

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. *

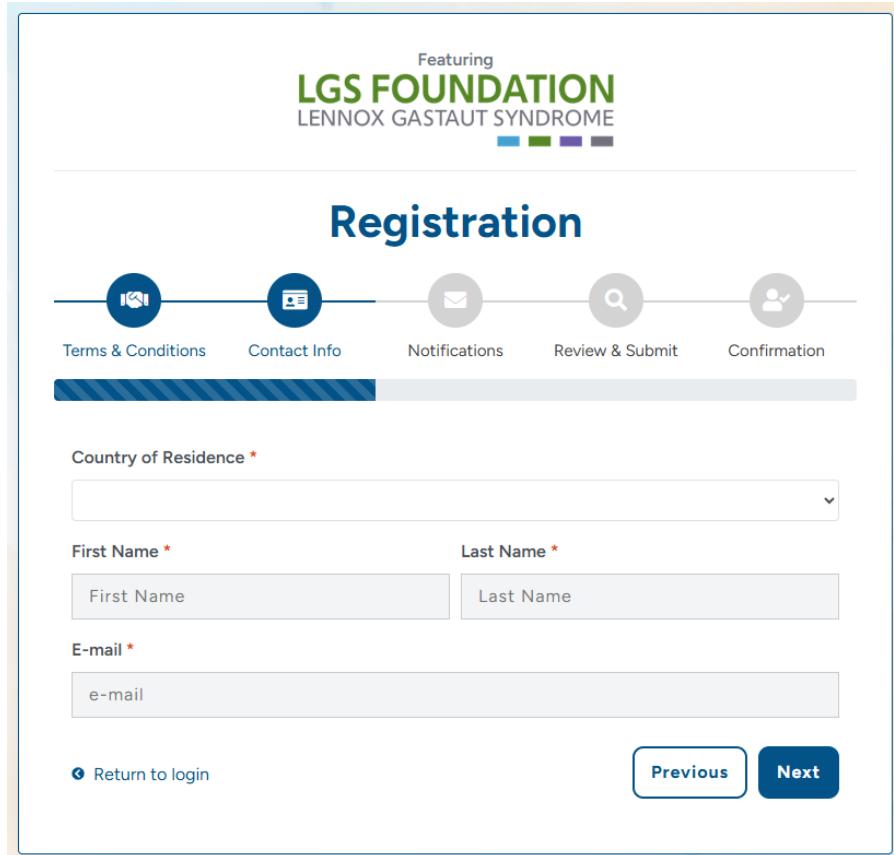
You agree to support the Platform's research activities by providing truthful, appropriate information and to not do anything that will put the Services or the information in the Platform at risk. *

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”.



Featuring
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Registration

Progress:

-  Terms & Conditions
-  Contact Info
-  Notifications
-  Review & Submit
-  Confirmation

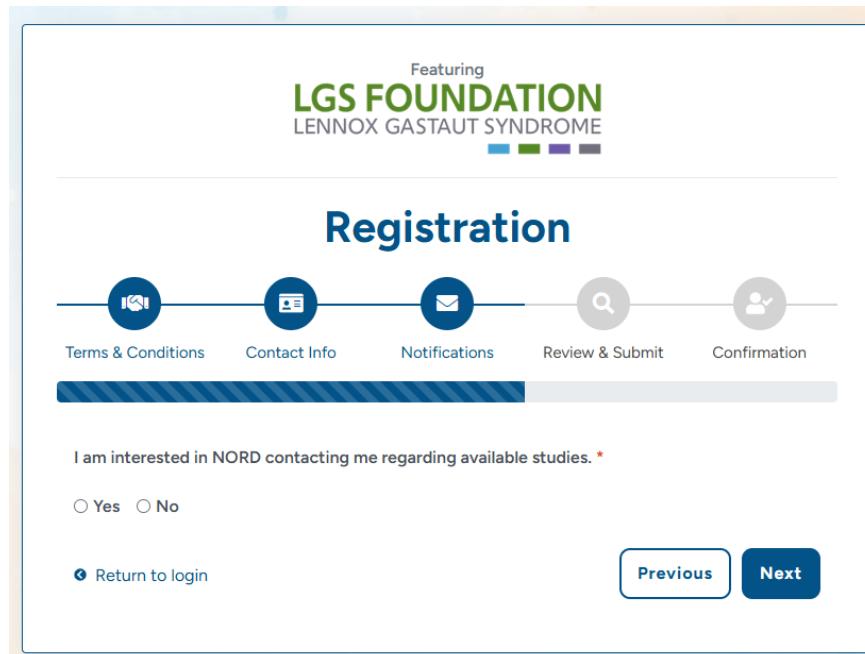
Country of Residence *

First Name * Last Name *

E-mail *

[Return to login](#) [Previous](#) [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”.



