



## 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



**Registration**

Progress bar: Terms & Conditions (filled), Contact Info (empty), Notifications (empty), Review & Submit (empty), Confirmation (empty).

Country of Residence \*

First Name \*      Last Name \*

E-mail \*

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

Featuring



**Registration**

Progress bar: Terms & Conditions (filled), Contact Info (filled), Notifications (filled), Review & Submit (empty), Confirmation (empty).

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 CALPAIN 3**

OVERCOMING WEAKNESS WITH STRENGTH

## Registration

Terms & Conditions      Contact Info      Notifications      Review & Submit      Confirmation

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

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

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

**Password**

Password

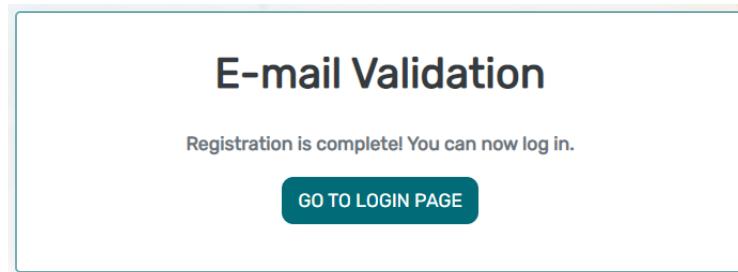
A password must be at least 8 characters long: X  
 - contain 1 uppercase letter X  
 - contain 1 lowercase letter X  
 - contain 1 digit X  
 - not contain text from top 1000 commonly used passwords X

**Repeat Password**

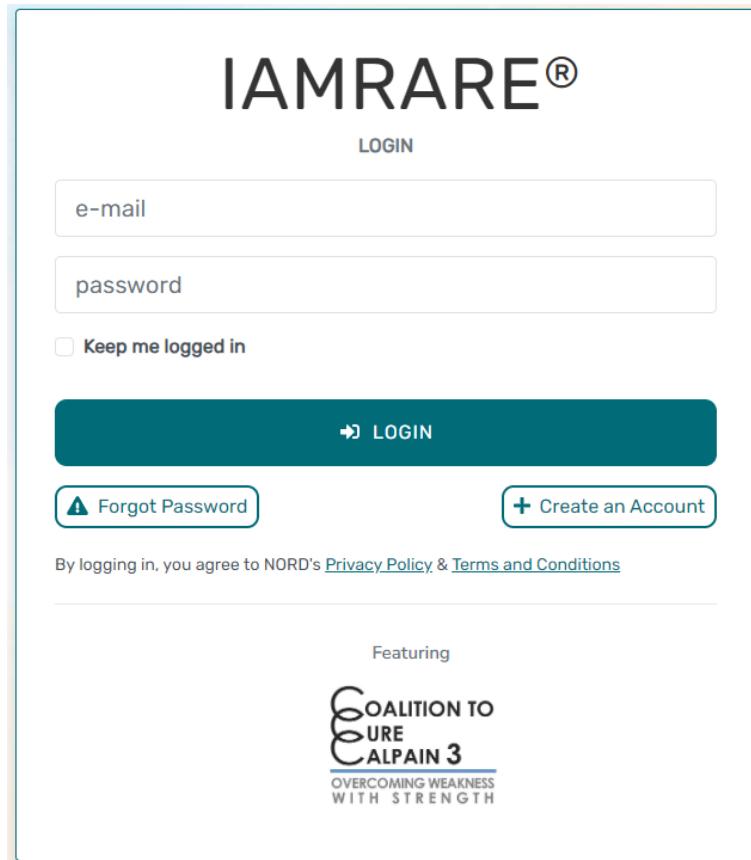
Repeat Password

**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.



## Añadir un participante

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

English ▾



# 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.

The modal window contains the following text:  
COALITION TO  
CURE  
CALPAIN 3  
OVERCOMING WEAKNESS  
WITH STRENGTH

**Add a Participant**

Are you adding yourself or another person?

