



Guía del usuario para el participante de LGMD2A/Calpainopathy Registry

Registrar una cuenta

- Paso 1: Lea los términos y condiciones y la política de privacidad y certifique los enunciados que se proporcionan. Cuando termine con esta página, haga clic en “Siguiente”.

Featuring

**COALITION TO
CURE
CALPAIN 3**
OVERCOMING WEAKNESS
WITH STRENGTH

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](#)

- Paso 2: Ingrese su información personal en los espacios que se proporcionan. Cuando termine con esta página, haga clic en “Siguiente”.

Featuring

COALITION TO
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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](#)

- Paso 3: Seleccione si le interesa que NORD se comunice con usted en relación con los estudios disponibles. Cuando termine con esta página, haga clic en “Siguiente”.

Featuring

COALITION TO
CURE
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OVERCOMING WEAKNESS
WITH STRENGTH

Registration

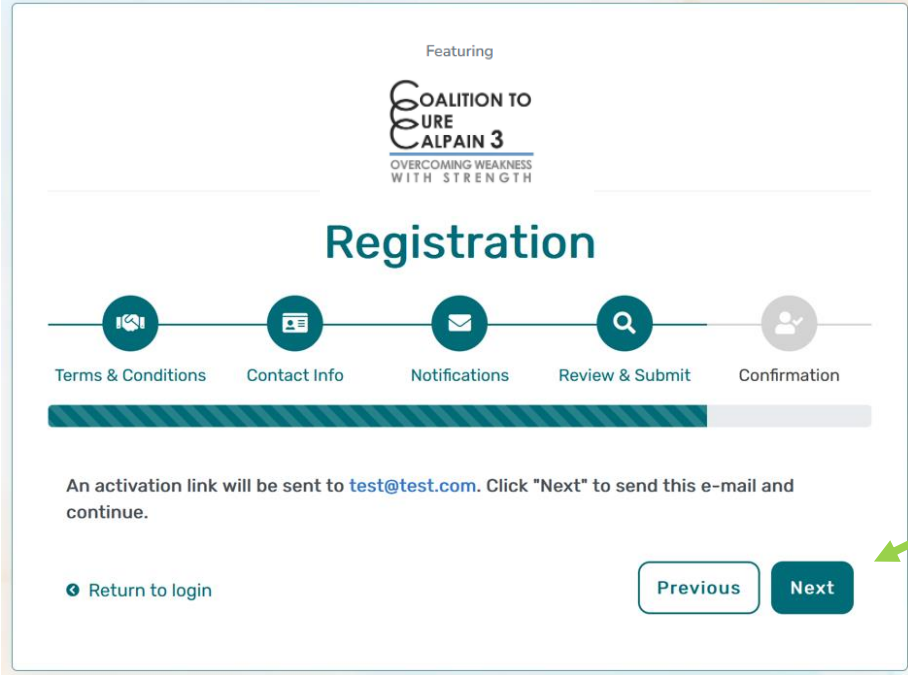
Terms & Conditions Contact Info Notifications Review & Submit Confirmation

I am interested in NORD contacting me regarding available studies. *

☒ Yes ☐ No

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

- Paso 4: Seleccione “Siguiente” para que se envíe un enlace de activación a su correo electrónico para completar el registro.



Featuring

**COALITION TO
CURE
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OVERCOMING WEAKNESS
WITH STRENGTH

Registration

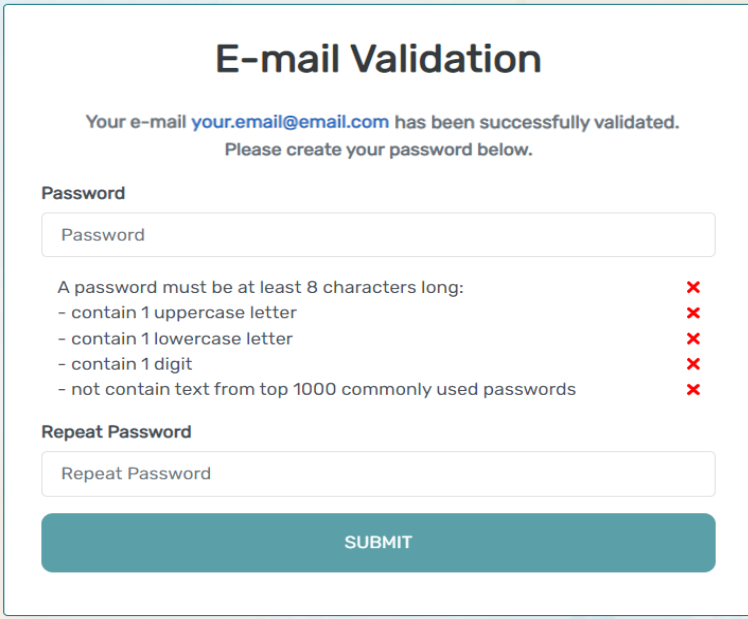
Terms & Conditions Contact Info Notifications Review & Submit Confirmation