Featuring
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LENNOX GASTAUT SYNDROME

Registration

Progress:

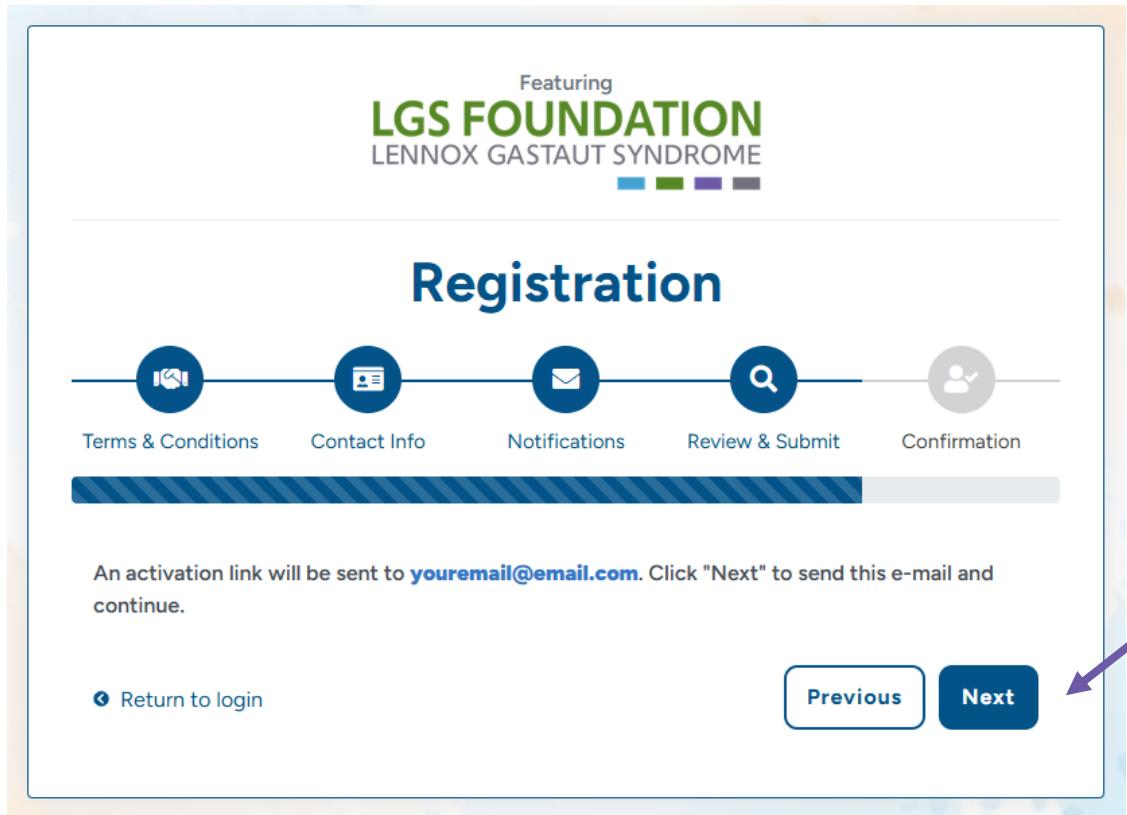
-  Terms & Conditions
-  Contact Info
-  Notifications
-  Review & Submit
-  Confirmation

