



Guide de l'utilisateur du LGMD2A/Calpainopathy Registry

Créez un compte

- Étape 1 : Lisez les conditions générales et la politique de confidentialité et confirmez les déclarations fournies. Lorsque vous en avez terminé avec cette page, cliquez sur « Suivant ».

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

- Étape 2 : Saisissez vos renseignements personnels dans les espaces prévus à cet effet. Lorsque vous en avez terminé avec cette page, cliquez sur « Suivant ».

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Terms & Conditions Contact Info Notifications Review & Submit Confirmation

Country of Residence *

First Name * Last Name *

E-mail *

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- Étape 3 : Indiquez si vous souhaitez être contacté(e) par NORD au sujet des études disponibles. Lorsque vous en avez terminé avec cette page, cliquez sur « Suivant ».

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

Yes No

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- Étape 4 : Sélectionnez « Suivant » pour déclencher l'envoi d'un lien d'activation par courriel afin de terminer l'inscription.

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

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- Étape 5 : Cliquez sur le lien qui vous a été envoyé par courriel électronique. Veuillez vérifier votre dossier Indésirables ou Spam si vous ne voyez pas ce courriel. Vous accéderez à l'écran suivant dans un nouvel onglet de votre navigateur. Définissez votre mot de passe et cliquez sur « Envoyer ».

E-mail Validation

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

Password

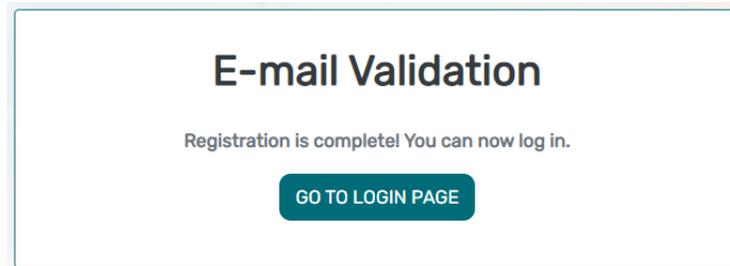
A password must be at least 8 characters long: ✘

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

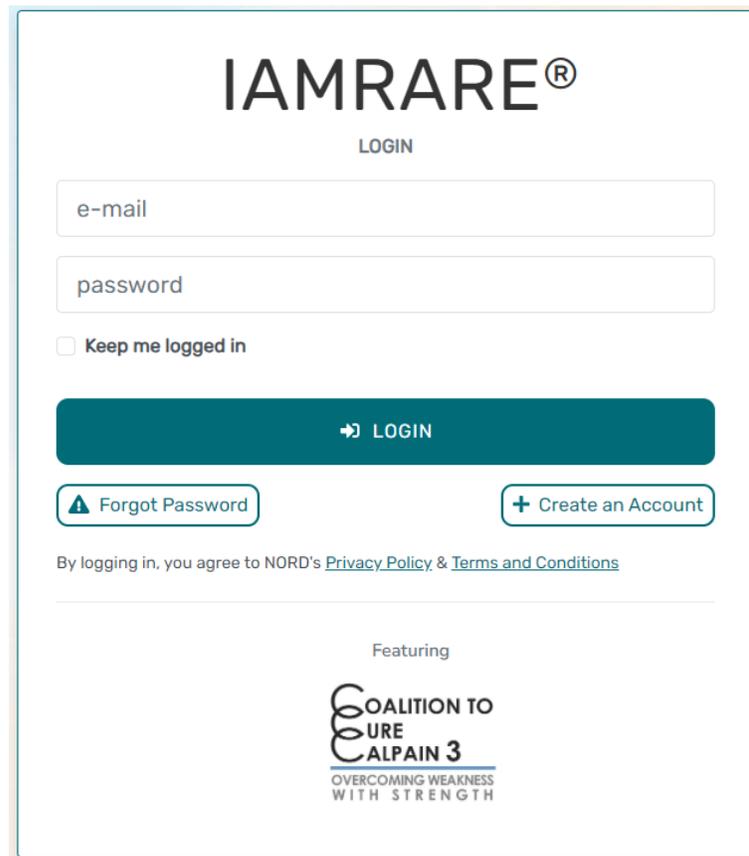
Repeat Password

[SUBMIT](#)

- Étape 6 : La validation est maintenant terminée. Sélectionnez « Afficher la page de connexion ».



- Étape 7 : Connectez-vous en utilisant votre adresse électronique et votre nouveau mot de passe.