An activation link will be sent to test@test.com. Click "Next" to send this e-mail and continue.

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

A green arrow points to the "Next" button.

- Paso 5: Haga clic en el enlace que se le envió por correo electrónico. Revise la carpeta de correo no deseado si no ve el correo electrónico. Lo llevará a la siguiente pantalla en una nueva pestaña de su navegador. Establezca su contraseña y haga clic en “Enviar”.



E-mail Validation

Your e-mail your.email@email.com has been successfully validated.
Please create your password below.

Password

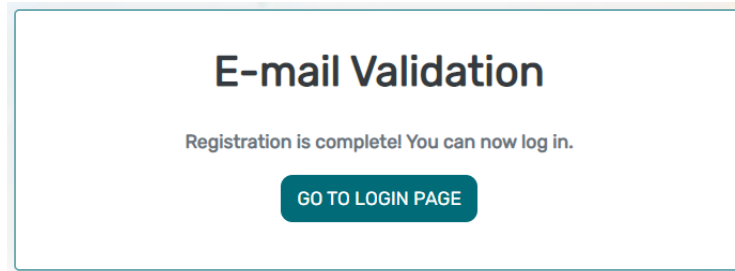
A password must be at least 8 characters long: ✗

- contain 1 uppercase letter ✗
- contain 1 lowercase letter ✗
- contain 1 digit ✗
- not contain text from top 1000 commonly used passwords ✗

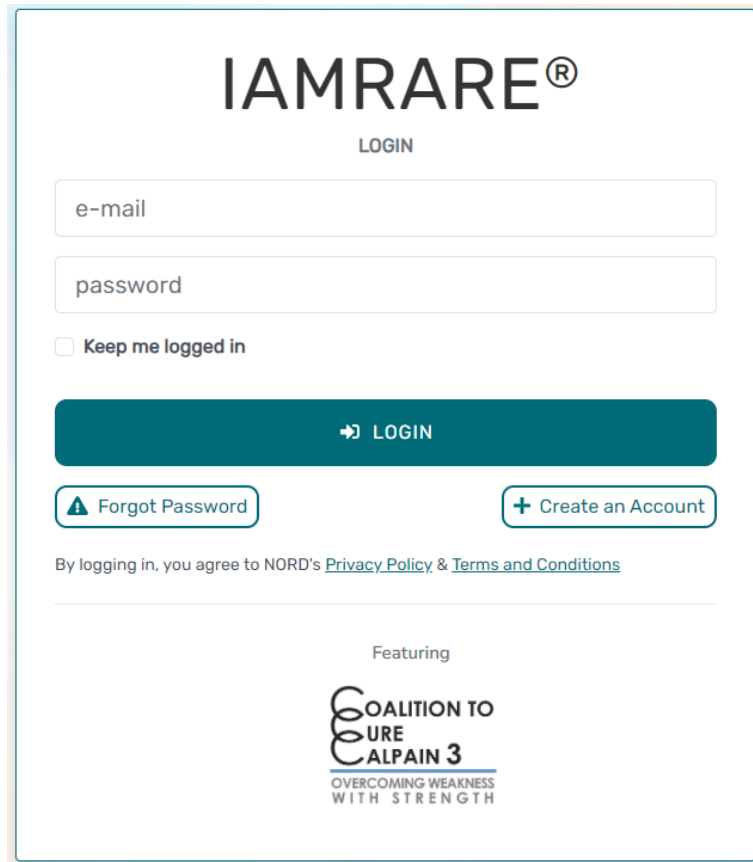
Repeat Password

[SUBMIT](#)

- Paso 6: Ya está completa su validación. Seleccione “Ir a la página de inicio de sesión”.

