

# The Genetic Cardiomyopathy Registry (GCR) 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".

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• Step 2: Enter your personal information in the spaces provided. When you are finished with this page, click "Next".

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Terms & Conditions	Contact Info	Notification	Review & Submit	Confirmation	
Country of Reside	nce *	Las	t Name *	v	
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• 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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Ferms & Conditions	Contact Info	Notifications	Review & Submit	Confirmation
	NORD contacting	me regarding ava	ilable studies. *	
I am interested in				
I am interested in • Yes • No				

• Step 4: Select "Next" so that an activation link is sent to your e-mail to complete registration.



• 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".

Your e-mail your.email@email.com has been successfully validated. Please create your password below.				
assword				
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	×			
epeat Password				
Repeat Password				

• Step 6: Your validation is now complete. Select "Go to Login Page".



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

e-mail	
password	۲
Keep me logged in	
*) L	OGIN
Forgot Password	+ Create an Account
By logging in, you agree to the <u>Privacy Poli</u>	<u>cy</u> & <u>Terms and Conditions</u> of NORD.

### 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? ③	Self Other
Preferred First Name *	Current Last name *
Preferred First Name	Current Last Name
First Name on Birth Certificate *	Middle Name on Birth Certificate *
First Name on Birth Certificate	Type 'NA' if none
Last Name on Birth Certificate *	Date of Birth * ③
Last Name on Birth Certificate	mm/dd/yyyy
Sex Recorded on Birth Certificate * (?)	
Country of Residence * ③	State/Province/Region of Residence * ③
	State/Province/Region
Country of Birth *	City/Municipality of Birth *
	City/Municipality of Birth
What Is Your Relationship to ?* ⑦	
	-

#### **Consent to the Study**

• Step 1: Click on "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."

In several gebbe to participate in our study indude:   Baddiguat, At individual diagnosed with genetic consolomyopathy, or a suspicious family history of cardiomyopathy, who is at least 18 years of age, the age of majority in their state, province or courty, and able to provide consent for themself.   Baddivature diagnosed with genetic 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 courty.   Present lu subout 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.	Consent to The Genetic Cardiomyopathy Registry (GCR)	
<form></form>	Consent Overview	
<form></form>	Those eligible to participate in our study include: <u>Participant</u> : 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 themself. <u>Legally Authorized Representative</u> : 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	
<form></form>	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.	
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<text><text><text><text><text><text><text><text><text><text><section-header></section-header></text></text></text></text></text></text></text></text></text></text>	Consent for a Person with a Legally Authorized Representative (Caregiver)	
Propertieverspress: By a constrained	Consent to Participate in the Genetic Cardiomyopathy Registry and to Allow Data to be Shared for Future Research	11
I we many and the second conversation of the second conversation conversat	Title: Genetic Cardiomyopathy Registry	
Species CPR Special CPR As a research study for individual sub research st	Principal Investigator: Kathy Crispell, MD, FACC	
<ul> <li>A privational</li> <li>We notice that can be any can serve any shudy dip individuals with genetic candiomyopathy: or a suspicious family history of candiomyopathy on behalf of the person in your care. We note its from with upey you should sum:</li> <li>We we optical weights any control weights any control weights and the person in your care. We have that its minute you should sum the your should sup on the person in your care. We have that the contacts above if you have any other questions.</li> <li>Persons</li> </ul>	E-mail: patientquestions@geneticcardiomyopathy.org	
<ul> <li>I we invited to take part in a research study for individuals with genetic cardiomyopathy, on a suspicious family history of cardiomyopathy, on behalf of the person in your care. We have that its the invite the person in the density significant numbers of people with genetic subtypes of cardiomyopathies. More research in exceeded to better understand how specific invitence states cause disease, and to develop specific gene based therapies and other therapies. Adequate numbers of people with specific genetic subtypes of cardiomyopathies. More research in exceeded to better understand how specific invitence states cause disease, and to develop specific gene based therapies and other therapies. Adequate numbers of people with specific genetic subtypes of arritery of the specific genetic subtypes of cardiomyopathies. More research in the specific genetic subtypes of arritery of the specific genetic subtypes of the specific</li></ul>	Sponsor: DCM Foundation	
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Authorization The following statements are intended to: 4. Akee sure that you have had the time and opportunity to consider whether you and the Study Participant want to participate in this registry: 4. Akee sure that you have had the time and opportunity to consider whether you and the Study Participant want to participate in this registry: 4. Akee had your questions answered; and 4. Agree to participate in the study as described. To will be asked to acknowledge: 4. That you have read the consent form and have no further questions about the registry and the Study Participant's participation: 4. That you wish to provide the Study Participant's personal data to the registry for the purposes of the Study: 4. That you allow for this data to be used for future research: 4. That you allow for this data to be used for future research: 5. That you allow for this data to be study to the Study Participant to the extent they are able to understand; and 5. That you are of legal age. 5. This wour and figal alignature 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 bores in the following section. 5. Lacknowledge that I am at least 18 wears of age and am able to provide consent on behalf of the Study Participant I fores on in my carel. I have read this	Previous	
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Previous	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.

