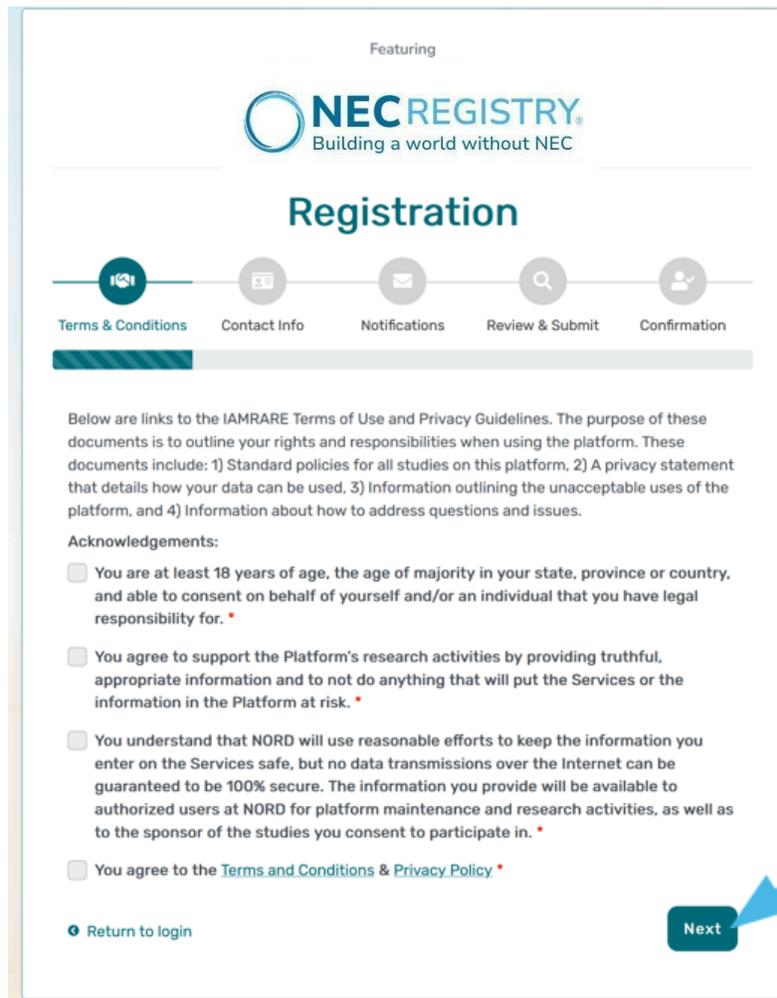


The Necrotizing Enterocolitis (NEC) Registry Participant User Guide

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



NEC REGISTRY
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”.

Featuring

NEC REGISTRY
Building a world without NEC

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

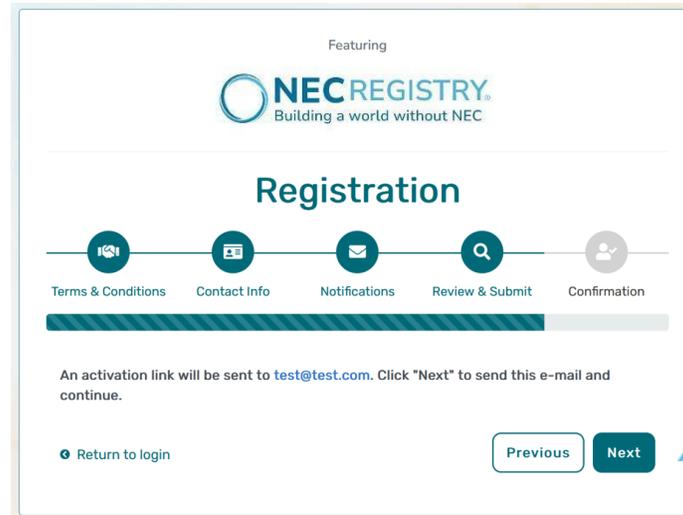
Terms & Conditions Contact Info Notifications Review & Submit Confirmation