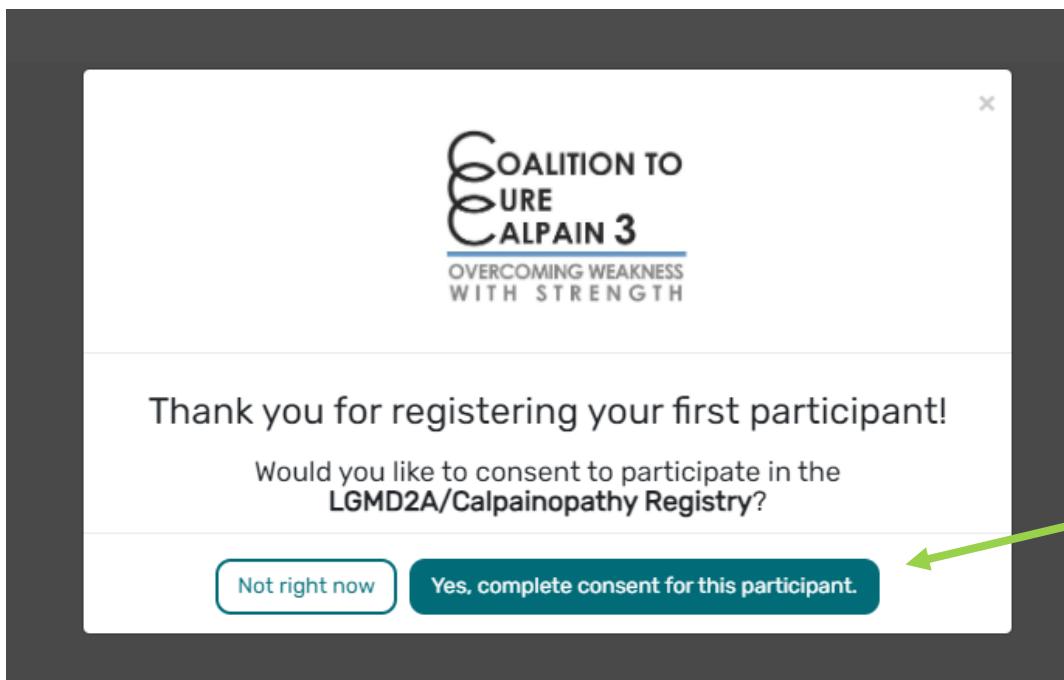
- Paso 3: Complete la información del participante.

Add Participant

Who Is Being Added as a Participant? <small>?</small>	<input type="radio"/> Self	<input checked="" type="radio"/> 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 * <small>?</small>	
Last Name on Birth Certificate	mm/dd/yyyy	
Sex Recorded on Birth Certificate * <small>?</small>		
Country of Residence * <small>?</small>	State/Province/Region of Residence * <small>?</small>	
Country of Residence	State/Province/Region	
Country of Birth *	City/Municipality of Birth *	
Country of Birth	City/Municipality of Birth	
What Is Your Relationship to ? * <small>?</small>		

### Consentimiento para el estudio

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



- **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](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, LGMD1I, and LGMDD4 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”.

