




## LGMD2A/Calpainopathy Registry 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 of LGMD2A/Calpainopathy, select **Participant Account**.
  - If you are entering information for **someone else** who has LGMD2A/Calpainopathy, select **Caregiver Account**.

Featuring



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### 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”.

The screenshot shows the 'Caregiver Registration' page at Step 2, 'Acknowledgements'. At the top, there is a 'Featuring' section with an icon of three people. Below this is a progress bar with five steps: 'Terms & Conditions', 'Contact Info', 'Notifications', 'Review & Submit', and 'Confirmation'. The 'Terms & Conditions' step is currently active. The main content area contains a paragraph explaining the purpose of the Terms of Use and Privacy Guidelines, followed by a section titled 'Acknowledgements' with four checkboxes, all of which are checked. The checkboxes are: '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.', and 'You agree to the Terms and Conditions & Privacy Policy'. At the bottom left is a 'Return to login' link, and at the bottom right is a 'Next' button.

- **Step 3:** Enter your personal information in the spaces provided. When you are finished with this page, click “Next”.

The screenshot shows the 'Caregiver Registration' page at Step 3, 'Personal Information'. The layout is similar to Step 2, with the 'Terms & Conditions' step highlighted in the progress bar. The main content area contains a 'Country of Residence' dropdown menu, followed by 'First Name' and 'Last Name' input fields, and an 'E-mail' input field. At the bottom left is a 'Return to login' link, and at the bottom right are 'Previous' and 'Next' buttons.

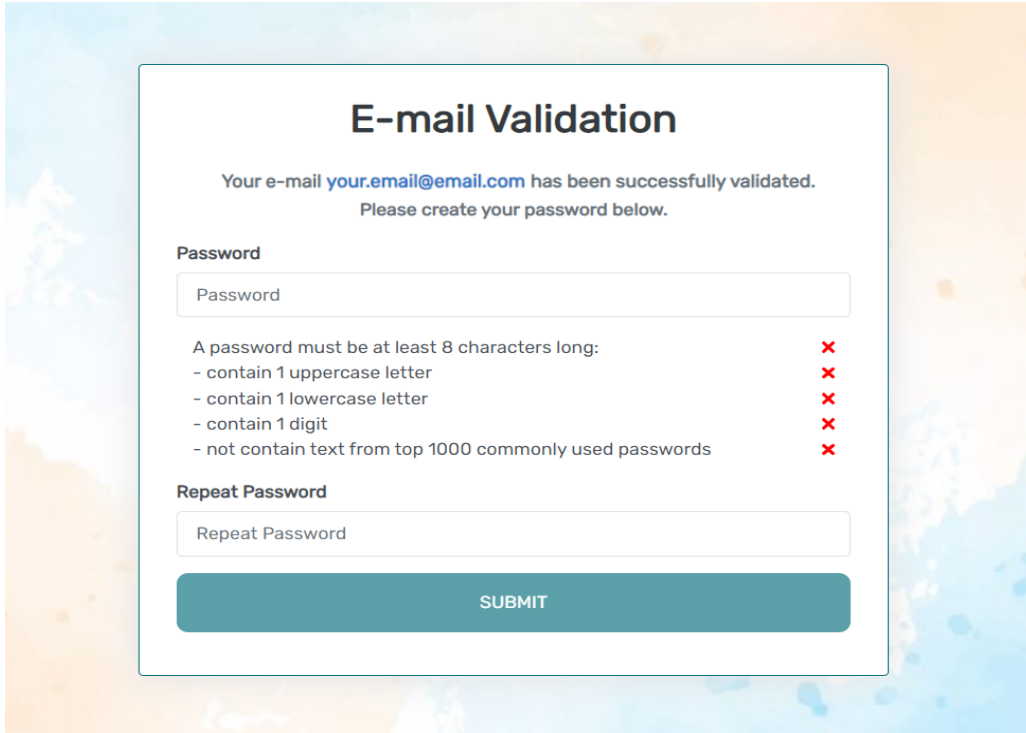
Step 4: Select whether you are interested in being contacted by NORD regarding available studies. When you are finished with this page, click “Next”.