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

Yes No

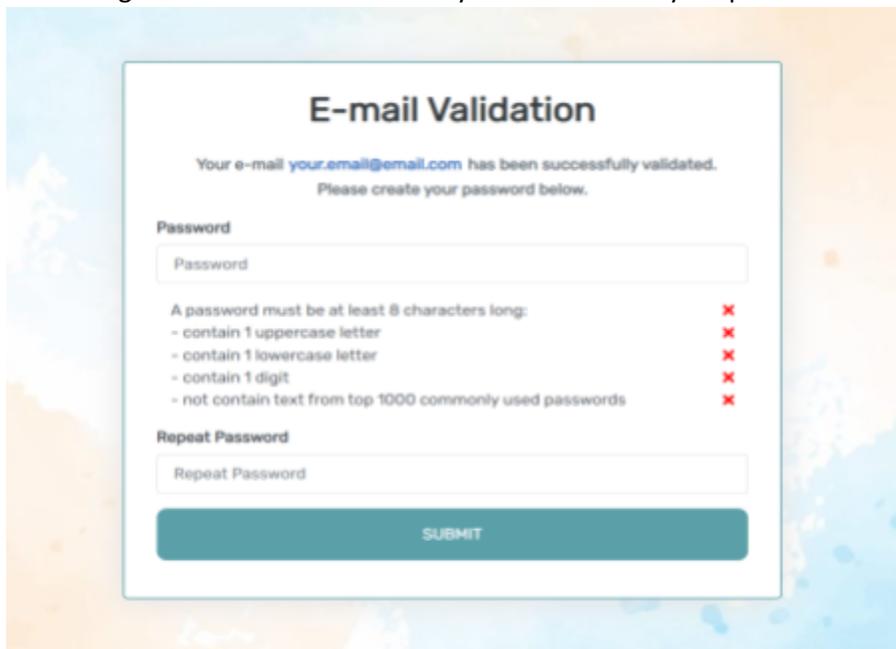
[Return to login](#) [Previous](#) [Next](#)

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



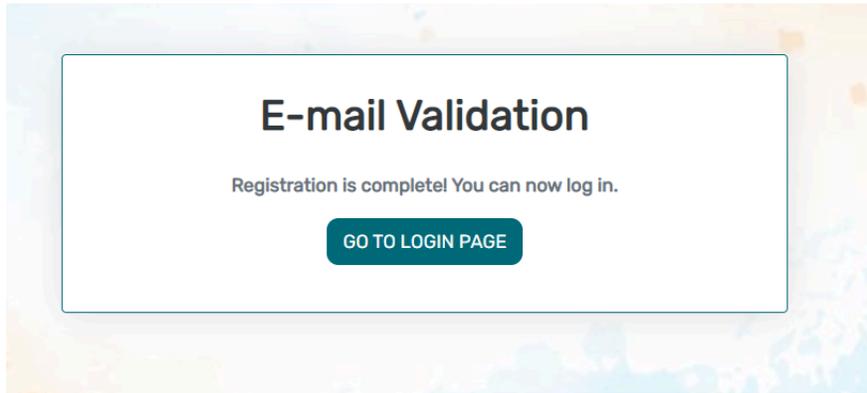
The screenshot shows the 'Registration' page for NEC Registry. At the top, it says 'Featuring NEC REGISTRY Building a world without NEC'. Below this is a progress bar with five steps: 'Terms & Conditions', 'Contact Info', 'Notifications', 'Review & Submit', and 'Confirmation'. The 'Review & Submit' step is currently active. 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”.