Consent to LGMD2A/Calpainopathy Registry

Jane Smith

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®

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**

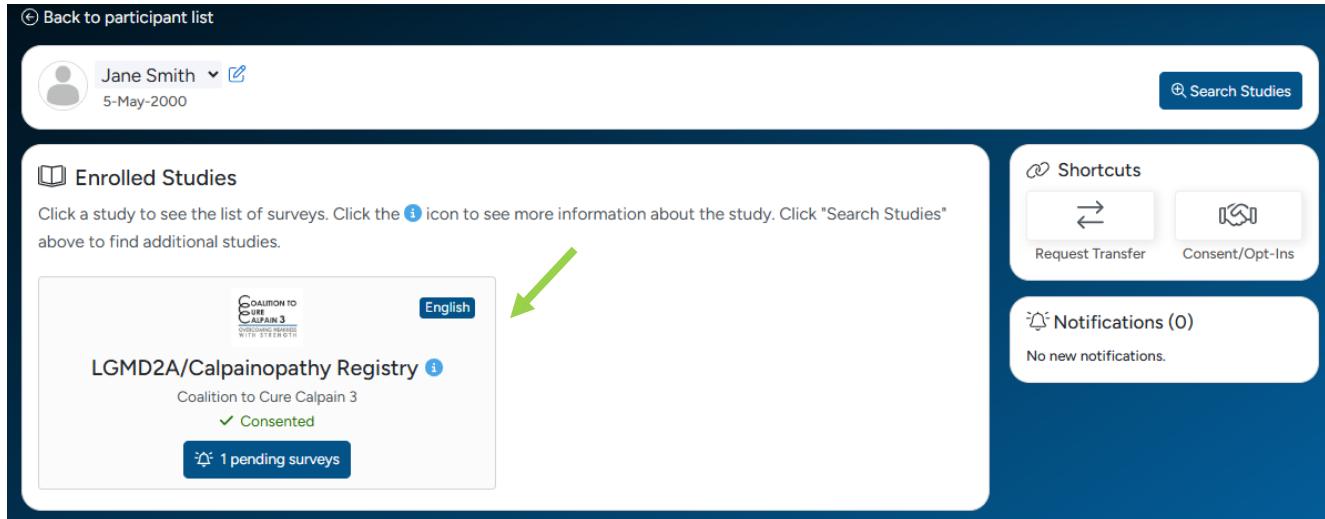
Request Transfer  Consent/Opt-Ins

**Notifications (0)**

No new notifications.

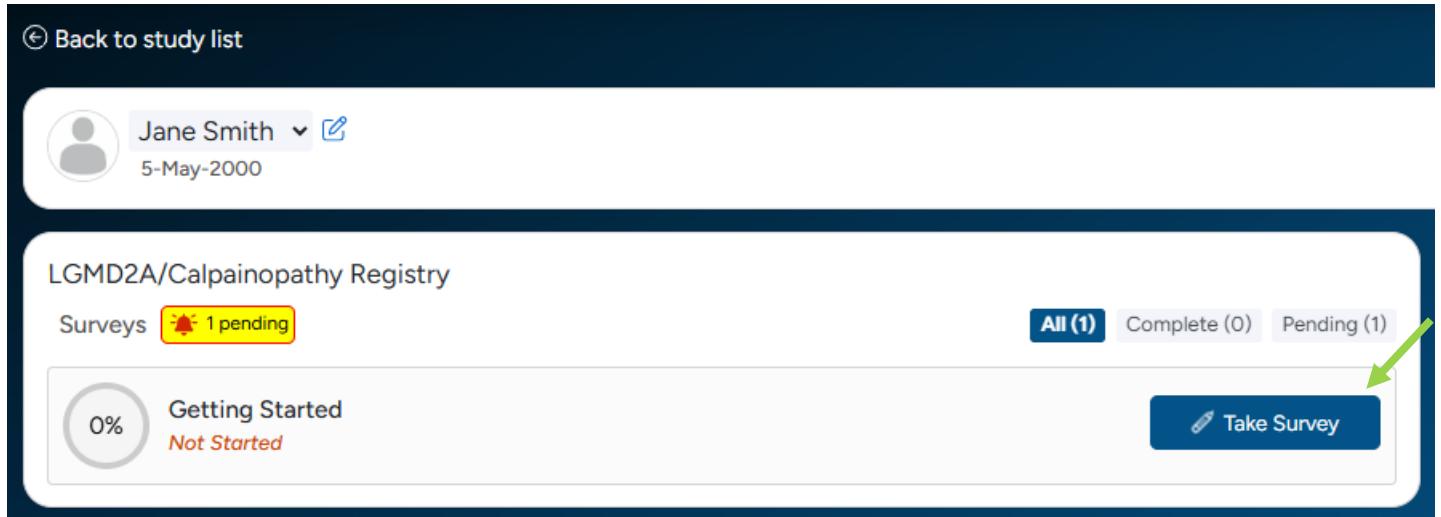


- Paso 2: Haga clic en el estudio correspondiente.