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

Yes No

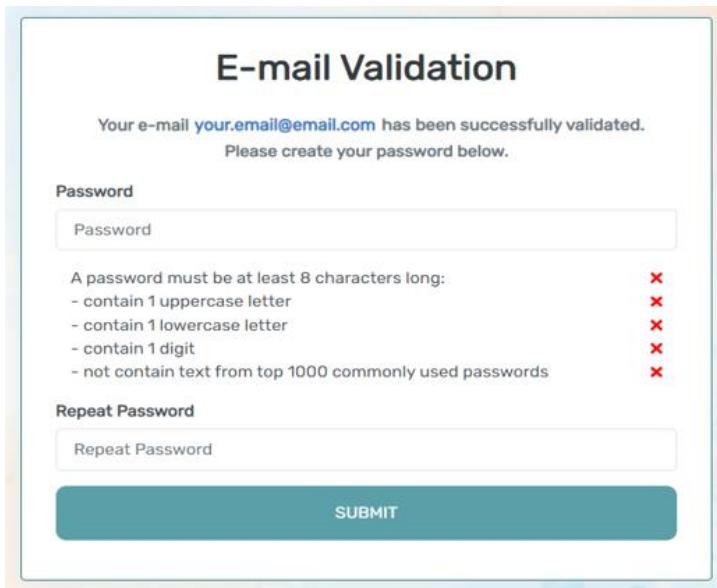
[Return to login](#) [Previous](#) [Next](#)

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



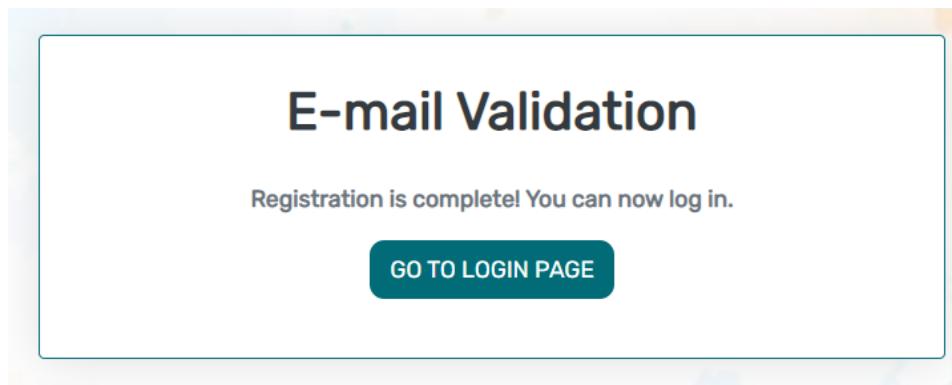
The screenshot shows the 'Registration' step of the LGS Foundation registration process. At the top, the LGS Foundation logo is displayed with the text 'Featuring LGS FOUNDATION LENNOX GASTAUT SYNDROME'. Below the logo is a horizontal navigation bar with five steps: 'Terms & Conditions', 'Contact Info', 'Notifications', 'Review & Submit', and 'Confirmation'. The 'Notifications' step is highlighted with a blue circle and a checkmark icon. A progress bar below the navigation bar shows the user is on step 4 of 5. A message in the center of the screen states: 'An activation link will be sent to youremail@email.com. Click "Next" to send this e-mail and continue.' Below this message are three buttons: 'Return to login', 'Previous', and a large 'Next' button. A purple arrow points to the 'Next' button.

- 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”.