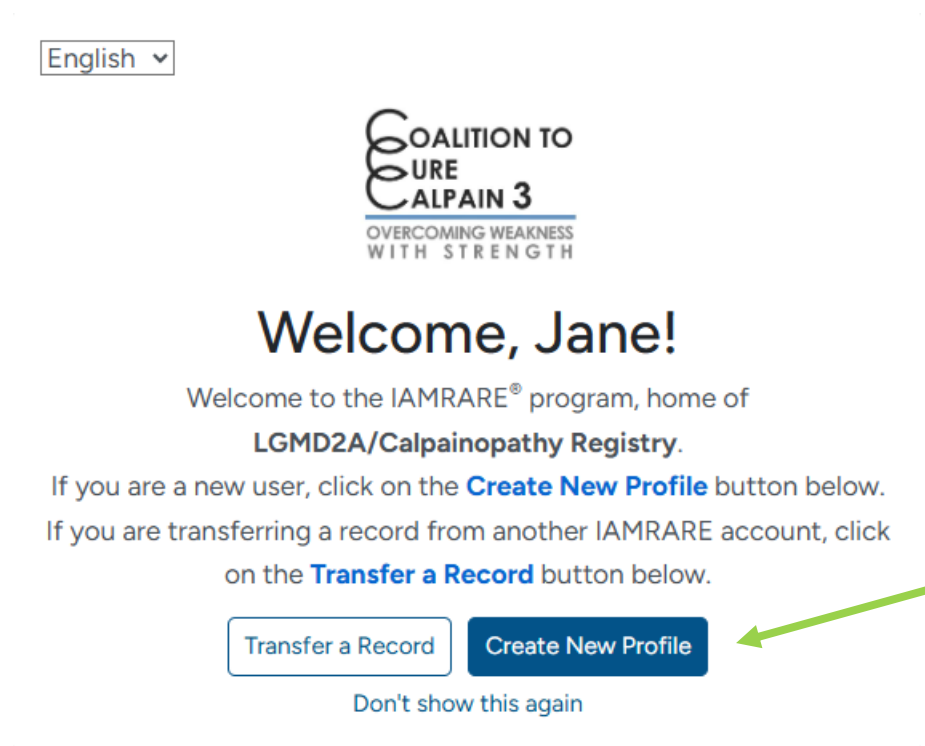


- Paso 7: Inicie sesión utilizando su nuevo correo electrónico y contraseña.

The login page for IAMRARE. It features the "IAMRARE®" logo at the top, followed by the word "LOGIN". There are input fields for "e-mail" and "password". Below these is a checkbox labeled "Keep me logged in". A large teal button with a right arrow icon and the text "LOGIN" is prominent. Below the button are two links: "Forgot Password" (with a warning icon) and "Create an Account" (with a plus icon). A line of text states: "By logging in, you agree to NORD's [Privacy Policy](#) & [Terms and Conditions](#)". At the bottom, it says "Featuring" above the logo for the "COALITION TO CURE CALPAIN 3", which includes the tagline "OVERCOMING WEAKNESS WITH STRENGTH".

Añadir un participante

- Paso 1: Para empezar, haga clic en Crear perfil nuevo.



English ▾

**COALITION TO
CURE
ALPAIN 3**
OVERCOMING WEAKNESS
WITH STRENGTH

Welcome, Jane!

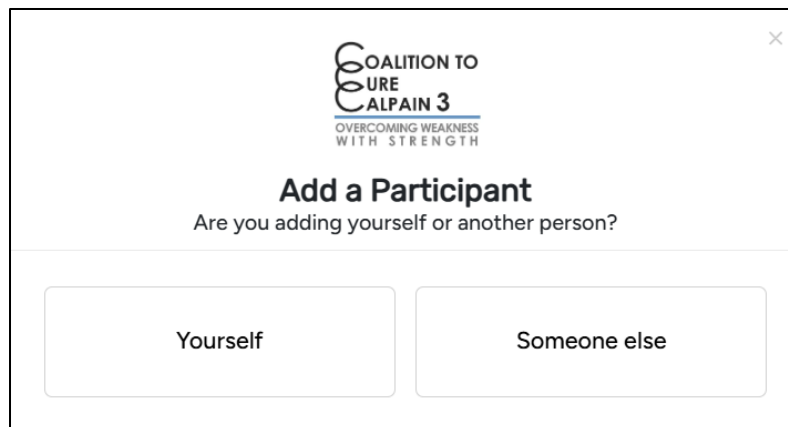
Welcome to the IAMRARE® program, home of
LGMD2A/Calpainopathy Registry.