The screenshot shows the 'Caregiver Registration' form. At the top, there is a 'Featuring' section with an icon of three people. Below this is a progress bar with five steps: 'Terms & Conditions', 'Contact Info', 'Notifications', 'Review & Submit', and 'Confirmation'. The 'Terms & Conditions' step is currently active, indicated by a dark blue bar. Below the progress bar, there is a text input field containing the text 'I am interested in NORD contacting me regarding available studies. \*'. Below this field are two radio buttons: 'Yes' and 'No'. At the bottom left, there is a link 'Return to login'. At the bottom right, there are two buttons: 'Previous' and 'Next'.

- Step 5: Select “Next” so that an activation link is sent to your e-mail to complete registration.

The screenshot shows the 'Caregiver Registration' form at Step 5. The progress bar now shows that the 'Review & Submit' step is active. Below the progress bar, there is a text input field containing the text 'An activation link will be sent to your.email@email.com. Click "Next" to send this e-mail and continue.'. At the bottom left, there is a link 'Return to login'. At the bottom right, there are two buttons: 'Previous' and 'Next'. A green arrow points to the 'Next' button.

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

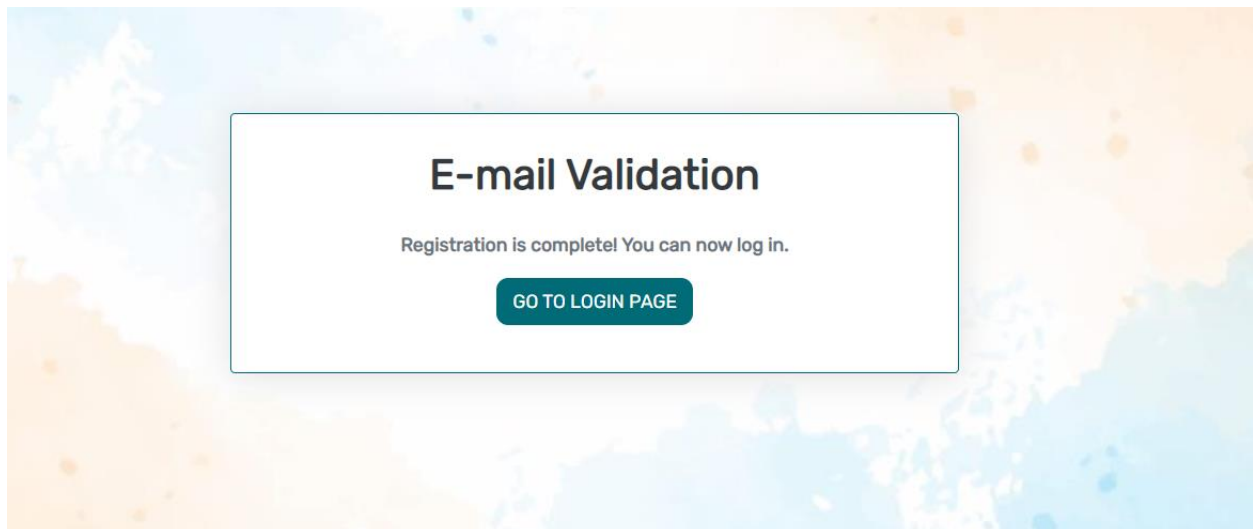
**Password**

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 7: Your validation is now complete. Select “Go to Login Page”.