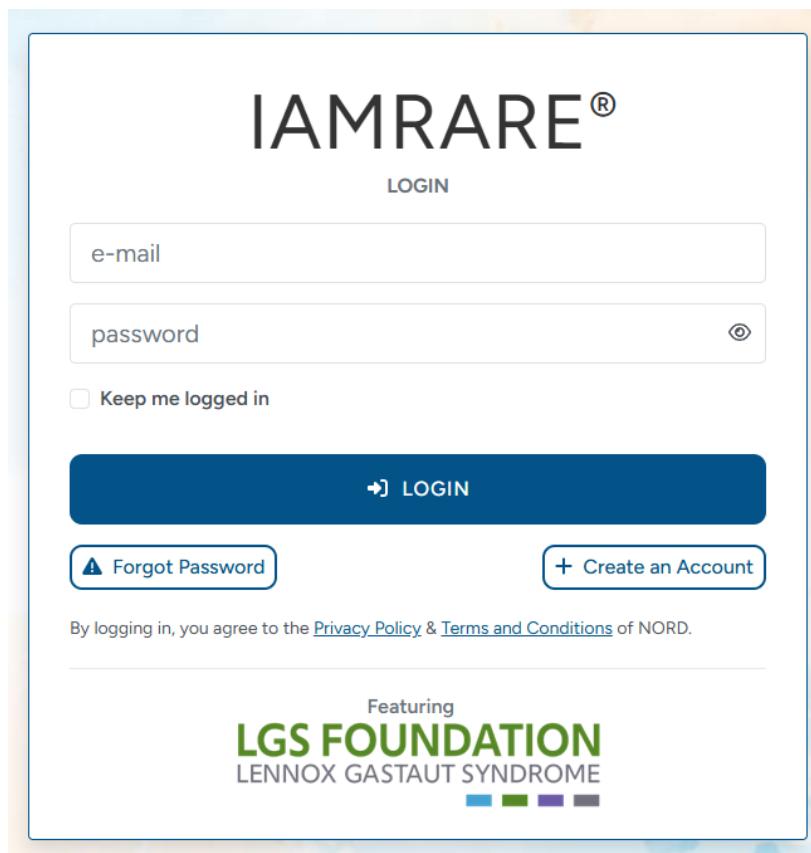


The screenshot shows the 'E-mail Validation' step. The title 'E-mail Validation' is at the top. Below it, a message says: 'Your e-mail your.email@email.com has been successfully validated. Please create your password below.' There are two input fields: 'Password' and 'Repeat Password'. Below the 'Password' field is a list of validation rules with red 'X' marks: 'A password must be at least 8 characters long.' (X), '- contain 1 uppercase letter' (X), '- contain 1 lowercase letter' (X), '- contain 1 digit' (X), and '- not contain text from top 1000 commonly used passwords' (X). A large 'SUBMIT' button is at the bottom.

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

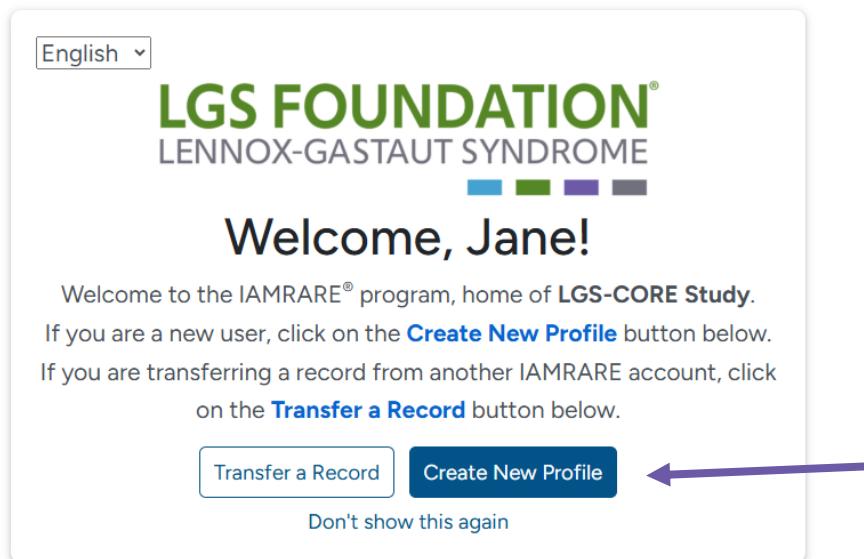


- Step 7: Log in using your new e-mail and password.

