


LGS-CORE Study 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”.


Featuring
LGS FOUNDATION
LENNOX GASTAUT SYNDROME


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

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

The screenshot shows a registration form titled "Registration" for the LGS Foundation (Lennox Gastaut Syndrome). The form is part of a five-step process: Terms & Conditions, Contact Info, Notifications, Review & Submit, and Confirmation. The "Contact Info" step is currently active, indicated by a blue bar under the "Contact Info" icon. The form fields include: "Country of Residence" (a dropdown menu), "First Name" (a text input field), "Last Name" (a text input field), and "E-mail" (a text input field). At the bottom, there is a "Return to login" link and two buttons: "Previous" and "Next".

- Step 3: 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 same registration form, but now at Step 3. The "Notifications" step is active, indicated by a blue bar under the "Notifications" icon. The form field is: "I am interested in NORD contacting me regarding available studies." (a text input field). Below the field, there are two radio buttons: "Yes" and "No". At the bottom, there is a "Return to login" link and two buttons: "Previous" and "Next".

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

Featuring
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Registration

Terms & Conditions Contact Info Notifications Review & Submit Confirmation

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

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

- 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”.

E-mail Validation

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

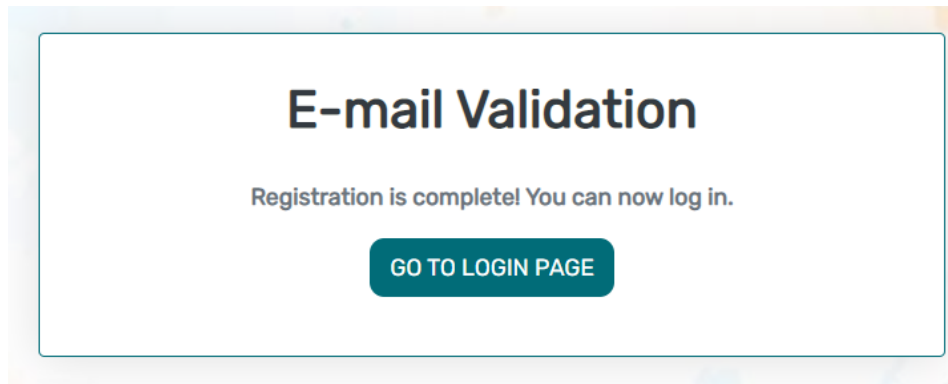
Password

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 ✗

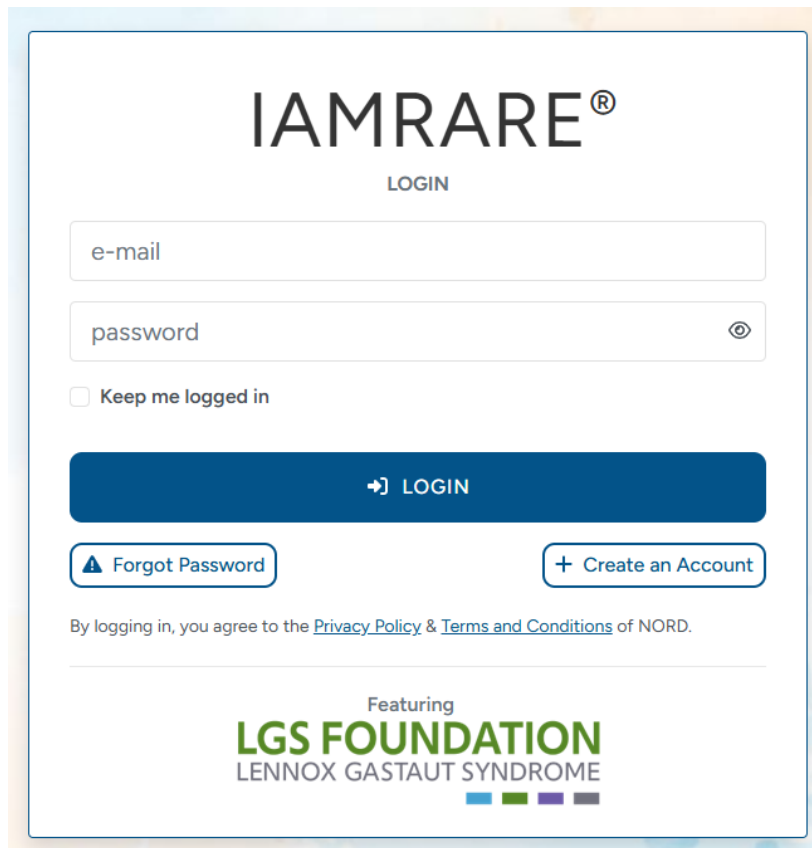
Repeat Password

[SUBMIT](#)

- Step 6: Your validation is now complete. Select “Go to Login Page”.



