




The Necrotizing Enterocolitis (NEC) Registry 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


Building a world without NEC


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”.

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NEC REGISTRY
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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](#)

- 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

NEC REGISTRY
Building a world without NEC

Registration

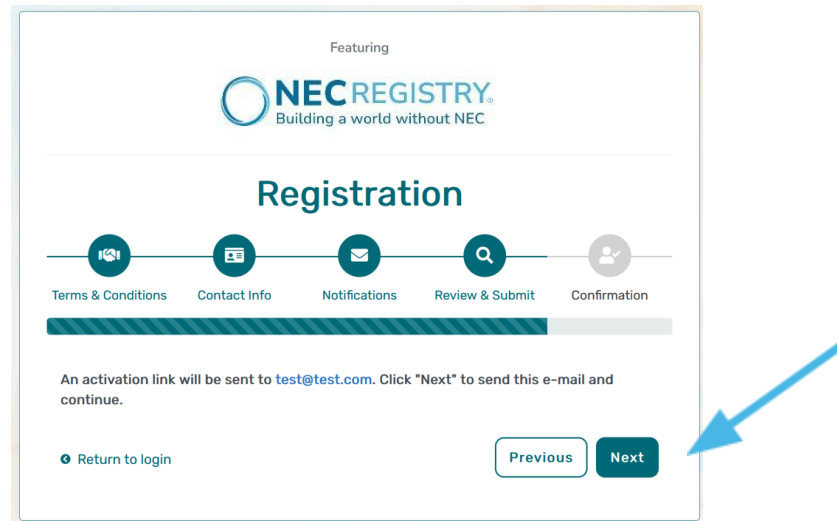
Terms & Conditions Contact Info Notifications Review & Submit Confirmation

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

☒ Yes ☐ No

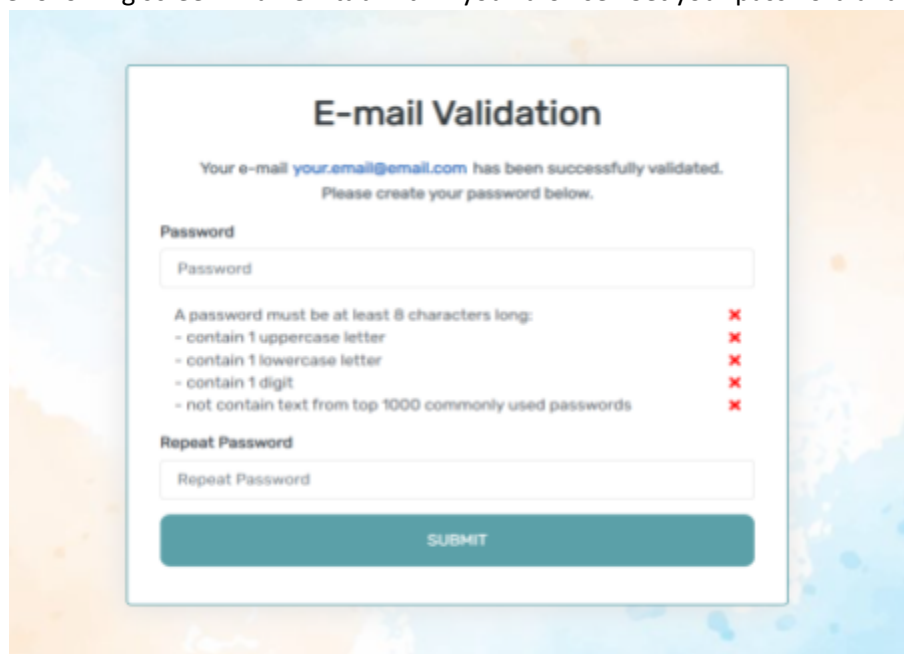
[Return to login](#) [Previous](#) [Next](#)