Ajouter un participant

- Étape 1 : Pour commencer, cliquez sur Créer un nouveau profil.

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.

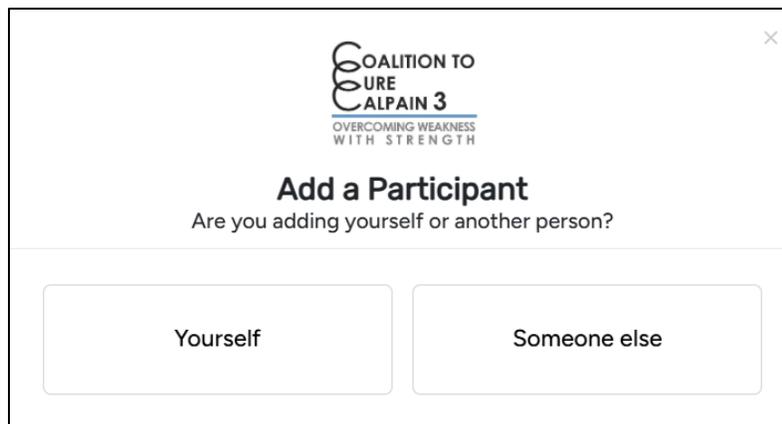
If you are transferring a record from another IAMRARE account, click
on the **Transfer a Record** button below.

Transfer a Record

Create New Profile

Don't show this again

- Étape 2 : Sélectionnez la personne sur laquelle vous allez fournir des informations.



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WITH STRENGTH

Add a Participant

Are you adding yourself or another person?

Yourself

Someone else

- Étape 3 : Complétez les renseignements relatifs au Participant.

Add Participant [X]

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 ? * ⓘ

Donnez votre consentement à l'étude

- Étape 1 : Cliquez sur « Oui, remplir le formulaire de consentement pour ce participant ».

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?

- Étape 2 : Faites défiler vers le bas et lisez attentivement le formulaire de consentement. Une fois la chaque page terminée, cliquez sur le bouton « Suivant ». Après avoir cliqué sur « Suivant » et avoir accédé au formulaire d'autorisation, lisez attentivement les déclarations. Si vous êtes d'accord pour participer à l'étude, veuillez lire chaque déclaration et donner votre consentement. Après avoir coché les cases, cliquez sur « Suivant ».

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, LMGD1, and LMGDD4 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.

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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.

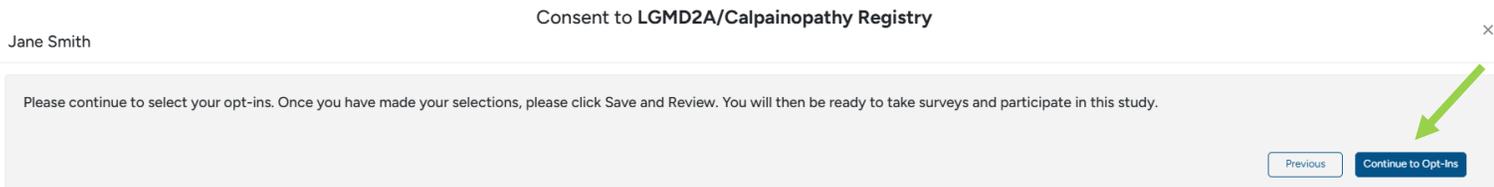
I wish to provide the Study Participant's research data to the LGMD2A/Calpainopathy Registry for the purposes described above under Study Aims.

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.

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- Étape 3 : Après avoir cliqué sur « Suivant » et atteint la page de remerciement, cliquez sur « Poursuivre vers les options de participation ».



- Étape 4 : Après avoir cliqué sur « Poursuivre vers les options de participation », lisez attentivement les options. Si vous souhaitez recevoir des informations sur le sujet, cochez la case et cliquez sur « Enregistrer et vérifier ».