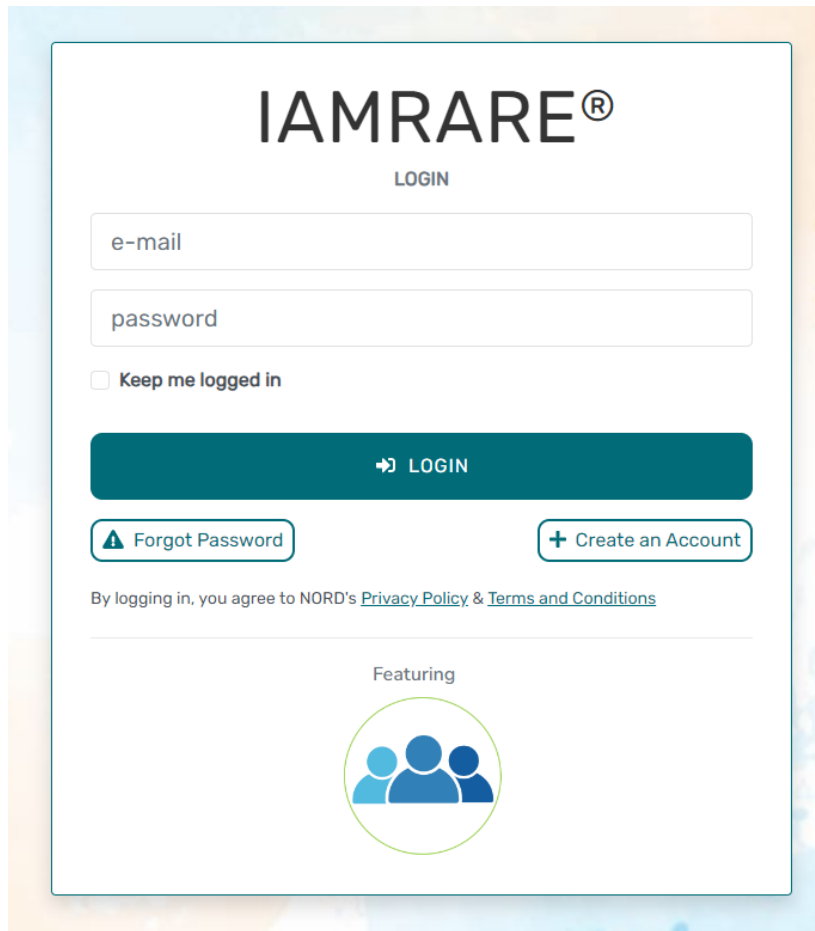


**E-mail Validation**

Registration is complete! You can now log in.

**GO TO LOGIN PAGE**

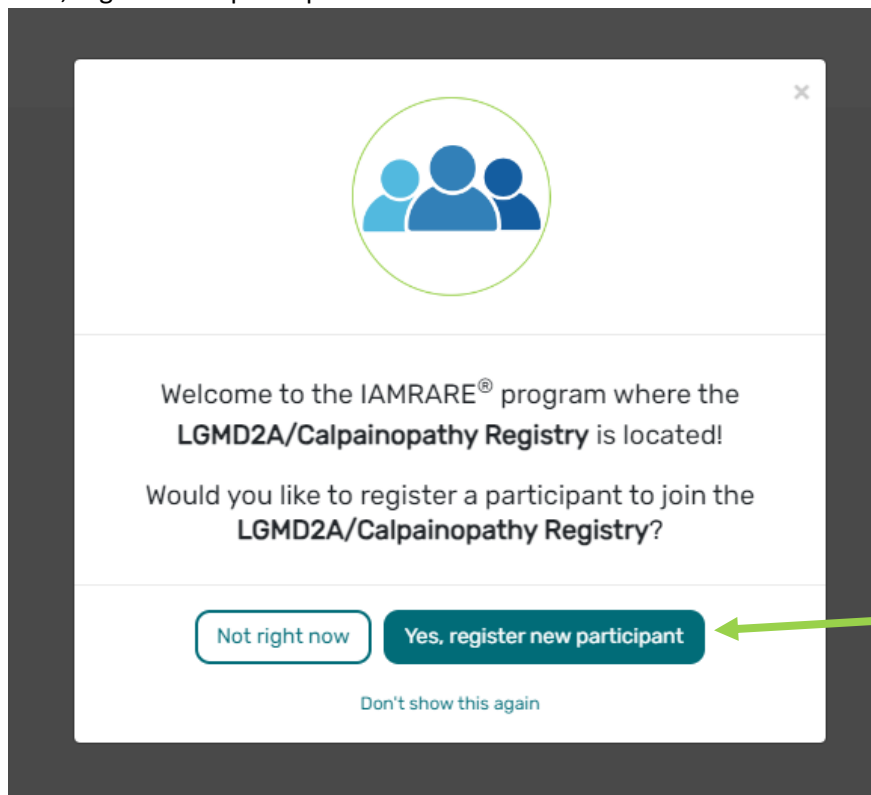
- Step 8: Log in using your new e-mail and password.