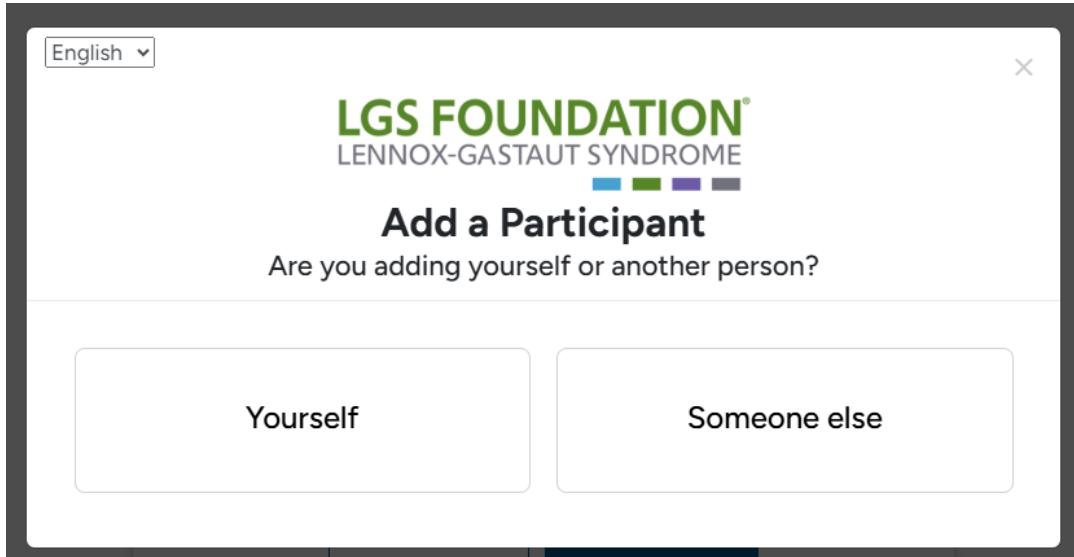


Add a Participant

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



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



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

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 * mm/dd/yyyy

Sex Recorded on Birth Certificate * Type 'NA' if none

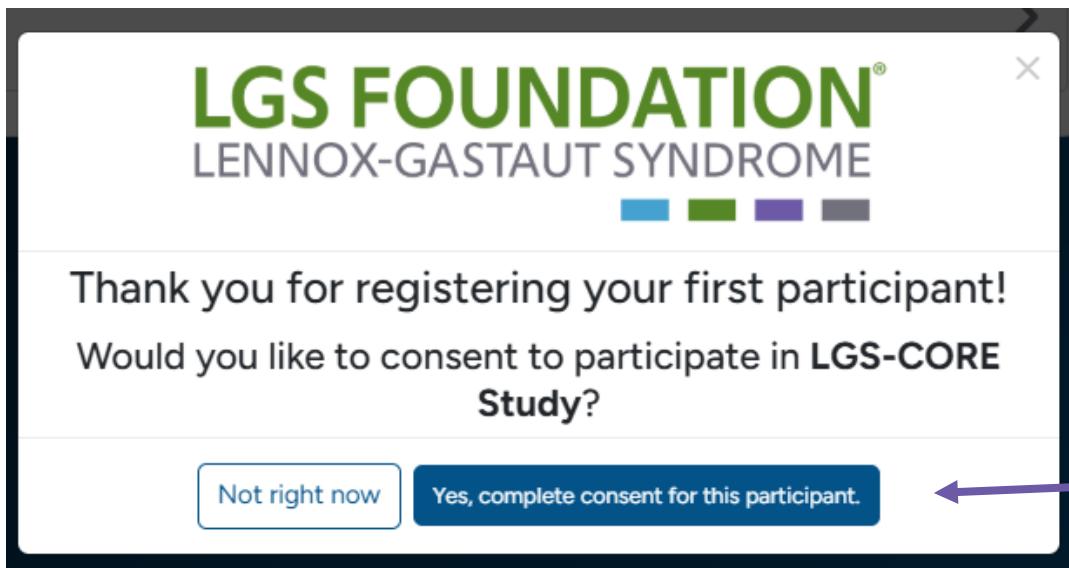
Country of Residence* State/Province/Region of Residence * Type 'NA' if none

Country of Birth* City/Municipality of Birth* City/Municipality of Birth

What Is Your Relationship to ? * Choose relationship

Consent to the Study

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



- 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 X

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 X

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

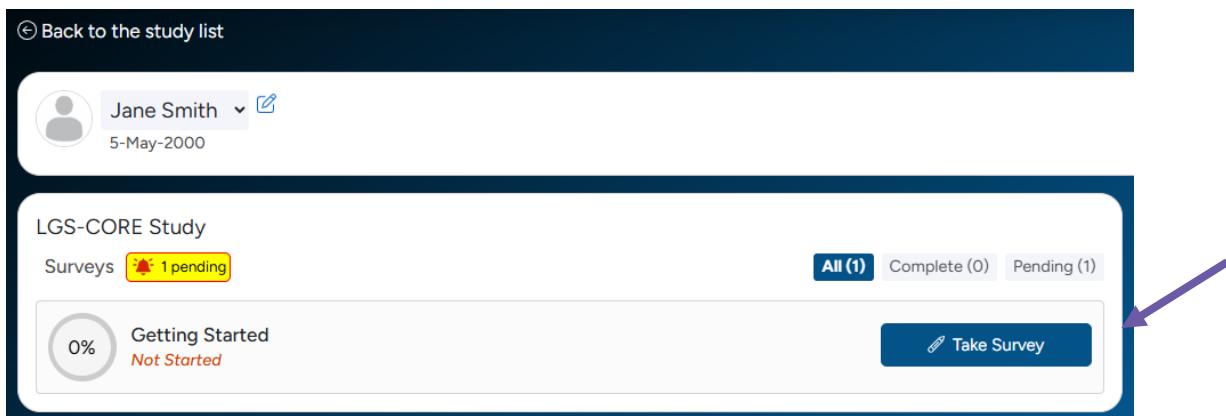
Interest in learning about LGS and LGS-Related DEE educational programs and resources from [Lennox-Gastaut Syndrome \(LGS\) Foundation](#)

