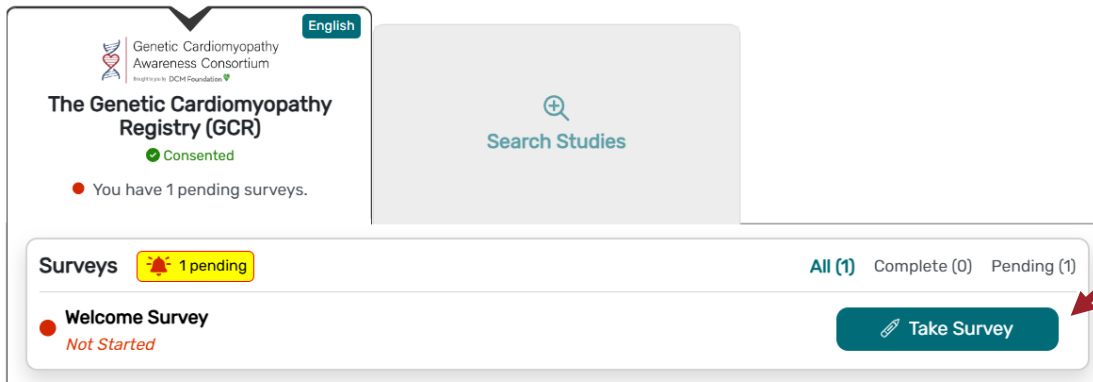
Opt-Ins for The Genetic Cardiomyopathy Registry (GCR)

Select Opt-Ins for this study

- Interest in genetic testing
- Interest in learning more about [The DCM Foundation](#)
- Interest in hearing about other relevant research studies and clinical trials from [The DCM Foundation](#)

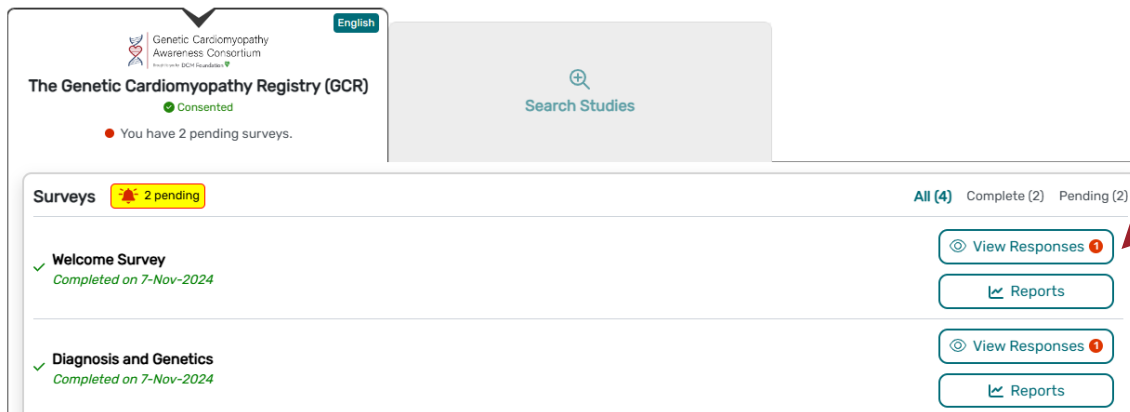
[Save and Review](#)

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



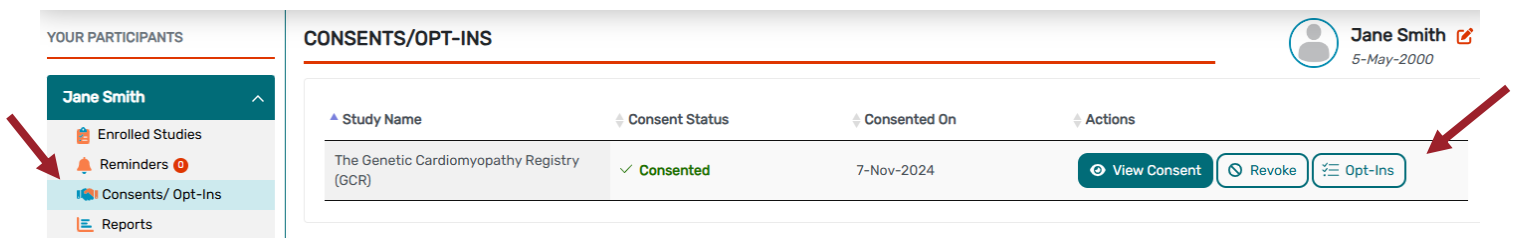
View Responses and Reports

- 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.