The image shows the IAMRARE LOGIN page. At the top, the logo "IAMRARE®" is displayed in a large, bold, black font, with "LOGIN" centered below it in a smaller, black font. Below the text are two input fields: "e-mail" and "password". Underneath these fields is a checkbox labeled "Keep me logged in". A prominent teal button with a right-pointing arrow and the text "LOGIN" is centered below the checkbox. Below the button are two smaller buttons: "Forgot Password" (with a warning icon) and "Create an Account" (with a plus icon). At the bottom of the form area, there is a line of text: "By logging in, you agree to NORD's [Privacy Policy & Terms and Conditions](#)". Below this is a section titled "Featuring" with a circular icon containing three stylized human figures.

### Add a Participant

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



The image shows a dialog box with a white background and a dark grey border. At the top center is a circular icon with three stylized human figures. Below the icon, the text reads: "Welcome to the IAMRARE® program where the **LGMD2A/Calpainopathy Registry** is located!" followed by "Would you like to register a participant to join the **LGMD2A/Calpainopathy Registry**?" At the bottom, there are two buttons: "Not right now" and "Yes, register new participant". A green arrow points to the "Yes, register new participant" button. Below the buttons 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 \*

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 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.”



Thank you for registering your first participant!

Would you like to consent to participate in the  
LGMD2A/Calpainopathy 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.”

## Consent to LGMD2A/Calpainopathy Registry

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

Title: LGMD2A/Calpainopathy Registry

Principal Investigator: Jennifer Levy, PhD, Scientific Director, Coalition to Cure Calpain 3

Phone: (203) 293-8864

Email: [Registry@CureCalpain3.org](mailto:Registry@CureCalpain3.org)

#### Key Information

You are invited to take part in a research study for individuals with Calpainopathy 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:

- The purpose of the study is to improve the understanding of the symptoms of Calpainopathy and how they change over time. The study will also allow participants, if they choose, to be contacted about research studies and clinical trials.
- If you choose to participate on behalf of the participant, you will be asked to complete web-based surveys when you enroll and at least once a year. This will take approximately 30 minutes to complete.
- There are no anticipated risks of physical harm to participating in the study. The surveys ask questions about the impact of Calpainopathy on the life of the participant, which you may find unpleasant.
- There are no direct benefits to your participation in the LGMD2A/Calpainopathy Registry. Learnings from the study may increase our understanding of the disease and availability of therapies for Calpainopathy patients.
- 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 person in your care. As the guardian or legally authorized representative for the Study Participant, we encourage you to discuss the registry with the Study Participant to the extent compatible with their understanding. Detailed information about your participation in this study follows.

#### Purpose of this Informed Consent Document

This document will give you the information for you to decide if you want to join this study on behalf of the participant or not. This consent document is structured to follow the framework provided by federal regulations. While we hope the information we provide will answer most of your questions, it may not answer them all. If you have any remaining questions, please contact the Principal Investigator at the phone or email listed above.