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](#)

- Paso 2: Seleccione la persona sobre la que proporcionará información.



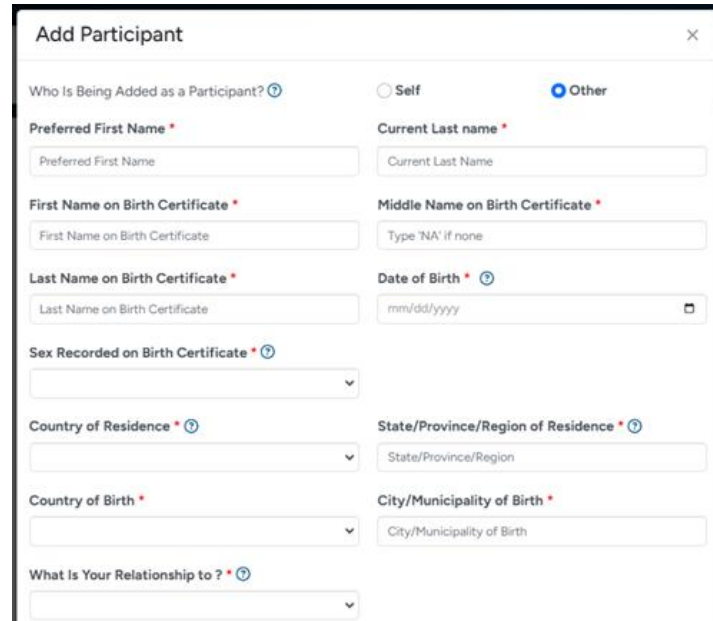
**COALITION TO
CURE
ALPAIN 3**
OVERCOMING WEAKNESS
WITH STRENGTH

Add a Participant

Are you adding yourself or another person?

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

- Paso 3: Complete la información del participante.



The 'Add Participant' form is a web-based interface for adding a new participant. It features a title bar with a close button (X). Below the title, there are two radio buttons: 'Self' and 'Other', with 'Other' selected. The form is organized into several sections with labels and input fields. The first section contains 'Preferred First Name' and 'Current Last name'. The second section contains 'First Name on Birth Certificate' and 'Middle Name on Birth Certificate'. The third section contains 'Last Name on Birth Certificate' and 'Date of Birth'. The fourth section contains 'Sex Recorded on Birth Certificate'. The fifth section contains 'Country of Residence' and 'State/Province/Region of Residence'. The sixth section contains 'Country of Birth' and 'City/Municipality of Birth'. The final section contains 'What Is Your Relationship to?'. All input fields are empty, and the form is styled with a clean, modern design.