Opt-Ins for LGMD2A/Calpainopathy Registry

Select Opt-Ins for this study

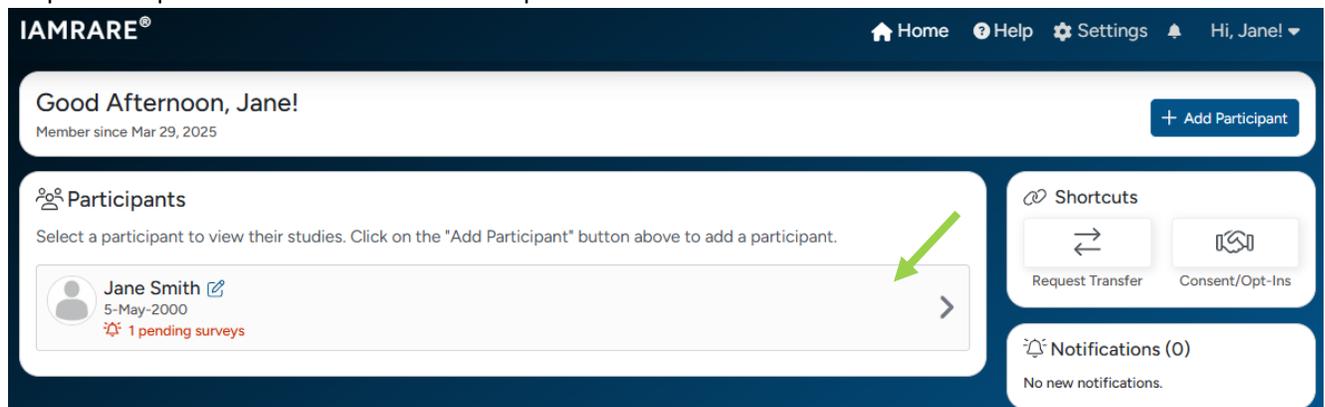
- Interest in hearing about relevant clinical trials
- Interest in donating specimens or DNA (biobanking) for future research
- Interest in genetic testing
- If eligible, I have interest in receiving **Coalition to Cure Calpain 3** merchandise that would be sent via electronic or postal mail
- Interest 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

- Étape 5 : Une fois que vous avez vérifié votre consentement, cliquez sur « Fermer ». Vous pourrez alors commencer à répondre à des enquêtes.

Répondre à des enquêtes

- Étape 1 : Cliquez sur le nom de votre Participant.



- Étape 2 : Cliquez sur l'étude appropriée.

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.

LGMD2A/Calpainopathy Registry **English** **i**

Coalition to Cure Calpain 3

✓ Consented

🔔 1 pending surveys

Shortcuts

Request Transfer Consent/Opt-Ins

Notifications (0)

No new notifications.

- Étape 3 : Cliquez sur « Répondre à l'enquête » pour accéder à une enquête 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](#)

Afficher les réponses et les rapports

- Étape 1 : Après avoir répondu à une enquête, vous pourrez consulter vos réponses à cette enquête ainsi que les graphiques pour toutes les questions programmées pour afficher des graphiques. Cliquez sur « Voir les réponses » pour voir l'enquête terminée. Cliquez sur « Rapports » pour afficher les graphiques disponibles.

The screenshot shows a user profile for Jane Smith (5-May-2000) at the top. Below, the study title 'LGMD2A/Calpainopathy Registry' is displayed. A 'Surveys' section indicates '6 pending' surveys. A filter bar shows 'All (7)', 'Complete (1)', and 'Pending (6)'. A survey card for 'Getting Started' (Completed on 28-Mar-2025) is shown with a green checkmark. Two green arrows point to the 'View Responses (1)' and 'Reports' buttons on the right side of the card.

Afficher le consentement et les options

- Étape 1 : Après avoir donné votre consentement à l'étude, vous pouvez consulter le document de consentement à tout moment. Naviguez jusqu'à la page des Études avec inscription. Cliquez ensuite sur « Consentement/Options de participation » pour voir le document de consentement et les options de participation

The screenshot shows the 'Enrolled Studies' page for Jane Smith. It includes a 'Back to participant list' link at the top left, a 'Search Studies' button at the top right, and a 'Shortcuts' section with 'Request Transfer' and 'Consent/Opt-Ins' buttons. A green arrow points to the 'Back to participant list' link, and another points to the 'Search Studies' button.

- Étape 2 : Vous pouvez révoquer votre consentement à tout moment en cliquant sur « Révoquer ». Vous pouvez également modifier vos options de participation en cliquant sur « Options de participation ».