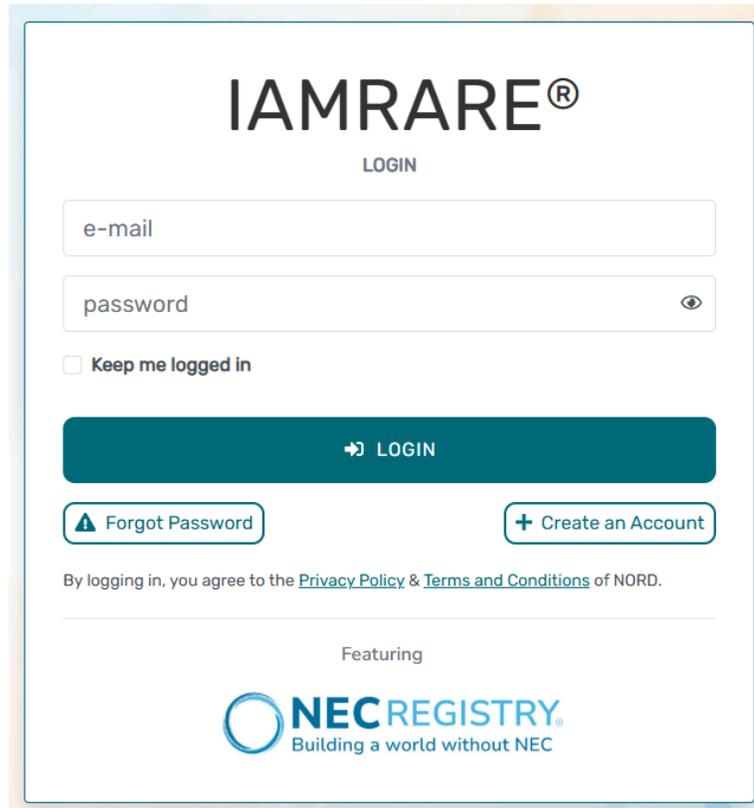


The screenshot shows the 'E-mail Validation' page. It states: 'Your e-mail your.email@email.com has been successfully validated. Please create your password below.' There are two password input fields: 'Password' and 'Repeat Password'. Below the first field, there are four password requirements, each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

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

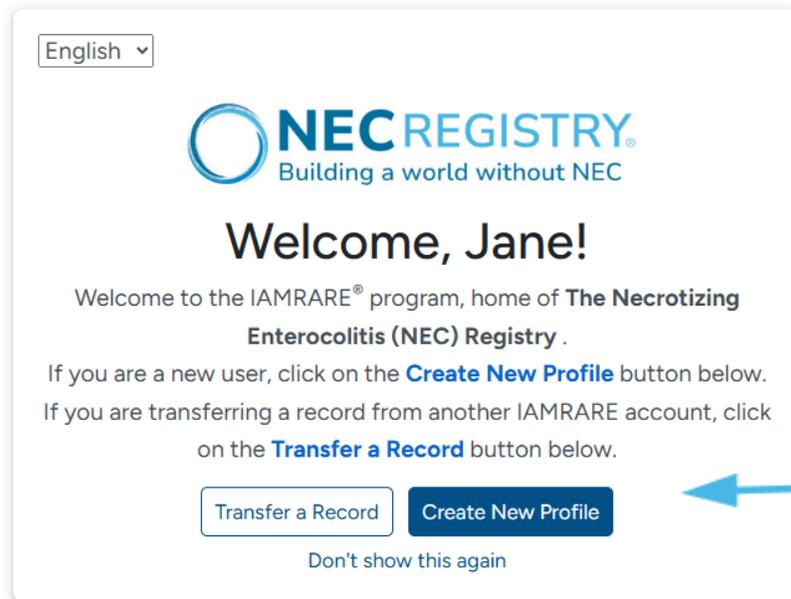


- Step 7: Log in using your new e-mail and password.