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 *

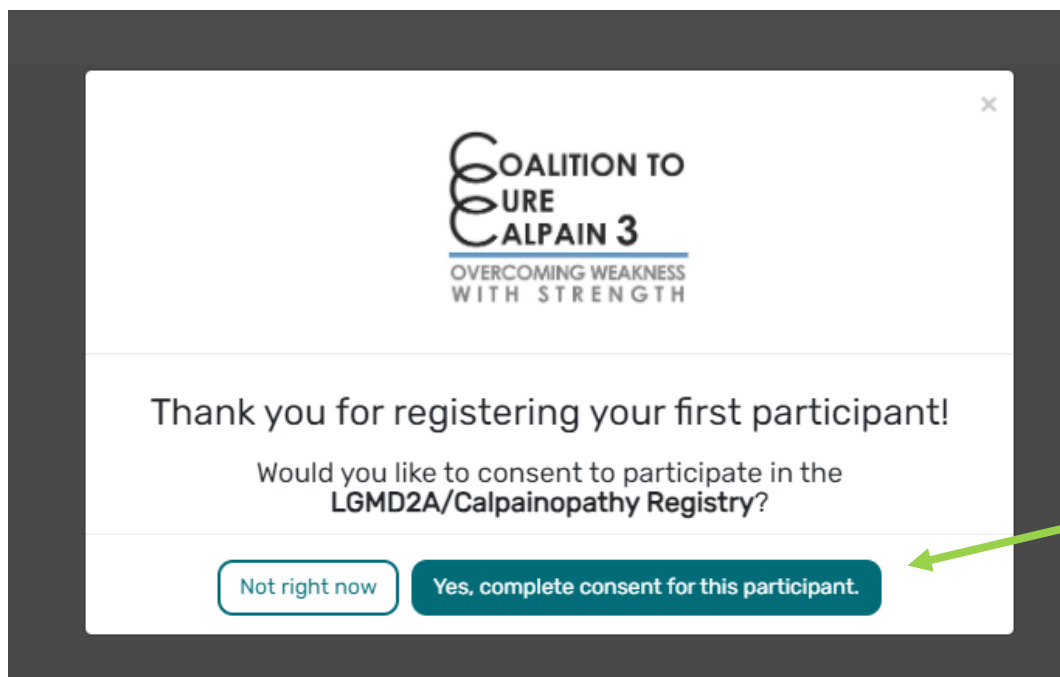
Country of Birth *

City/Municipality of Birth *

What Is Your Relationship to? *

Consentimiento para el estudio

- Paso 1: Haga clic en “Sí, completar el consentimiento para este participante”.



The consent form is a web-based interface for obtaining consent for a participant. It features a title bar with a close button (X). Below the title, there is a logo for the 'COALITION TO CURE CALPAIN 3' with the tagline 'OVERCOMING WEAKNESS WITH STRENGTH'. The main text reads 'Thank you for registering your first participant!' followed by 'Would you like to consent to participate in the LGMD2A/Calpainopathy Registry?'. At the bottom, there are two buttons: 'Not right now' and 'Yes, complete consent for this participant.'. A green arrow points to the 'Yes, complete consent for this participant.' button.

COALITION TO CURE CALPAIN 3
OVERCOMING WEAKNESS WITH STRENGTH

Thank you for registering your first participant!

Would you like to consent to participate in the LGMD2A/Calpainopathy Registry?

- Paso 2: Desplácese hacia abajo y lea el formulario de consentimiento con detenimiento. Una vez que termine cada página, haga clic en el botón “Siguiente”. Una vez que llegue al formulario de autorización, lea los enunciados con detenimiento. Si se siente cómodo otorgando su consentimiento para participar en el estudio, lea cada declaración y autorice su consentimiento. Después de marcar las casillas, haga clic en “Siguiente”.

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

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, LMGD1L, 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

- Paso 3: Una vez que haga clic en “Siguiente” y llegue a la página de agradecimiento, haga clic en “Continuar recibiendo los servicios aceptados”.

Jane Smith

Consent to LGMD2A/Calpainopathy Registry

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

- Paso 4: Una vez que haga clic en “Continuar recibiendo los servicios aceptados”, lea detenidamente los servicios aceptados. Si le gustaría recibir información sobre el tema, marque la casilla y haga clic en “Guardar y revisar”.

Opt-Ins for LGMD2A/Calpainopathy Registry

Select Opt-Ins for this study

- ☐ Interest in hearing about relevant clinical trials
- ☐ Interest in donating specimens or DNA (biobanking) for future research
- ☐ Interest in genetic testing
- ☐ If eligible, I have interest in receiving **Coalition to Cure Calpain 3** merchandise that would be sent via electronic or postal mail
- ☐ Interest in hearing about news and other studies from **Coalition to Cure Calpain 3**.
- ☐ Interest in learning about upcoming events such as webinars and conferences

Save and Review

- Paso 5: Una vez que haya revisado su consentimiento, haga clic en “Cerrar”. Luego tendrá acceso para empezar a responder encuestas.

Llenado de encuestas

- Paso 1: Haga clic en su participante.

IAMRARE®

Home Help Settings Hi, Jane!

Good Afternoon, Jane!
Member since Mar 29, 2025

+ Add Participant

Participants

Select a participant to view their studies. Click on the "Add Participant" button above to add a participant.