#### Definitions

For the purpose of enrolling in this registry, a legal adult is defined as a person who is at least 18 years of age, the age of majority in their state, province or country, and able to consent for themselves or on behalf of a Study Participant. On this form, “Study Participant” refers to the person with Calpainopathy (including LGMD2A, LGMDR1 Calpain 3-related, LMGD11, and LGMD4 Calpain 3-related) who is not of legal age or is an adult who requires someone to act on their behalf. Registry information will be collected on individuals who have Calpainopathy. “You” refers to the person reading this form and providing the information; in this case a family member or guardian who is legally responsible for the healthcare of the Study Participant. “We” refers to the organization, Coalition to Cure Calpain 3.

Institutional Review Board (IRB) is an independent group that reviews research proposals to make sure they properly protect participants.

Next

## Consent to LGMD2A/Calpainopathy 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 LGMD2A/Calpainopathy Registry on behalf of the Study Participant. All four items must be checked “Yes” to participate in the LGMD2A/Calpainopathy Registry. After signing, a copy of the consent form will be emailed 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 LGMD2A/Calpainopathy Registry have been answered to my satisfaction, and I understand the purpose of the registry and the risks of participation.

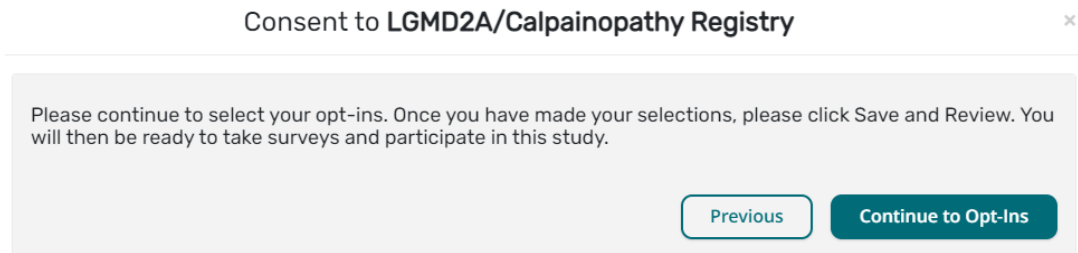
I wish to provide the Study Participant’s research data to the LGMD2A/Calpainopathy Registry for the purposes described above under Study Aims.

I wish to provide the Study Participant’s research data to the LGMD2A/Calpainopathy Registry for future research within recognized ethical standards for scientific research, as described under How We Use Your Data.