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



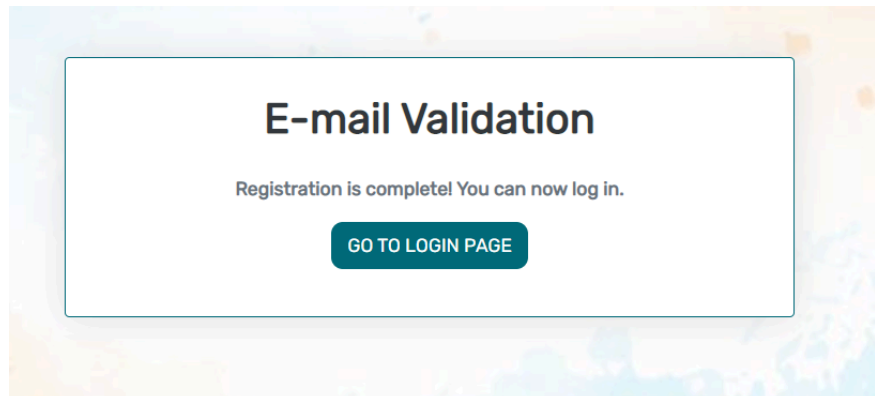
The screenshot shows the 'Registration' progress screen for the NEC Registry. At the top, it says 'Featuring NEC REGISTRY Building a world without NEC'. Below this is a progress bar with five steps: 'Terms & Conditions', 'Contact Info', 'Notifications', 'Review & Submit', and 'Confirmation'. The 'Review & Submit' step is currently active, indicated by a blue bar. Below the progress bar, a message states: 'An activation link will be sent to test@test.com. Click "Next" to send this e-mail and continue.' At the bottom, there is a 'Return to login' link and two buttons: 'Previous' and 'Next'. A blue 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”.

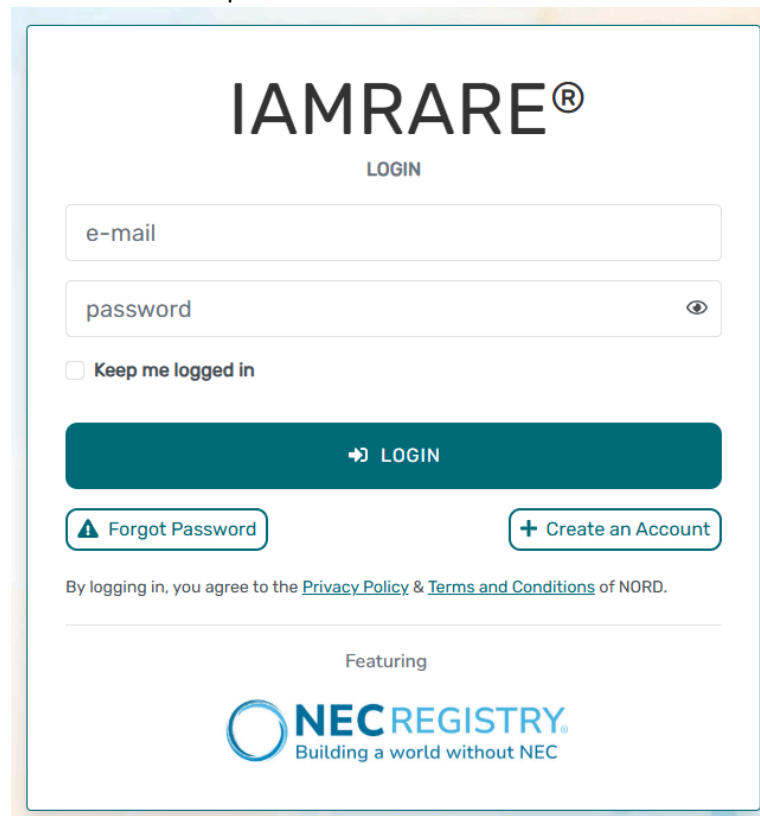


The screenshot shows the 'E-mail Validation' screen. It states: 'Your e-mail your.email@email.com has been successfully validated. Please create your password below.' There are two input fields: 'Password' and 'Repeat Password'. Below the 'Password' field, there are four password requirements listed with red 'X' marks indicating they are not met: 'A password must be at least 8 characters long:', 'contain 1 uppercase letter', 'contain 1 lowercase letter', 'contain 1 digit', and 'not contain text from top 1000 commonly used passwords'. At the bottom, there is a large blue 'SUBMIT' button.