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

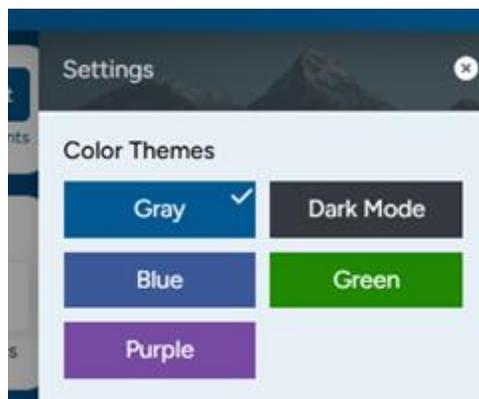
Study Name	Consent Status	Consented On	Actions
LGMD2A/Calpainopathy Registry	✓ Consented	28-Mar-2025	View Consent Revoke Opt-Ins

Paramètre de mode sombre

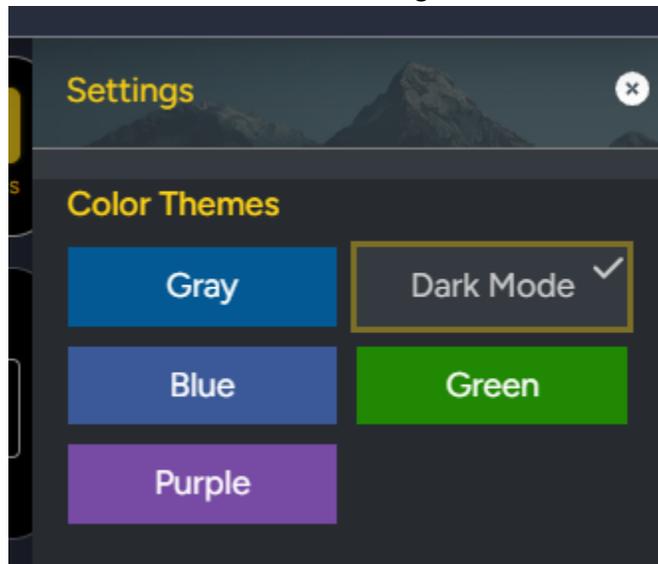
- Étape 1 : Vous pouvez visualiser la plateforme en mode sombre. Cliquez d'abord sur Paramètres



- Étape 2 : Sélectionnez le Mode foncé.



- Étape 3 : Quittez le menu Paramètres et votre choix sera sauvegardé.

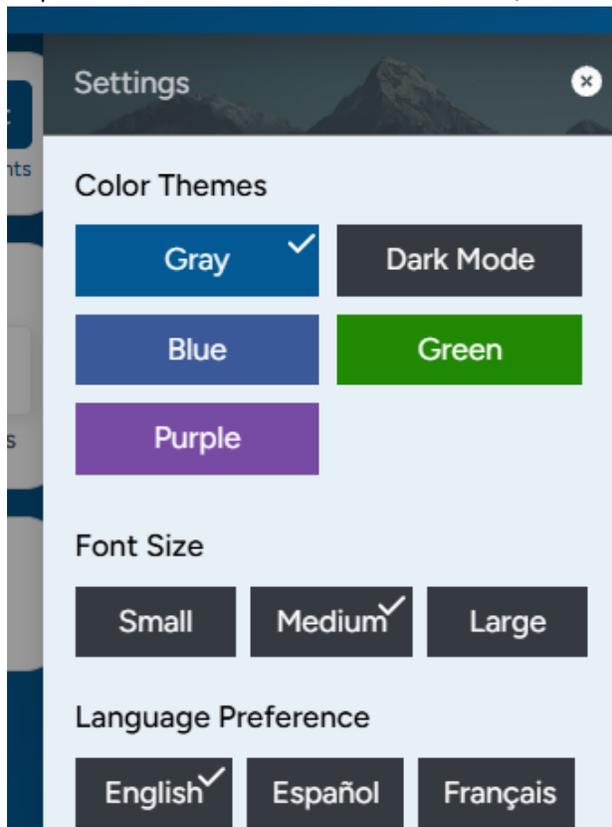


Paramètres d'affichage

- Étape 1 : Vous pouvez modifier les paramètres d'affichage de la plateforme. Cliquez d'abord sur Paramètres.



- Étape 2 : Sélectionnez un thème de couleur, une taille de police ou une langue.

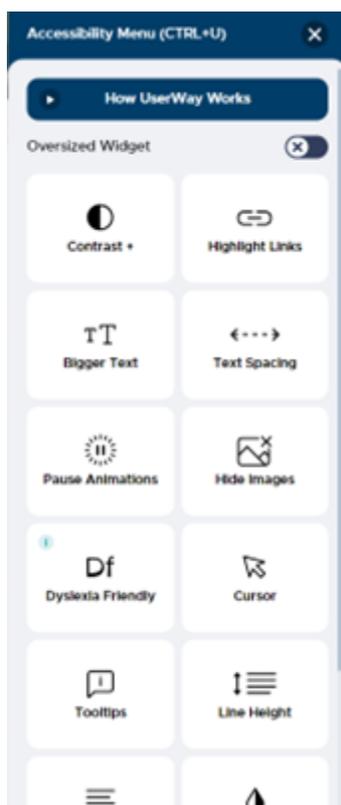


- Étape 3 : Quittez le menu Paramètres et votre choix sera sauvegardé.