Jane Smith
5-May-2000
1 pending surveys

Shortcuts

Request Transfer Consent/Opt-Ins


Notifications (0)
No new notifications.

- Paso 2: Haga clic en el estudio correspondiente.

← Back to participant list

Jane Smith 5-May-2000 [Search Studies](#)

Enrolled Studies
Click a study to see the list of surveys. Click the [i](#) icon to see more information about the study. Click "Search Studies" above to find additional studies.

 **English**


LGMD2A/Calpainopathy Registry [i](#)

Coalition to Cure Calpain 3
✓ Consented

[🔔 1 pending surveys](#)

Shortcuts
[Request Transfer](#) [Consent/Opt-Ins](#)

Notifications (0)
No new notifications.



- Paso 3: Haga clic en "Responder encuesta" para una encuesta disponible.

← Back to study list


Jane Smith 5-May-2000

LGMD2A/Calpainopathy Registry

Surveys [🔔 1 pending](#) [All \(1\)](#) [Complete \(0\)](#) [Pending \(1\)](#)

[0%](#) **Getting Started**
Not Started

[📝 Take Survey](#)



Ver respuestas e informes

- Paso 1: Una vez que ha enviado una encuesta, puede ver sus respuestas, así como los gráficos de las preguntas que están programadas para mostrarlos. Haga clic en “Ver respuestas” para ver la encuesta que completó. Haga clic en “Informes” para ver los gráficos disponibles.

The screenshot shows the user profile for Jane Smith (5-May-2000) with a 'Back to study list' link. Below the profile, the study 'LGMD2A/Calpainopathy Registry' is listed with '6 pending' surveys. A 'Getting Started' status is shown as 'Completed on 28-Mar-2025'. Two buttons, 'View Responses 1' and 'Reports', are highlighted with green arrows.

Ver el consentimiento y los servicios aceptados

- Paso 1: Una vez que haya dado su consentimiento para el estudio, podrá verlo en cualquier momento. Navegue hasta la página Estudios en los que está inscrito. Luego, haga clic en “Consentimientos/servicios aceptados” para ver el consentimiento y los servicios aceptados.

The screenshot shows the 'Enrolled Studies' section for Jane Smith. A 'Search Studies' button is highlighted with a green arrow. Below the study list, there are 'Shortcuts' for 'Request Transfer' and 'Consent/Opt-Ins'.

- Paso 2: Puede revocar su consentimiento en cualquier momento haciendo clic en “Revocar”. También puede editar los servicios aceptados haciendo clic en “Servicios aceptados”.

The screenshot shows the 'Consents/Opt-Ins' table for Jane Smith. The table has columns for Study Name, Consent Status, Consented On, and Actions. The row for 'LGMD2A/Calpainopathy Registry' shows a 'Consented' status on '28-Mar-2025'. The 'Actions' column contains three buttons: 'View Consent', 'Revoke', and 'Opt-Ins'. The 'View Consent' and 'Revoke' buttons are highlighted with green arrows.

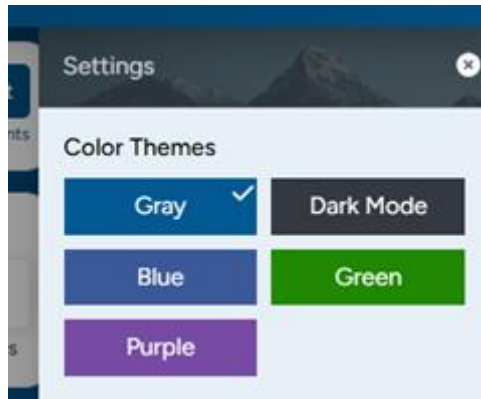
Study Name	Consent Status	Consented On	Actions
LGMD2A/Calpainopathy Registry	✓ Consented	28-Mar-2025	View Consent Revoke Opt-Ins