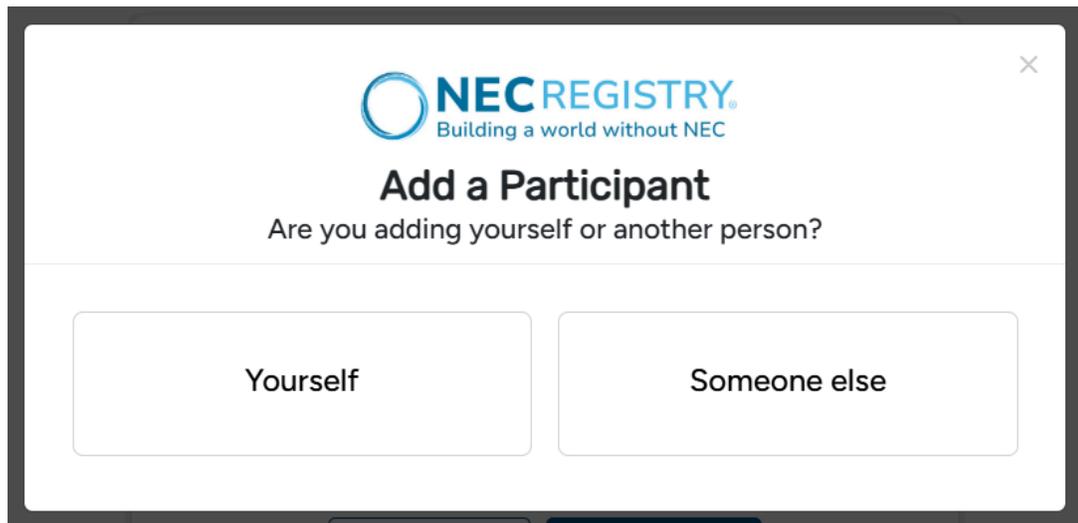


Add a Participant

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



- Step 2: The participant is the person who had NEC. This is who you will be providing information about. If you are the parent/caregiver of a child who had NEC and survived or had NEC and tragically passed away, choose “Someone else”.



- Step 3: Fill out the Participant’s information. If you are the parent/caregiver of a child who had NEC and survived or had NEC and tragically passed away, fill in the information about your child.

Add Participant X

A Participant is the individual who has the rare disease, condition, and/or diagnosis.

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 ?**

- 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 Overview

Terms to know:

Participant: The individual diagnosed with necrotizing enterocolitis (NEC) whose information will be entered into the Registry. To join the registry you will fit one of the following categories.

Adult Survivor of NEC: is an individual who is at least 18 years of age, the age of majority in your state, province or country, and able to provide your own consent. You are referred to as the Participant and will enter information about yourself into the Registry.

Legally Authorized Representative (LAR): is an individual (such as a family member or guardian) who is legally responsible for the healthcare of a minor (child under the age of 18 and currently living) who was diagnosed with necrotizing enterocolitis (NEC) or a living adult survivor of NEC who is unable to contribute their own data. The LAR must be at least 18 years of age and the age of majority in their state, province, or country. The LAR will enter the Participant's information into the Registry.

Designated Representative (DR): A legal adult who was the caretaker of a child or adult (Participant) who has passed away, who had been diagnosed with necrotizing enterocolitis (NEC). The Designated Representative is defined as a spouse, parent, sibling, offspring, close relative, close friend, guardian and/or significant other of the individual who had NEC and had knowledge of and participated in their medical care. This Designated Representative must be at least 18 years of age, 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 (under 18 years old) diagnosed with necrotizing enterocolitis (NEC). I am a legal adult (over 18 years old) responsible for the healthcare of the Participant.
- They are an adult diagnosed with NEC and unable to contribute their own data. I am an adult responsible for the healthcare of the Participant.
- They were diagnosed with NEC as a minor and have passed away. I am an adult who was responsible for the healthcare of the Participant.
- They were diagnosed with NEC and passed away in adulthood. I am an adult who was responsible for the healthcare of the Participant.

Next

Consent to The Necrotizing Enterocolitis (NEC) Registry

Jane Smith

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

Consent to The Necrotizing Enterocolitis (NEC) Registry

Jane Smith



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



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 NEC 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 NEC Registry for the purposes described above under Study Aims.

I wish to provide the Study Participant's research data to the NEC Registry for future research within recognized ethical standards for scientific research, as described under How We Use Your Data.

I have explained the study to the Study Participant to the extent they are able to understand, and the Study Participant has given their assent to participate in this study.

I wish to provide research data about myself as described under How You Provide Data, where applicable, to the NEC Registry only for the purposes described under How We Use Data.

I acknowledge that I am at least 18 years of age and the age of majority in my state, province or country, and able to provide consent on behalf of the Study Participant.

- Step 3: Click "Next" and then click "Continue to Opt-Ins".

Consent to The Necrotizing Enterocolitis (NEC) Registry

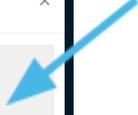
Jane Smith



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



- 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 [Close]

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.

The screenshot shows the IAMRARE user interface. At the top, there is a navigation bar with 'Home', 'Help', 'Settings', and 'Hi, Jane!'. Below the navigation bar, there is a 'Back to participant list' link. The main content area is divided into two columns. The left column is titled 'Enrolled Studies' and contains a card for 'The Necrotizing Enterocolitis (NEC) Registry'. The card shows the study name, 'NEC Society', 'Consented' status, and '1 pending surveys'. A blue arrow points to the '1 pending surveys' button. The right column contains 'Shortcuts' for 'Request Transfer' and 'Consent/Opt-Ins', and a 'Notifications (0)' section with 'No new notifications.'