Visibilité du microsite

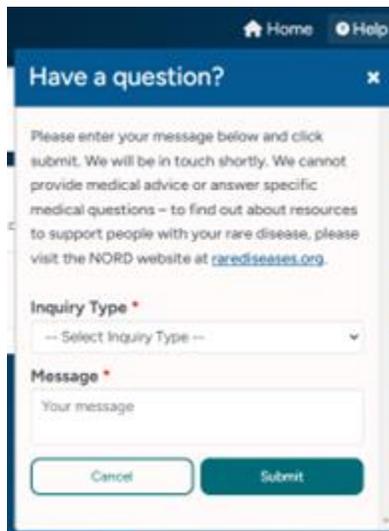
- Étape 1 : Vous pouvez modifier la façon dont vous visualisez le microsite [lgmd2a.iamrare.org] depuis le menu Accessibilité. Cliquez sur l'icône d'une personne en bas de l'écran. Vous pouvez modifier les paramètres tels que le contraste, la taille et l'espacement du texte.

 <p>For Researchers Drive Research</p> <p>This is a unique rare disease patient registry. Are you interested in using our data to further your rare disease research?</p> <p>LEARN MORE</p>	 <p>For Patients Get Involved</p> <p>Information collected during this study may be used to help provide opportunities for patients and researchers to collaborate in the rare disease community.</p> <p>LEARN MORE</p>
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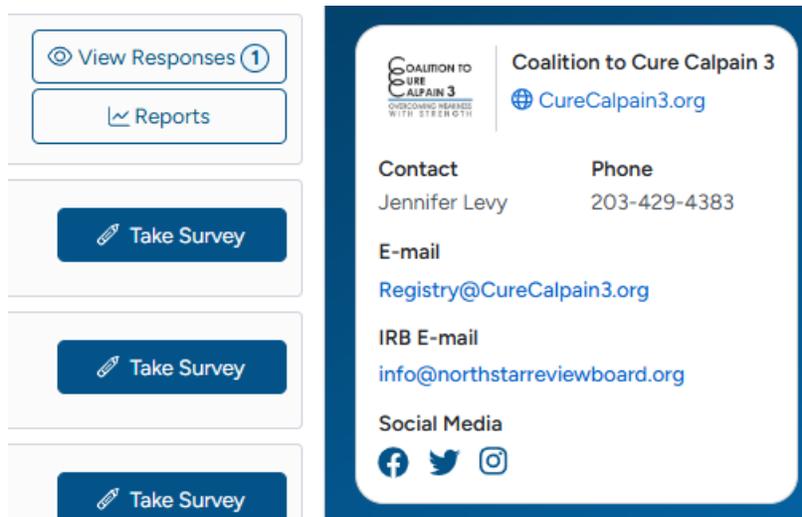
Vous avez besoin d'aide ?

- Étape 1 : Si vous avez besoin d'aide lors de l'utilisation de la plateforme, cliquez sur Aider.
- Étape 2 : Sélectionnez un type de demande et tapez un message.



The screenshot shows a mobile application interface with a blue header containing 'Home' and 'Help' icons. Below the header is a white box with a blue border titled 'Have a question?'. Inside the box, there is a paragraph of text: 'Please enter your message 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.' Below the text is a dropdown menu labeled 'Inquiry Type *' with the option '-- Select Inquiry Type --'. Underneath is a text input field labeled 'Message *' with the placeholder 'Your message'. At the bottom of the form are two buttons: 'Cancel' and 'Submit'.

- Étape 3 : Cliquez sur « Envoyer ».
- Vous pouvez également contacter directement le commanditaire de l'étude en utilisant les coordonnées figurant sur votre tableau de bord ou sur le site web de l'étude.



The image shows two parts of a user interface. On the left is a vertical menu with four items: 'View Responses 1', 'Reports', and two 'Take Survey' buttons. On the right is a contact information card for the 'Coalition to Cure Calpain 3'. The card features the organization's logo and name, the website 'CureCalpain3.org', and contact details for Jennifer Levy, including a phone number (203-429-4383), an email address (Registry@CureCalpain3.org), and an IRB email address (info@northstarreviewboard.org). It also includes social media icons for Facebook, Twitter, and Instagram.