Configuración del modo oscuro

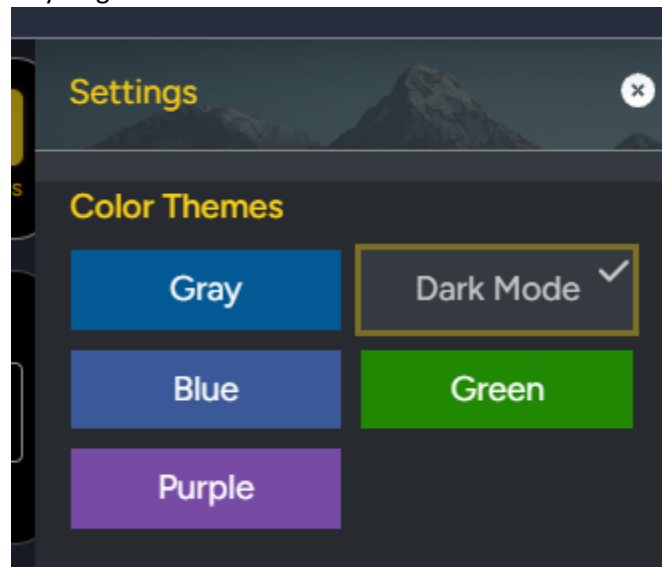
- Paso 1: Puede ver la plataforma en modo oscuro. Primero, haga clic en Ajustes.



- Paso 2: Seleccione Modo oscuro.



- Paso 3: Salga del menú Ajustes y se guardará su selección.

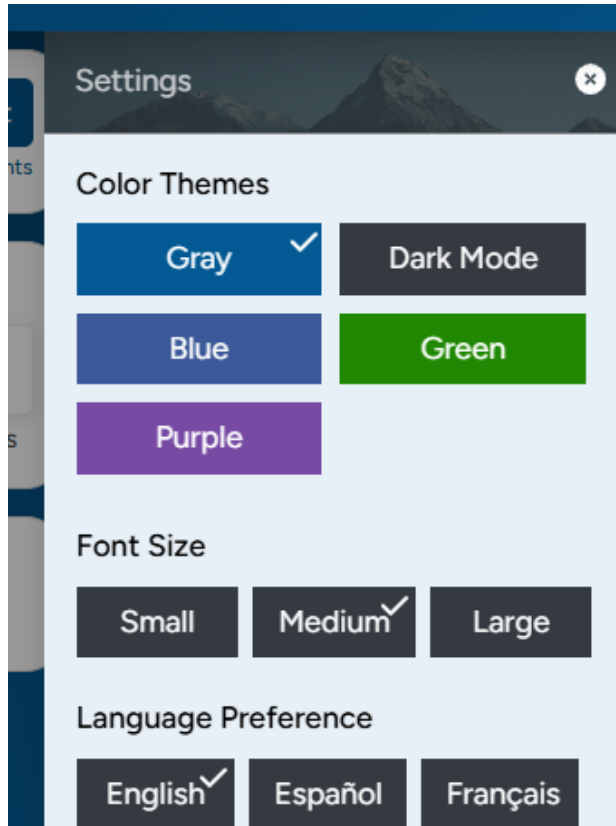


Ajustes de visualización

- Paso 1: Puede cambiar los ajustes de visualización de la plataforma. Primero, haga clic en Ajustes.



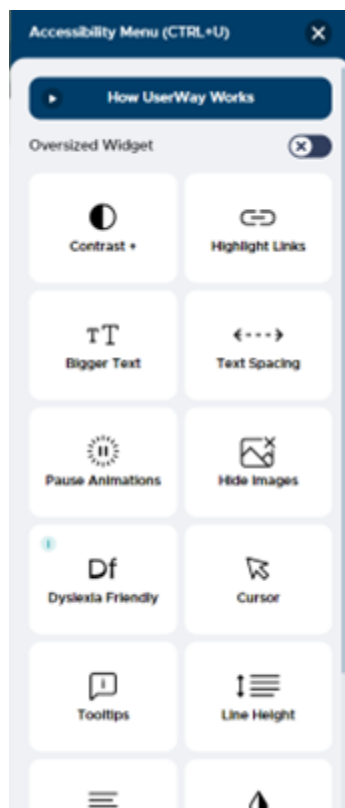
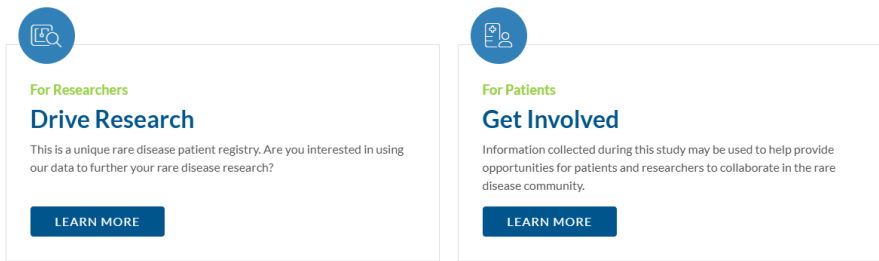
- Paso 2: Seleccione un tema de color, un tamaño de fuente o una preferencia de idioma.