[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.



Back to the study list

Jane Smith 5-May-2000

LGS-CORE Study

Surveys 1 pending

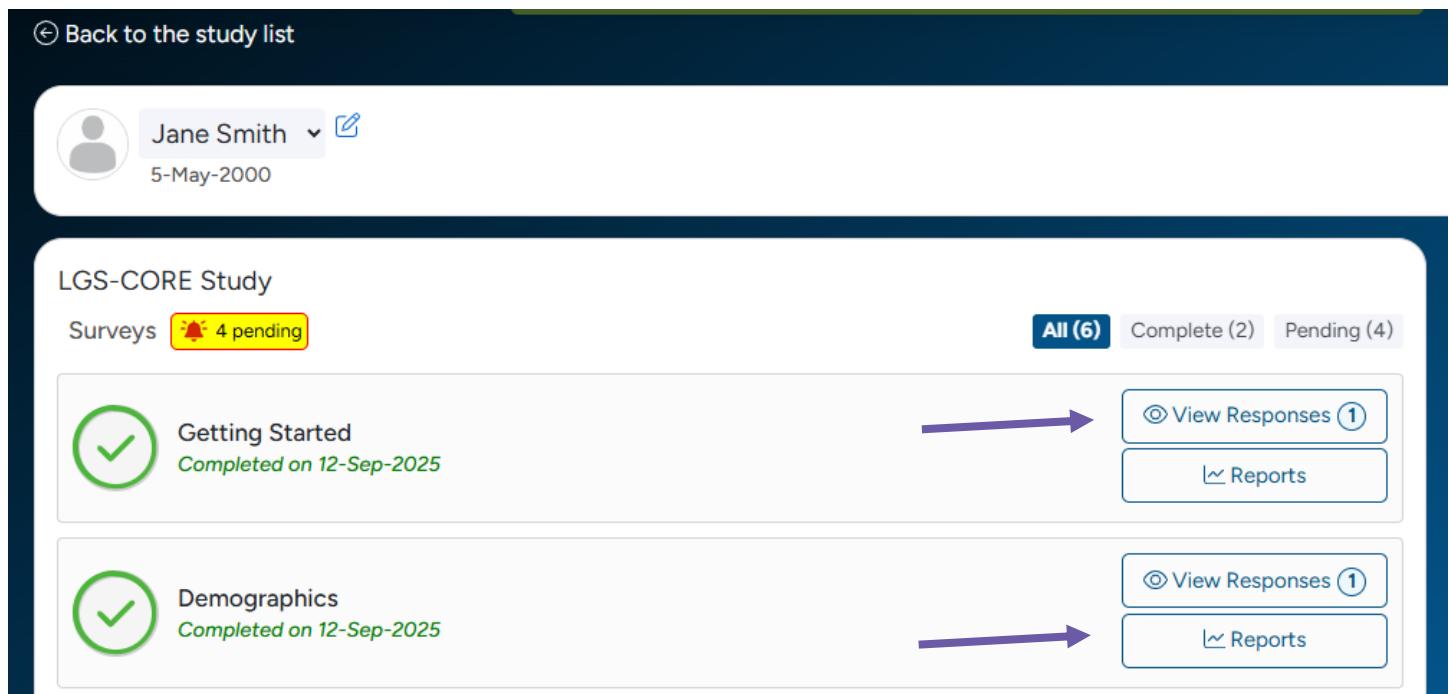
All (1) Complete (0) Pending (1)

0% Getting Started Not Started

Take 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.