## **Taking Surveys**

• Step 1: Click on your Participant.

IAMRARE®	📌 Home	? Help	🏟 Settings	٠	Hi, Jane! 🔻
Good Morning, Jane! Member since Mar 28, 2025			l	+ Ad	d Participant
양 Participants Select a participant to view their studies. Click on the "Add Participant" button above to add a participant.			2 Shortcuts $\overrightarrow{\leftarrow}$ request Transfer	Con	ISI Isent/Opt-Ins
5-May-2000 ☆ 1 pending surveys	>		<sup>1<sup>-</sup> Notifications</sup>		

• Step 2: Click on the appropriate study.

🕑 Back to participant list				
Jane Smith V 🖄 5-May-2000				
Enrolled Studies Click a study to see the list of surveys. Click the 3 icon to see more information about the study. Click "Search Studies" above to find additional studies.	$  \overrightarrow{\mathcal{O}} \  \  Shortcuts \\ \overrightarrow{\leftarrow} \\ Request \  \  Transfer $	Consent/Opt-Ins		
Genetic Cardiomyopathy Awareness Consortium The Genetic Cardiomyopathy Registry (GCR)	<sup>2</sup> Q <sup>2</sup> Notifications No new notifications			
The DCM Foundation ✓ Consented <sup>2</sup> © 1 pending surveys				

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

€ Back to study list	
Jane Smith V C 5-May-2000	
The Genetic Cardiomyopathy Registry (GCR) Surveys	All (1) Complete (0) Pending (1)
0% Welcome Survey Not Started	Stake 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.

Jane Smith V 2 5-May-2000	
The Genetic Cardiomyopathy Registry (GCR) Surveys 4 pending	All (5) Complete (1) Pending (4)
Welcome Survey Completed on 28-Mar-2025	© View Responses (1) ∠ Reports

#### **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".

Back to study list			
Jane Smith V C 5-May-2000			
쑴 Consents/Opt-Ins			
Study Name	Consent Status	Consented On	* Actions
The Genetic Cardiomyopathy Registry (GCR)	✓ Consented	28-Mar-2025	✓ View Consent

### **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.

IAMRARE®	🟫 Home 🛛 Help 💠 Settings 🌲 Hi, Jane! 🛩
Good Morning, Jane! Member since Mar 28, 2025	+ Add Participant
°⇔ Participants	@ Shortcuts

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

٦	Settings		Sec.	he.	*
nts	Color Themes				
	Gray	~	Darl	k Mode	
٦	Blue		G	reen	
S	Purple				
	Font Size				
	Small	Mediu	ım	Large	
	Language Pre	ferenc	е		
	English	Españ	ol	Français	5

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.

	Home OHe
Have a question?	
Please enter your message below i	and click
submit. We will be in touch shortly	We cannot
provide medical advice or answers	specific
medical questions - to find out abo	out resources
to support people with your rare d	isease, please
visit the NORD website at raredise	6165.07g.
Inquiry Type *	
- Select Inquiry Type	*
Select Inquiry Type Message *	*
	*
Message *	*
Message * Your message	e entre

- 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.

© View Responses ① └── Reports	Genetic Cardiomyopathy Awareness Consortium		
Take Survey	Contact Shauna Planck E-mail		
🖉 Take Survey	patientquestions@geneticcardiomyopat hy.org IRB E-mail info@northstarreviewboard.org Social Media () ()		
🖉 Take Survey			