The screenshot shows the participant dashboard for Jane Smith. At the top, there's a header with "Back to participant list", a profile picture for Jane Smith, her name "Jane Smith", a dropdown arrow, and a pencil icon. To the right is a search bar labeled "Search Studies". Below the header, there's a section titled "Enrolled Studies" with a sub-section "Shortcuts" containing "Request Transfer" and "Consent/Opt-Ins". Another section titled "Notifications (0)" says "No new notifications." In the center, there's a card for the "LGMD2A/Calpainopathy Registry". The card includes the study logo, "English" language selection, "Consented" status with a green checkmark, and a button indicating "1 pending surveys". A green arrow points from the text "Haga clic en el estudio correspondiente." to this card.

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



The screenshot shows the study details page for the "LGMD2A/Calpainopathy Registry". At the top, there's a header with "Back to study list", a profile picture for Jane Smith, her name "Jane Smith", a dropdown arrow, and a pencil icon. Below the header, there's a date "5-May-2000". The main content area shows the study title "LGMD2A/Calpainopathy Registry". Underneath it, there's a "Surveys" section with a yellow button labeled "1 pending". To the right of this are three buttons: "All (1)", "Complete (0)", and "Pending (1)". Below the survey count, there's a progress bar showing "0%" and the status "Not Started". On the far right, there's a blue button with a pencil icon labeled "Take Survey". A green arrow points from the text "Haga clic en “Responder encuesta” para una encuesta disponible." to the "Take Survey" button.

## 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 participant's profile at the top: Jane Smith (5-May-2000). Below it, the study "LGMD2A/Calpainopathy Registry" is listed. Under "Surveys", there is one completed survey titled "Getting Started" (Completed on 28-Mar-2025) with a green checkmark icon. To the right of the survey list, there are two buttons: "View Responses" (with a green arrow pointing to it) and "Reports". At the top right, there are filters for "All (7)", "Complete (1)", and "Pending (6)".

## 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.

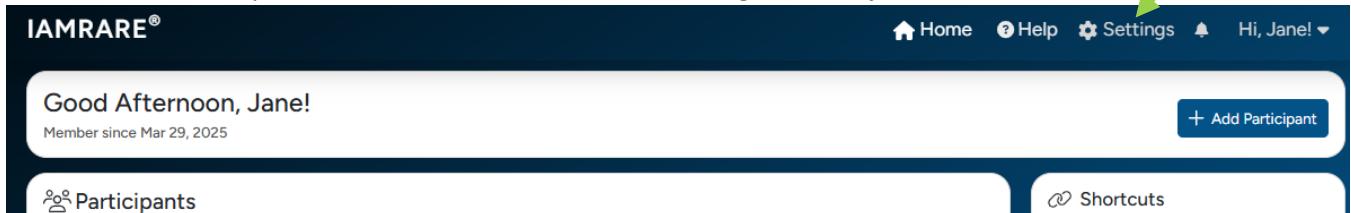
The screenshot shows the participant's profile at the top: Jane Smith (5-May-2000). Below it, the section "Enrolled Studies" is shown with a green arrow pointing to the "Back to participant list" link. A message says: "Click a study to see the list of surveys. Click the ⓘ icon to see more information about the study. Click "Search Studies" above to find additional studies." To the right, there is a "Shortcuts" section with "Request Transfer" and "Consent/Opt-Ins" buttons, each with a green arrow pointing to it. A "Search Studies" button is also visible at the top right.

- 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 participant's profile at the top: Jane Smith (5-May-2000). Below it, the section "Consents/Opt-Ins" is shown with a green arrow pointing to the "Back to study list" link. A table lists a single consent record: "LGMD2A/Calpainopathy Registry" (Study Name), "Consented" (Consent Status), "28-Mar-2025" (Consented On). To the right of the table, there are three buttons: "View Consent" (with a green arrow pointing to it), "Revoke" (with a green arrow pointing to it), and "Opt-Ins".