- Paso 3: Salga del menú Ajustes y se guardará su selección.

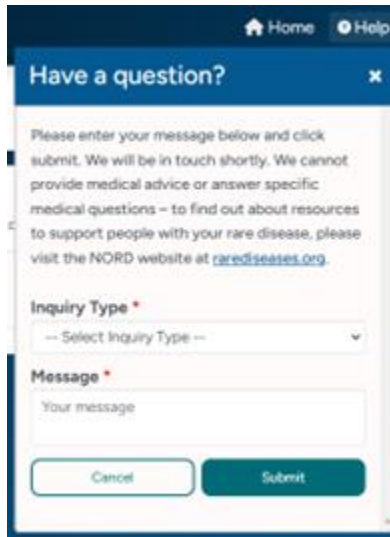
Visibilidad del micrositio

- Paso 1: Puede cambiar la manera en que ve el micrositio (lgmd2a.iamrare.org) usando un menú de accesibilidad. Haga clic en el icono de una persona que está en la parte inferior de la pantalla. Puede cambiar ajustes como el contraste, el tamaño del texto y el espaciado del texto.



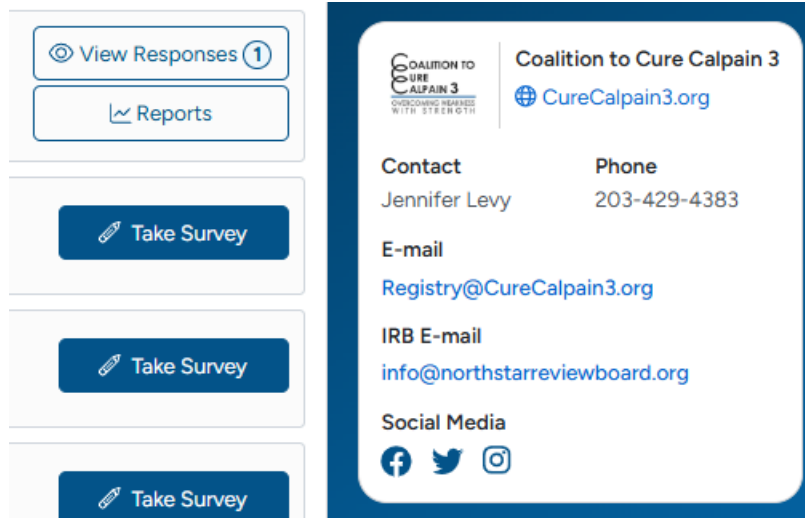
¿Necesita ayuda?

- Paso 1: Si necesita ayuda mientras utiliza la plataforma, haga clic en Ayuda.
- Paso 2: Seleccione un tipo de consulta y escriba un mensaje.



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?'. The modal contains a text area for a message, a dropdown menu for 'Inquiry Type' with the placeholder '-- Select Inquiry Type --', and a 'Submit' button. A 'Cancel' button is also visible at the bottom left of the modal.

- Paso 3: Haga clic en Enviar.
- También puede comunicarse directamente con el patrocinador del estudio usando la información de contacto que se muestra en el panel de control o en el sitio web del estudio.



The screenshot shows a contact information panel for the 'Coalition to Cure Calpain 3'. The panel includes the following information:

- Coalition to Cure Calpain 3** logo and website: CureCalpain3.org
- Contact**: Jennifer Levy
- Phone**: 203-429-4383
- E-mail**: Registry@CureCalpain3.org
- IRB E-mail**: info@northstarreviewboard.org
- Social Media**: Facebook, Twitter, and Instagram icons.