Back to the study list

Jane Smith 5-May-2000

LGS-CORE Study

Surveys 4 pending

All (6) Complete (2) Pending (4)

Getting Started Completed on 12-Sep-2025

Demographics Completed on 12-Sep-2025

View Responses (1)

Reports

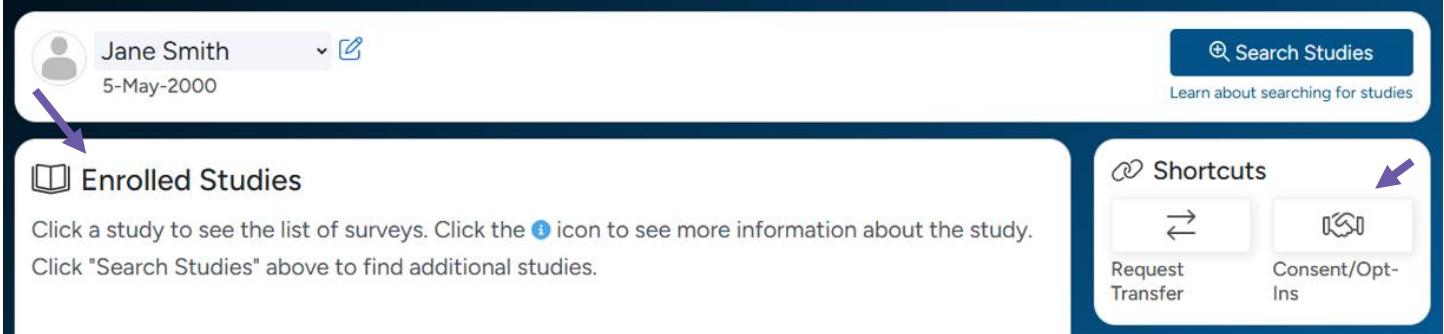
View Responses (1)

Reports

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

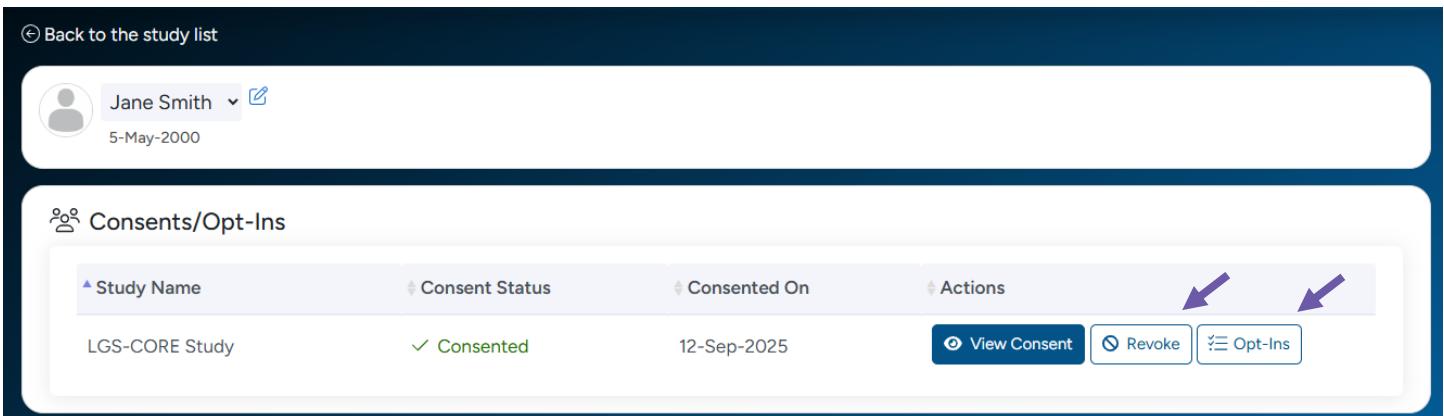
Enrolled Studies

Click a study to see the list of surveys. Click the *info* 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.