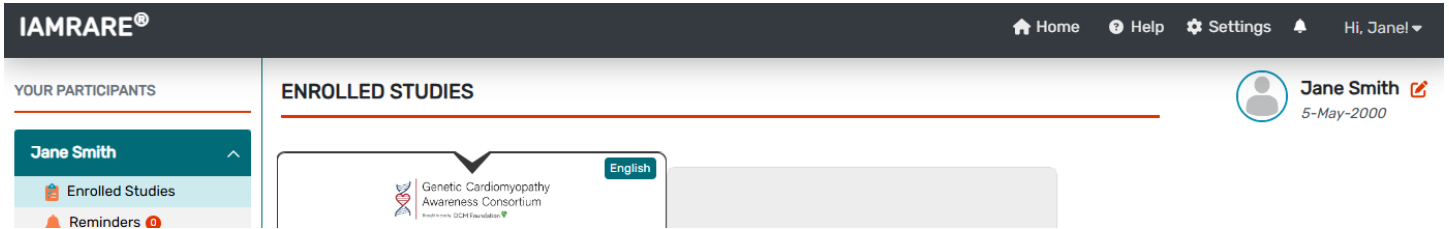
View Consent and Opt-Ins

- 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".

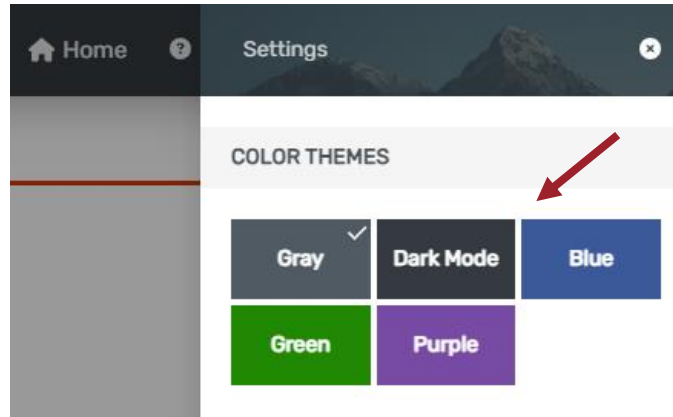


Dark Mode Settings

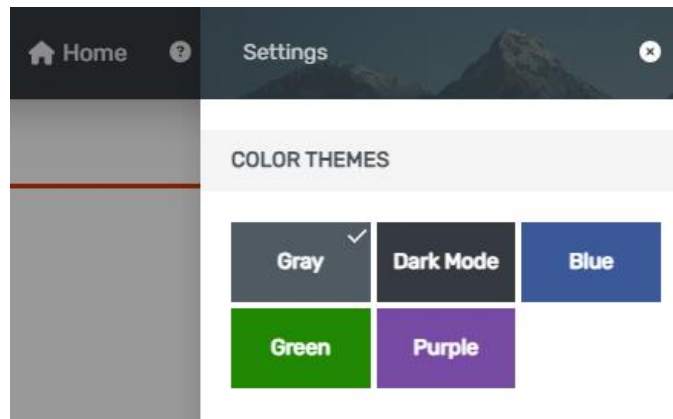
- Step 1: You can view the platform in Dark Mode. First, click Settings.



- Step 2: Select Dark Mode.

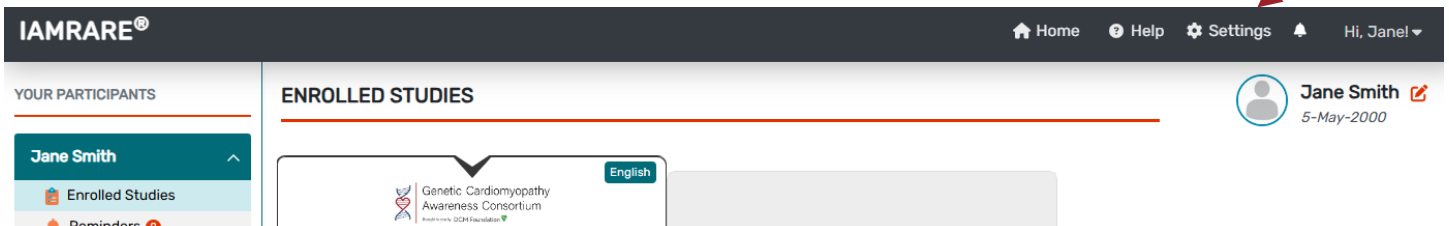


- Step 3: Exit the Settings menu, and your selection will be saved.



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.

The screenshot shows a settings menu with three sections:

- COLOR THEMES:** Gray (checked), Dark Mode, Blue, Green, Purple.
- FONT SIZE:** Small, Medium (checked), Large.
- LANGUAGE PREFERENCE:** English (checked), Español, Français.

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

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 'Have a question?' form with the following elements:

- Header: Home, Help, Settings
- Text: "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."
- Field: Inquiry Type (dropdown menu with "-- Select Inquiry Type --")
- Field: Message (text input with "Your message")
- Buttons: 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.

Contact



Genetic Cardiomyopathy
Awareness Consortium

Brought to you by DCM Foundation 

Sponsor

The DCM Foundation

Contact

Shauna Planck

E-mail

patientquestions@geneticcardiomyopathy.org

Website

<https://geneticcardiomyopathy.org/>

IRB E-mail

info@northstarreviewboard.org

Study available in:

English

Social Media