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

The screenshot shows the 'The Necrotizing Enterocolitis (NEC) Registry' study page. At the top, there is a 'Back to study list' link. Below the navigation bar, there is a user profile for 'Jane Smith' with the date '5-May-2020'. The main content area is titled 'The Necrotizing Enterocolitis (NEC) Registry' and shows 'Surveys' with '1 pending' status. There are three tabs: 'All (1)', 'Complete (0)', and 'Pending (1)'. Below the tabs, there is a progress indicator showing '0% Getting Started' and 'Not Started'. A blue arrow points to the 'Take Survey' button.

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.

The screenshot shows the 'The Necrotizing Enterocolitis (NEC) Registry' study page. At the top, there is a 'Back to study list' link. Below the navigation bar, there is a user profile for 'Jane Smith' with the date '5-May-2020'. The main content area is titled 'The Necrotizing Enterocolitis (NEC) Registry' and shows 'Surveys' with '4 pending' status. There are three tabs: 'All (5)', 'Complete (1)', and 'Pending (4)'. Below the tabs, there is a progress indicator showing 'Getting Started' and 'Completed on 5-May-2025'. A blue arrow points to the 'View Responses' button, which has a '1' next to it. There is also a 'Reports' button below it.

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

- 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

Dark Mode Settings

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

IAMRARE®

Home Help Settings Hi, Jane!

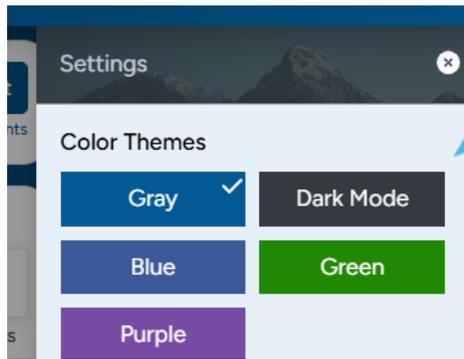
Good Afternoon, Jane!
Member since Nov 16, 2024

+ Add Participant

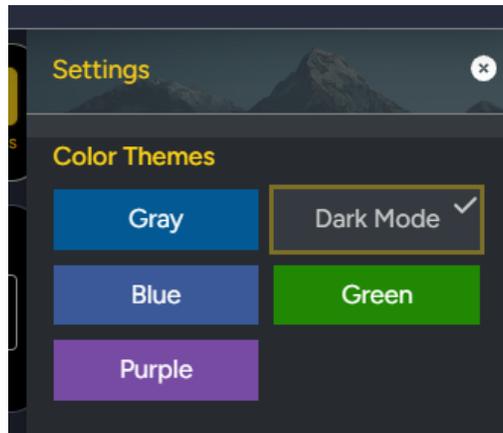
Participants

Shortcuts

- Step 2: Select Dark Mode.



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

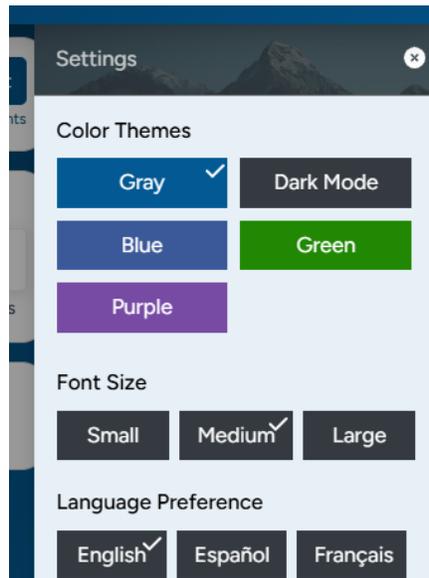


Display Settings

- 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 is titled "Have a question?" and has a close button (X) in the top right corner. It contains 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 are two required fields: "Inquiry Type" with a dropdown menu showing "-- Select Inquiry Type --" and "Message" with a text input field containing "Your message". At the bottom of the form 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

 necsociety.org

Contact

Erin Pryor

Phone

530-448-8088

E-mail

registry@necsociety.org

IRB E-mail

info@northstarreviewboard.org

Social Media