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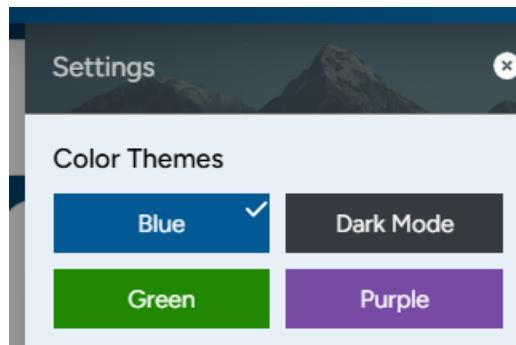
Good Afternoon, Jane!
Member since Nov 16, 2024

Add Participant

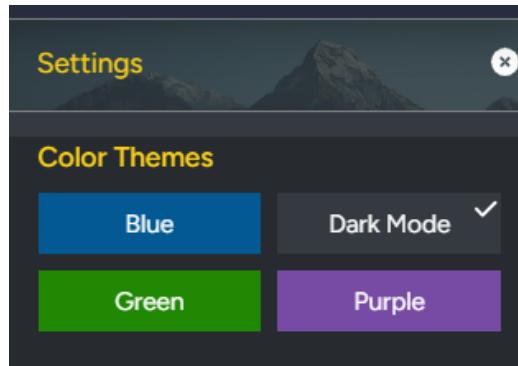
Participants

Shortcuts

- Step 2: Select Dark Mode.



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



Display Settings

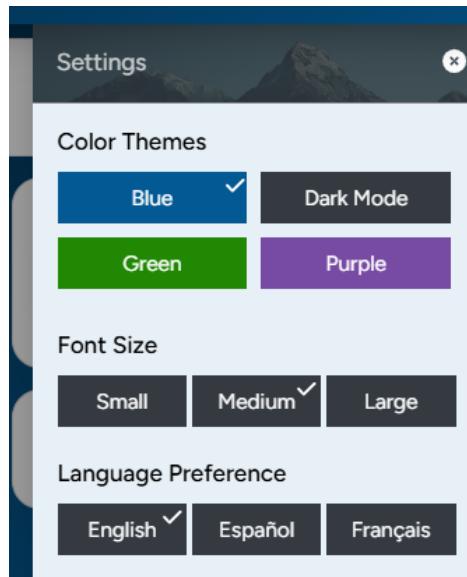
- Step 1: You can change the platform display settings. First, click Settings.

Good Afternoon, Jane!
Member since Nov 16, 2024

+ Add Participant

Participants Shortcuts

- 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?

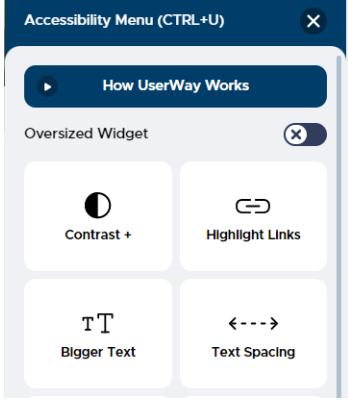


For Patients

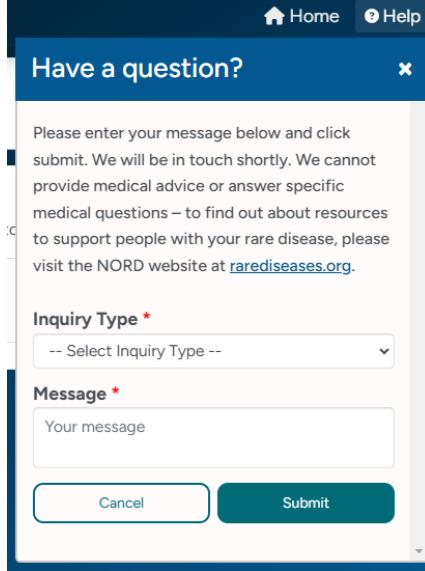
Get Involved

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





The screenshot shows the 'Accessibility Menu (CTRL+U)' with the title 'How UserWay Works'. It includes an 'Oversized Widget' toggle, four buttons: 'Contrast +' (with a circular icon), 'Highlight Links' (with a link icon), 'Bigger Text' (with a text icon), and 'Text Spacing' (with a text icon).



The screenshot shows a 'Have a question?' form. It includes a 'Home' link, a 'Help' link, and a title 'Have a question?'. The form asks: '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'. It has fields for 'Inquiry Type' (a dropdown menu) and 'Message' (a text area), and buttons for 'Cancel' and 'Submit'.

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.

LGS FOUNDATION
LENNOX GASTAUT SYNDROME



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