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




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

A screenshot of the IAMRARE LOGIN page. The header shows "IAMRARE®" and "LOGIN". There are input fields for "e-mail" and "password" (with a toggle icon). Below the password field is a checkbox labeled "Keep me logged in". A large teal button labeled "LOGIN" is in the center. Below it are two buttons: "Forgot Password" (with a warning icon) and "Create an Account" (with a plus icon). At the bottom, it says "By logging in, you agree to the [Privacy Policy](#) & [Terms and Conditions](#) of NORD." and "Featuring" followed by the "NECREGISTRY®" logo and the tagline "Building a world without NEC".

Add a Participant

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

English ▾

 **NEC REGISTRY**
Building a world without NEC

Welcome, Jane!

Welcome to the IAMRARE[®] program, home of **The Necrotizing Enterocolitis (NEC) 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](#)

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

 **NEC REGISTRY**
Building a world without NEC

Add a Participant

Are you adding yourself or another person?

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

- 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

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 ?

Consent to the Study

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



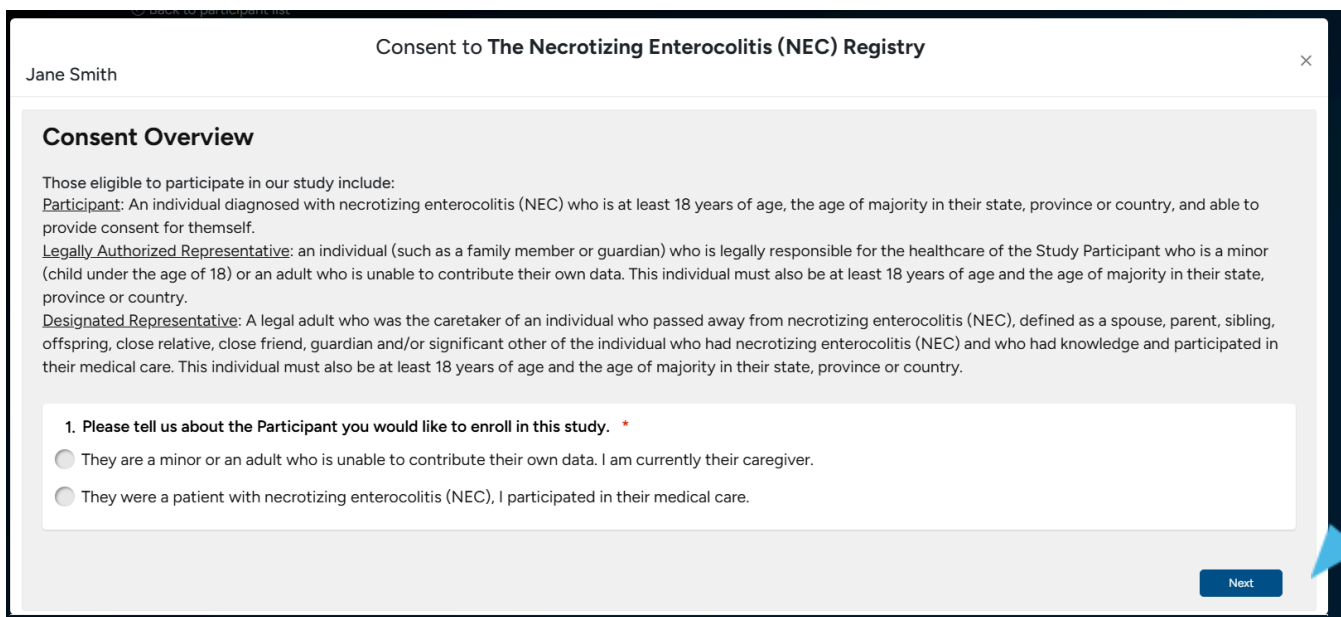
NEC REGISTRY
Building a world without NEC

Thank you for registering your first participant!

Would you like to consent to participate in The Necrotizing Enterocolitis (NEC) Registry ?

Not right now 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.”