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



Add a Participant

- Step 1: To start, click Create New Profile.



English ▾

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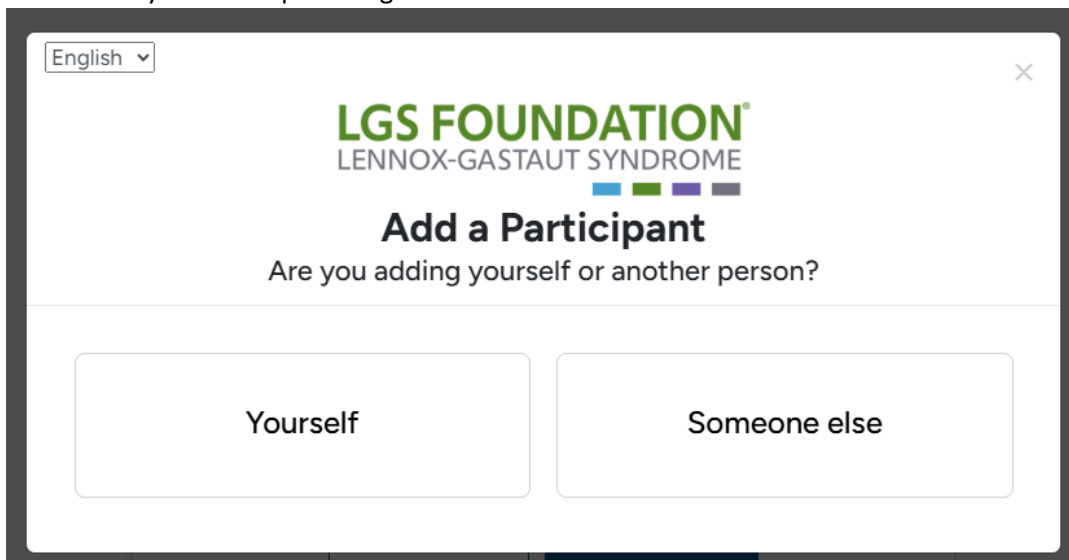
Welcome, Jane!

Welcome to the IAMRARE® program, home of **LGS-CORE Study**.
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](#)

- Step 2: Select who you will be providing information about.



English ▾

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Add a Participant

Are you adding yourself or another person?

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

- Step 3: Fill out the Participant's information.

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* ⓘ [Calendar Icon]

Sex Recorded on Birth Certificate* ⓘ [Dropdown Arrow]

Country of Residence* ⓘ [Dropdown Arrow]

State/Province/Region of Residence* ⓘ

Country of Birth* [Dropdown Arrow]

City/Municipality of Birth*

What Is Your Relationship to ? * ⓘ [Dropdown Arrow]

Consent to the Study

- Step 1: Click on “Yes, complete consent for this participant.”

LGS FOUNDATION
LENNOX-GASTAUT SYNDROME

Thank you for registering your first participant!
Would you like to consent to participate in **LGS-CORE Study?**

- 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.”

Back to the participant list

Consent to LGS-CORE Study

Jane Smith

Consent Overview

Those eligible to participate in our study include:

Legally Authorized Representative: an individual (such as a family member or guardian) who is legally responsible for the healthcare of the Study Participant diagnosed with LGS or LGS-Related DEE. This Study Participant is a minor (child under the age of 18) or an adult who is unable to contribute their own data. The Legally Authorized Representative must also be at least 18 years of age and the age of majority in their state, province or country.

Designated Representative: A legal adult who was the caretaker of an individual who passed away from LGS or LGS-Related DEE. This individual is defined as a spouse, parent, sibling, offspring, close relative, close friend, guardian and/or significant other of the individual who had LGS or LGS-Related DEE and who had knowledge and participated in their medical care. This individual must also be at least 18 years of age and the age of majority in their state, province or country.

Please tell us about the Participant you would like to enroll in this study. *

☐ They are a minor or an adult with LGS or LGS-Related DEE who is unable to contribute their own data. I am currently their caregiver.