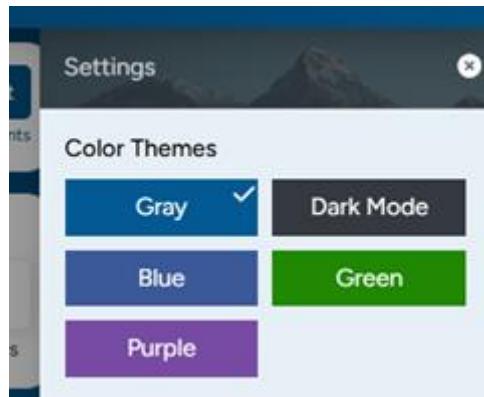
## Configuración del modo oscuro

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

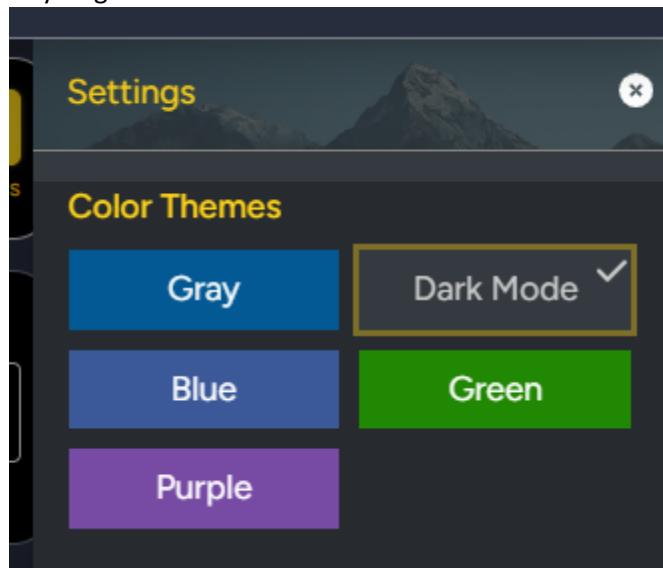


The screenshot shows the IAMRARE platform's main dashboard. At the top, there is a dark blue header bar with the text "IAMRARE®" on the left and navigation links for "Home", "Help", "Settings" (which has a green arrow pointing to it), and "Hi, Jane! ▾" on the right. Below the header, a white box displays a greeting "Good Afternoon, Jane!" and the text "Member since Mar 29, 2025". To the right of this box is a button "+ Add Participant". In the center of the dashboard, there are two sections: "Participants" (with a count of 205) and "Shortcuts".

- Paso 2: Seleccione Modo oscuro.