Consent to The Necrotizing Enterocolitis (NEC) Registry

Jane Smith

Consent Overview

Those eligible to participate in our study include:

Participant: An individual diagnosed with necrotizing enterocolitis (NEC) who is at least 18 years of age, the age of majority in their state, province or country, and able to provide consent for themselves.

Legally Authorized Representative: an individual (such as a family member or guardian) who is legally responsible for the healthcare of the Study Participant who is a minor (child under the age of 18) or an adult who is unable to contribute their own data. This individual 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 necrotizing enterocolitis (NEC), defined as a spouse, parent, sibling, offspring, close relative, close friend, guardian and/or significant other of the individual who had necrotizing enterocolitis (NEC) 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.

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

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

☐ They were a patient with necrotizing enterocolitis (NEC), I participated in their medical care.

Next

Jane Smith

Consent to The Necrotizing Enterocolitis (NEC) Registry

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

Consent to Participate in the NEC Registry and to Allow Data to be Shared for Future Research

Title: NEC Registry

Principal Investigator: Erin Pryor, MPH, RDN, LD Research Director

Phone: (530) 448-8088

E-mail: registry@necsociety.org

Sponsor: NEC Society

Key Information

You are invited to take part in a research study for individuals with necrotizing enterocolitis 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). We hope that this form will give you the information you need to make an informed and voluntary decision on whether or not to participate in the NEC Registry. The information in this document is required to protect

Previous

Next

Jane Smith

Consent to The Necrotizing Enterocolitis (NEC) 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 NEC Registry on behalf of the Study Participant. After signing, a copy of the consent form

Previous

Next

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

Jane Smith

Consent to The Necrotizing Enterocolitis (NEC) 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

- 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 The Necrotizing Enterocolitis (NEC) Registry

Select Opt-Ins for this study

- ☐ Interest in hearing about other studies from **NEC Society**
- ☐ Interest in hearing about relevant clinical trials
- ☐ Interest in donating specimens or DNA (biobanking) for future research
- ☐ Interest in learning more about **NEC Society**
- ☐ Interest in signing up for a **NEC Society** newsletter
- ☐ Support from other Patient Advocacy Groups
- ☐ Interest in learning about upcoming events such as webinars and conferences

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 on your Participant.

IAMRARE® Home Help Settings Hi, Jane! ▾

Good Afternoon, Jane!
Member since May 05, 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-2020
 1 pending surveys

Shortcuts

Request Transfer Consent/Opt-Ins

Notifications (0)
No new notifications.

- Step 2: Click on the appropriate study.

IAMRARE® Home Help Settings Hi, Jane! ▾

⊖ Back to participant list

Jane Smith ▾ 5-May-2020 [Search 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.

The Necrotizing Enterocolitis (NEC) Registry ⓘ
NEC Society
✓ Consented
🔔 1 pending surveys

Shortcuts
Request Transfer Consent/Opt-Ins

Notifications (0)
No new notifications.

- Step 3: Click "Take Survey" for an available survey.

⊖ Back to study list

Jane Smith ▾ 5-May-2020

The Necrotizing Enterocolitis (NEC) Registry

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. Click "View Responses" to see your completed survey.

⊖ Back to study list

Jane Smith ▾ 5-May-2020

The Necrotizing Enterocolitis (NEC) Registry

Surveys 🔔 4 pending **All (5)** Complete (1) Pending (4)

100% **Getting Started**
Completed on 5-May-2025

[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. You may revoke your consent at any time by clicking “Revoke”. You may also edit your Opt-Ins by clicking “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

This screenshot shows the 'Enrolled Studies' page for a participant named Jane Smith. At the top, there is a 'Back to participant list' link. Below it, the participant's name and date are shown. A 'Search Studies' button is available. The main section is titled 'Enrolled Studies' and contains instructions on how to view study details. On the right, there are 'Shortcuts' for 'Request Transfer' and 'Consent/Opt-Ins'. A blue arrow points to the 'Consent/Opt-Ins' shortcut.