☐ They were a patient with LGS or LGS-Related DEE and have passed away. I participated in their medical care.

Next

Consent to LGS-CORE Study

Jane Smith

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

Consent to Participate in the LGS-CORE Study and to Allow Your Data to be Shared for Future Research

Title: LGS and LGS-Related DEE Collaborative Outcomes Registry (LGS-CORE Study)

Principal Investigator: Tracy Dixon-Salazar, PhD

Phone: 718-374-3800

E-mail: research@lgsfoundation.org

Sponsor: LGS Foundation

Key Information

You are invited to take part in a research study for people with Lennox-Gastaut Syndrome (LGS) and LGS-Related Developmental and Epileptic Encephalopathy (DEE) on behalf of the person in your care who is not able to provide their own consent. Your role is called Legally Authorized Representative (LAR). This form will help you decide if you want to participate. You can contact the study staff above if you have any other questions. Their phone number and e-mail address are listed above.

Things you should know:

Previous Next

Consent to LGS-CORE Study

Jane Smith

Authorization

The following statements are intended to:

- Make sure that you have had the time and opportunity to consider whether you want to participate in this registry;
- Have had your questions answered; and
- Agree to participate in the study as described.

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 LGS-CORE Study 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 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 LGS-CORE Study have been answered to my satisfaction, and I understand the purpose of the registry and the risks of participation.

[Previous](#) [Next](#)

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

Consent to LGS-CORE Study

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](#)

- 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 LGS-CORE Study

Select Opt-Ins for this study

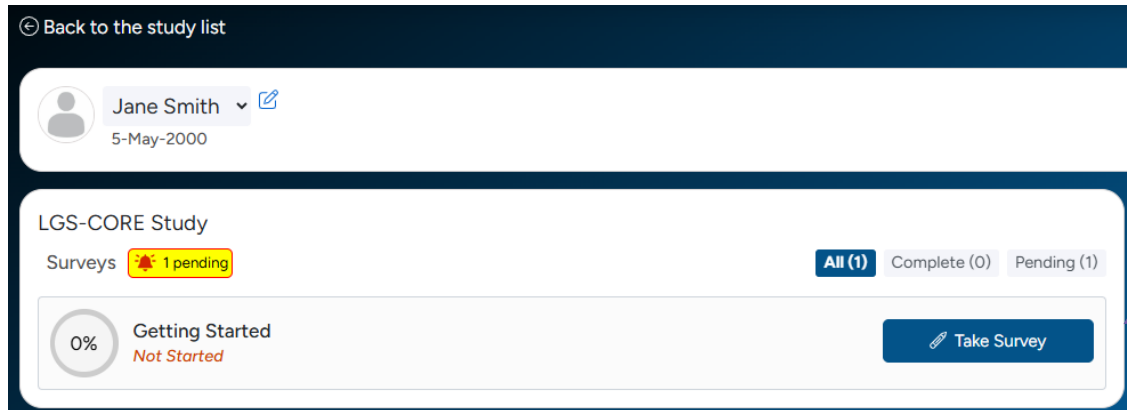
- ☐ Interest in hearing about other studies from [Lennox-Gastaut Syndrome \(LGS\) Foundation](#)
- ☐ Interest in hearing about relevant clinical trials
- ☐ Interest in donating specimens or DNA (biobanking) for future research
- ☐ Interest in genetic testing
- ☐ Interest in learning more about [Lennox-Gastaut Syndrome \(LGS\) Foundation](#)
- ☐ Interest in signing up for a [Lennox-Gastaut Syndrome \(LGS\) Foundation](#) newsletter
- ☐ Support from [Lennox-Gastaut Syndrome \(LGS\) Foundation](#) Ambassador / Care Coordinator
- ☐ If eligible, I have interest in receiving [Lennox-Gastaut Syndrome \(LGS\) Foundation](#) merchandise that would be sent via electronic or postal mail
- ☐ Interest in hearing about family conferences and events run by [Lennox-Gastaut Syndrome \(LGS\) Foundation](#)
- ☐ Support from other Patient Advocacy Groups
- ☐ For US Residents: If eligible, I would like to receive a thank you token that would be sent via electronic or postal mail.
- ☐ I agree to be contacted by [Lennox-Gastaut Syndrome \(LGS\) Foundation](#) regarding their initiatives.
- ☐ Interest in donating tissue, specimens, or DNA (biobanking) for future research
- ☐ Support from the [Lennox-Gastaut Syndrome \(LGS\) Foundation](#) Family Ambassador / Patient Navigator / Community Coordinator
- ☐ Interest in learning about LGS and LGS-Related DEE educational programs and resources from [Lennox-Gastaut Syndrome \(LGS\) Foundation](#)

[Save and Review](#)

- Step 5: Once you've reviewed your consent, click "Close". You will then have access to start taking surveys.