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

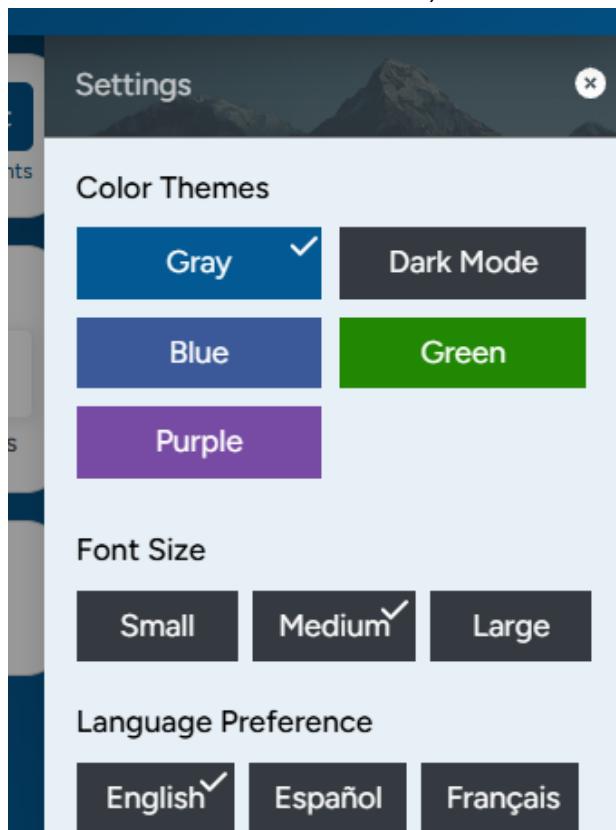


## Ajustes de visualización

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

The screenshot shows the IAMRARE platform's main dashboard. At the top, there is a dark header bar with the IAMRARE logo, a navigation menu with links for Home, Help, Settings, and a user profile for 'Hi, Jane!', and a notification bell icon. Below the header, a banner displays a welcome message 'Good Afternoon, Jane!' and the text 'Member since Mar 29, 2025'. To the right of the banner is a button labeled '+ Add Participant'. Below the banner, there are two tabs: 'Participants' and 'Shortcuts'. A green arrow points from the bottom right towards the 'Settings' link in the top right corner of the header.

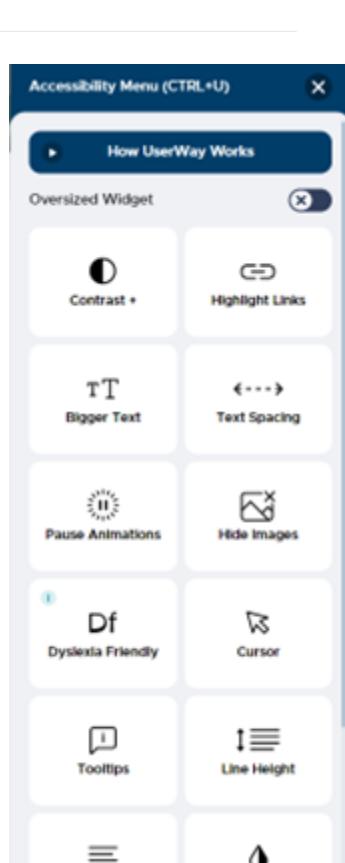
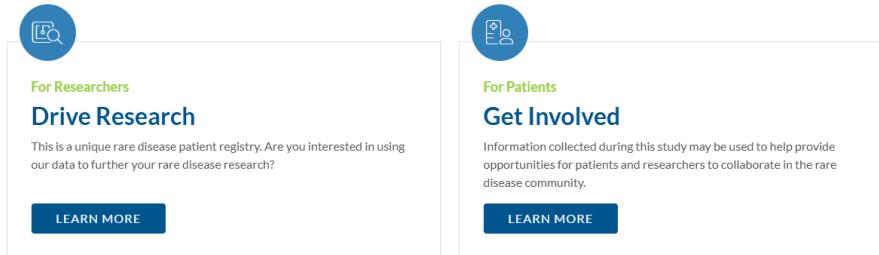
- Paso 2: Seleccione un tema de color, un tamaño de fuente o una preferencia de idioma.



- 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](https://lgmd2a.iamrare.org)) usando un menú de accesibilidad. Haga clic en el ícono 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 'Have a question?' pop-up window. At the top, there are 'Home' and 'Help' buttons. Below that, the title 'Have a question?' is displayed. A message instructs users to enter their message and click submit. It also mentions that they cannot provide medical advice or answer specific medical questions, and directs them to visit the NORD website at [rarediseases.org](http://rarediseases.org). The 'Inquiry Type' field is labeled with a red asterisk and contains a dropdown menu with the placeholder '---Select Inquiry Type---'. The 'Message' field is also labeled with a red asterisk and contains a text area with the placeholder 'Your message'. At the bottom, there are 'Cancel' and 'Submit' buttons.

- 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 study dashboard. On the left, there are three survey buttons: 'View Responses 1', 'Reports', and 'Take Survey'. In the center, there is a large button labeled 'Take Survey'. On the right, there is a section for the 'Coalition to Cure Calpain 3' study. It includes the study logo, the name 'Coalition to Cure Calpain 3', the website 'CureCalpain3.org', and contact information: Jennifer Levy (Phone: 203-429-4383), E-mail (Registry@CureCalpain3.org), IRB E-mail (info@northstarreviewboard.org), and Social Media links for Facebook, Twitter, and Instagram.