- 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 study list

Jane Smith 5-May-2020

Consents/Opt-Ins

Study Name	Consent Status	Consented On	Actions
The Necrotizing Enterocolitis (NEC) Registry	✓ Consented	5-May-2025	View Consent Revoke Opt-Ins

This screenshot shows the 'Consents/Opt-Ins' page for Jane Smith. It features a table with columns for 'Study Name', 'Consent Status', 'Consented On', and 'Actions'. The table lists 'The Necrotizing Enterocolitis (NEC) Registry' with a 'Consented' status. The 'Actions' column contains three buttons: 'View Consent', 'Revoke', and 'Opt-Ins'. Blue arrows point to the 'Revoke' and 'Opt-Ins' buttons.

Dark Mode Settings

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

IAMRARE®

Home Help Settings Hi, Jane! ▼

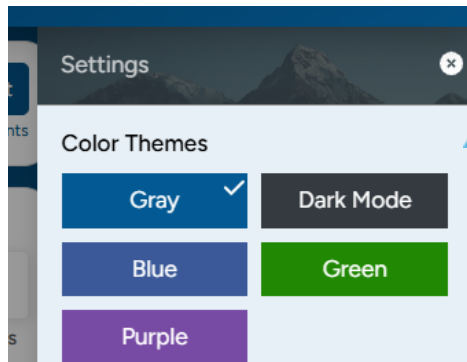
Good Afternoon, Jane!
Member since Nov 16, 2024

+ Add Participant

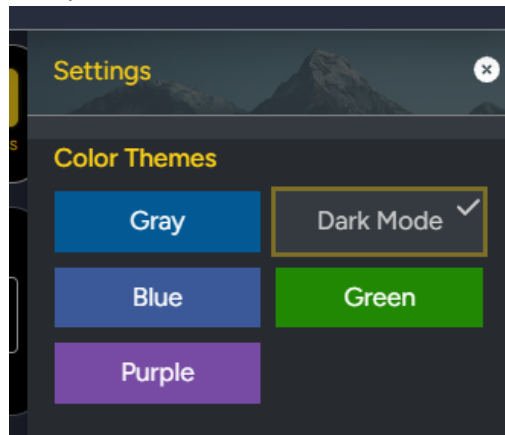
Participants Shortcuts

This screenshot shows the top navigation bar of the IAMRARE platform. It includes the logo, navigation links for Home, Help, and Settings, and a user greeting. Below the navigation bar, there is a welcome message and a date. A 'Add Participant' button is visible. At the bottom, there are tabs for 'Participants' and 'Shortcuts'. A blue arrow points to the 'Settings' link in the top navigation bar.

- Step 2: Select Dark Mode.



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

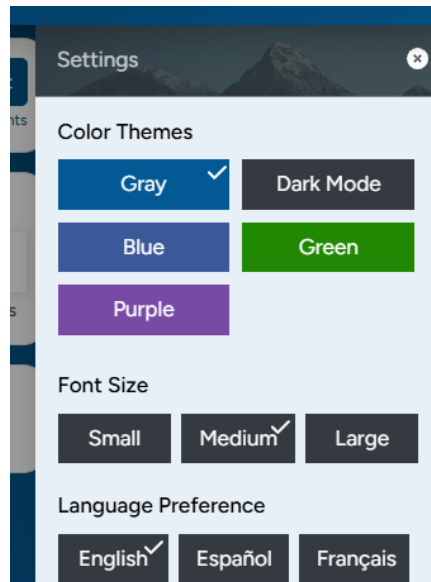


Display Settings

- 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.

Need Assistance?

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

A screenshot of a mobile application's 'Have a question?' form. The form has a title bar with 'Home' and 'Help' icons. The main text reads: '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 this is a dropdown menu for 'Inquiry Type' with the placeholder text '-- Select Inquiry Type --'. Underneath is a text input field for 'Message' with the placeholder text 'Your message'. At the bottom are two buttons: 'Cancel' and 'Submit'.

- 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.

All (5)Complete (1)Pending (4)


View Responses 1

Reports

Take Survey


Notifications (0)

No new notifications.



NEC SOCIETY.
Building a world without NEC

NEC Society

 necsociety.org

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info@northstarreviewboard.org

Social Media