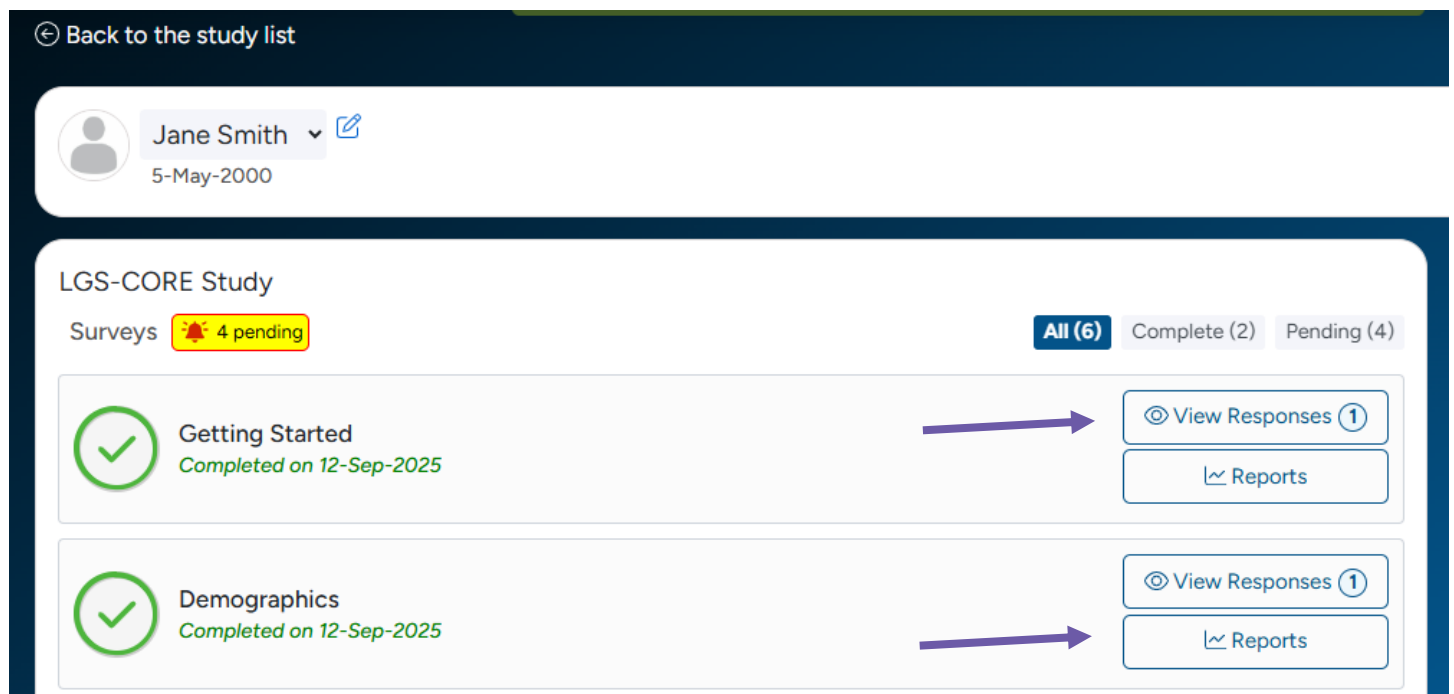
Taking Surveys

- Step 1: Click “Take Survey” for an available 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.



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.

← Back to participant list

Jane Smith
 5-May-2000

Search Studies
Learn about searching for studies

Enrolled Studies
 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.