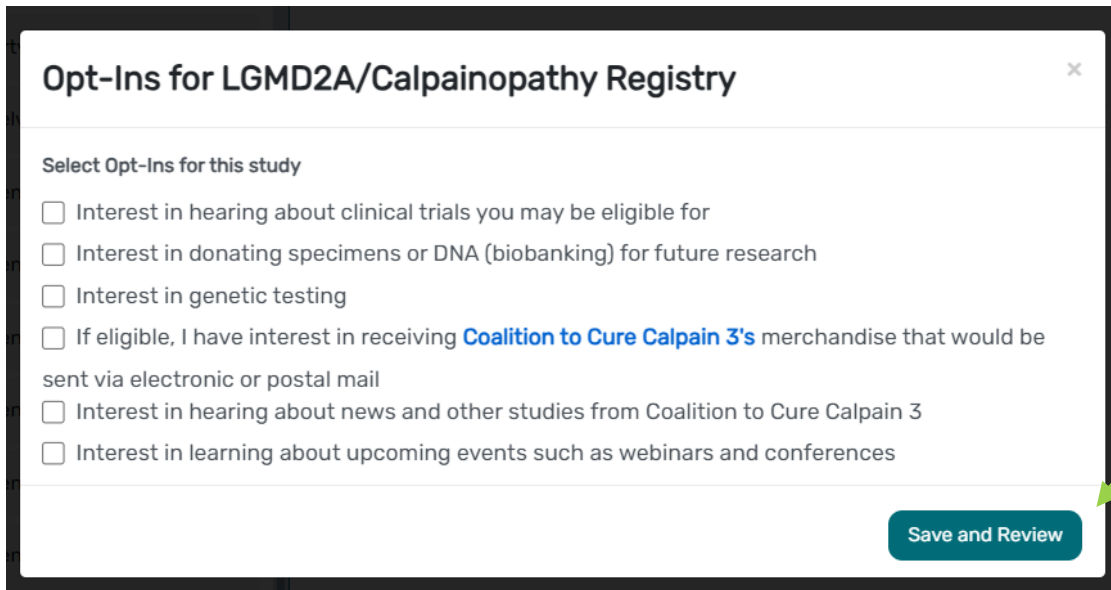
Previous

Next

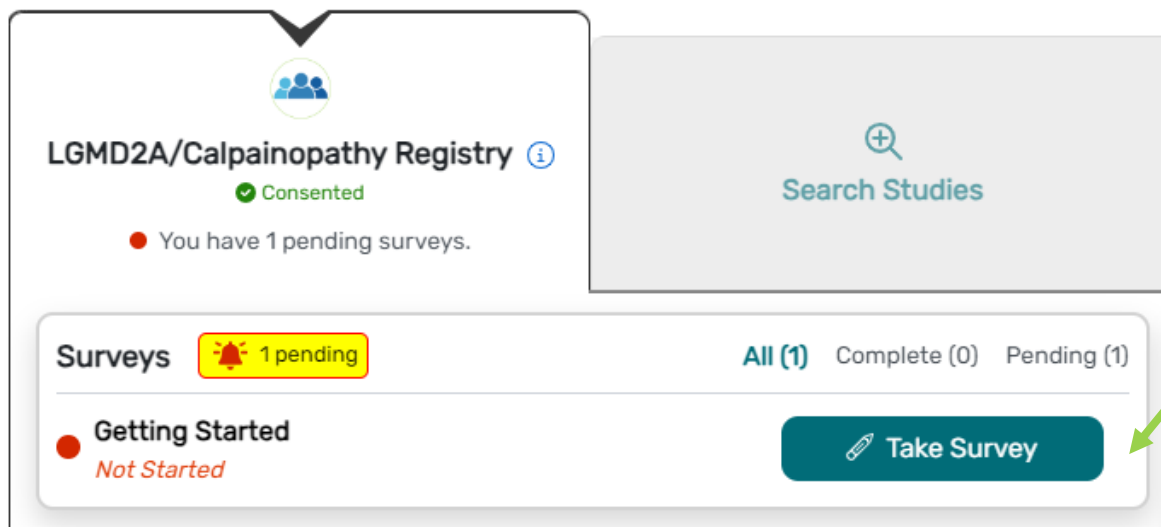
- Step 3: Once you click “Next” and reach the Thank You page, click “Continue to Opt-Ins”.



- 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”.



- 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.

The dashboard for the LGMD2A/Calpainopathy Registry shows a 'Consented' status and a notification for 5 pending surveys. A 'Search Studies' button is visible in the top right. The 'Surveys' section lists three surveys: 'Getting Started' (Completed on 15-Jun-2023), 'Demographics' (Not Started), and 'Diagnosis' (Completed on 15-Jun-2023). For 'Getting Started' and 'Diagnosis', there are buttons for 'View Responses' (with a red '1' indicator) and 'Reports'. For 'Demographics', there is a 'Take Survey' button. Two green arrows point to the 'View Responses' buttons for the 'Getting Started' and 'Diagnosis' surveys.

## 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”.

The 'CONSENTS/OPT-INS' section for Jane Smith (5-May-2005) shows a table with columns for Study Name, Consent Status, Consented On, and Actions. A green arrow points to the 'View Consent' button in the Actions column for the LGMD2A/Calpainopathy Registry study. The left sidebar shows a navigation menu with 'Consents/Opt-Ins' selected, also indicated by a green arrow.

Study Name	Consent Status	Consented On	Actions
LGMD2A/Calpainopathy Registry	Consented	6-Jun-2023	View Consent Revoke Opt-Ins