Shortcuts

Request Transfer
 Consent/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 the study list

Jane Smith
 5-May-2000

Consents/Opt-Ins

Study Name	Consent Status	Consented On	Actions
LGS-CORE Study	✓ Consented	12-Sep-2025	View Consent Revoke Opt-Ins

Dark Mode Settings

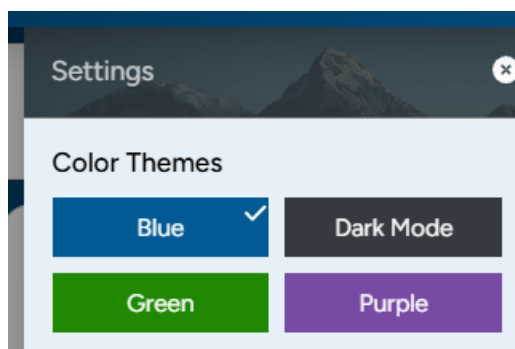
- Step 1: You can view the platform in Dark Mode. First, click Settings.

IAMRARE® Home Help Settings Hi, Jane!

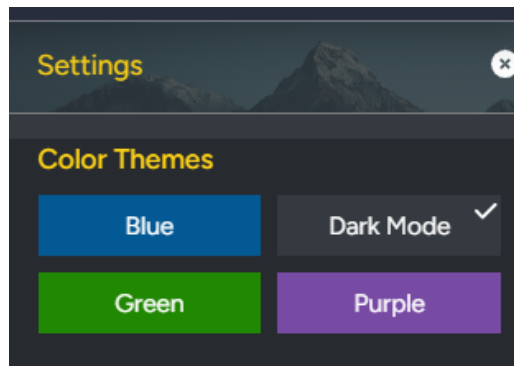
Good Afternoon, Jane!
Member since Nov 16, 2024

Participants
 Shortcuts

- Step 2: Select Dark Mode.



- Step 3: Exit the Settings menu, and your selection will be saved.

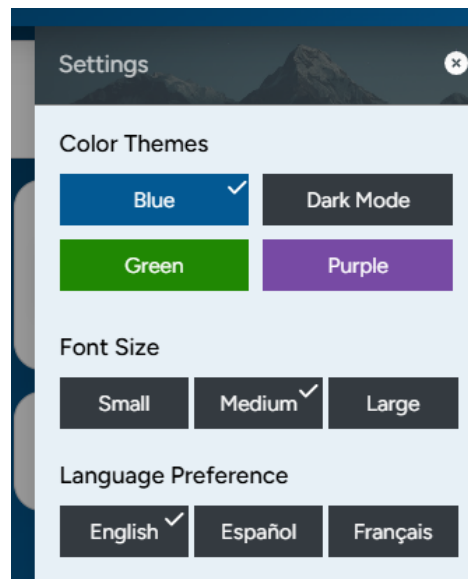


Display Settings

- Step 1: You can change the platform display settings. First, click Settings.




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



- Step 3: Exit the Settings menu, and your selection will be saved.

Microsite Visibility


- Step 1: You can change how you view the microsite [insert URL] using an Accessibility menu. Click the icon of a person at the bottom of the screen. You are able to change the settings such as the contrast, text sizing, and text spacing.



For Researchers

Drive Research


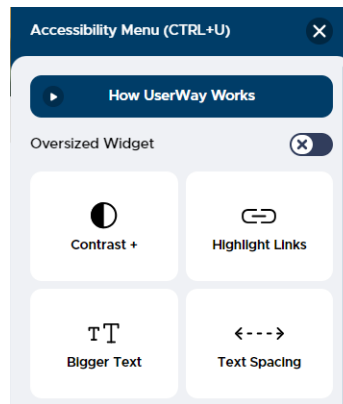
This is a unique rare disease patient registry. Are you interested in using our data to further your rare disease research?



For Patients


Get Involved

Information collected during this study may be used to help provide opportunities for patients and researchers to collaborate in the rare disease community.


A screenshot of a 'Have a question?' form. At the top, there are 'Home' and 'Help' links. The form has a title bar with a close button. The main text asks the user to enter a message and click submit, noting that medical advice cannot be provided. It directs users to visit 'rarediseases.org' for more resources. Below this, there is a dropdown menu for 'Inquiry Type' with the placeholder '-- Select Inquiry Type --'. A text input field for 'Message' is labeled 'Your message'. At the bottom, there are 'Cancel' and 'Submit' buttons.

Need Assistance?

- Step 1: If you need help while using the platform, click Help.
- Step 2: Select an Inquiry Type and type a message.
- 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.



Lennox-Gastaut Syndrome (LGS) Foundation
lgsfoundation.org

Contact
Tracy Dixon-Salazar, PhD

Phone
718-374-3800

E-mail
Research@LGSFoundation.org

IRB E-mail
info@northstarreviewboard.org

Social Media
