



The Facial Pain 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

THE FacialPain REGISTRY

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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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”.

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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.

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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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- 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.

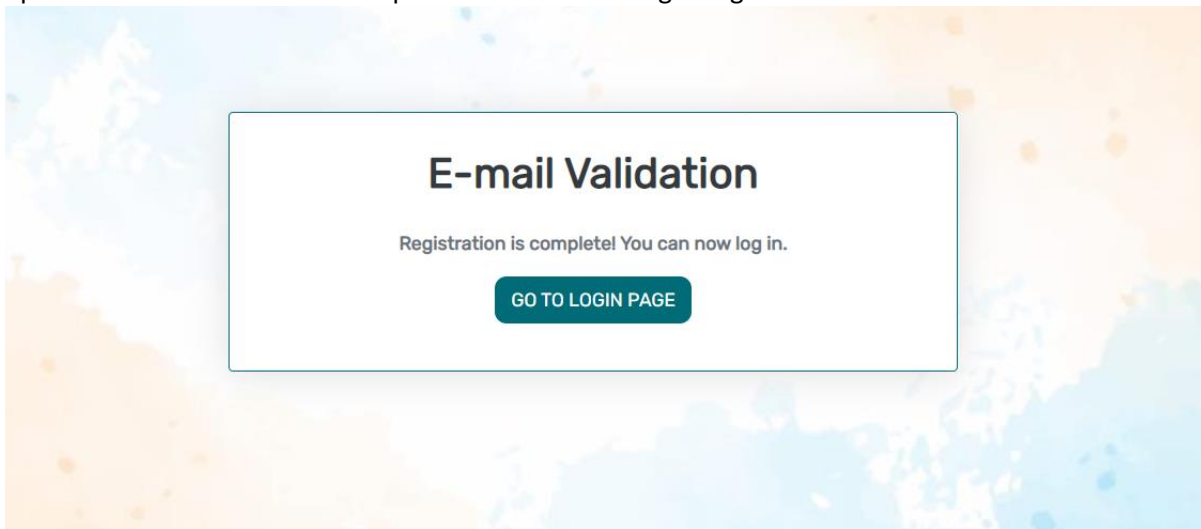
Password

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”.

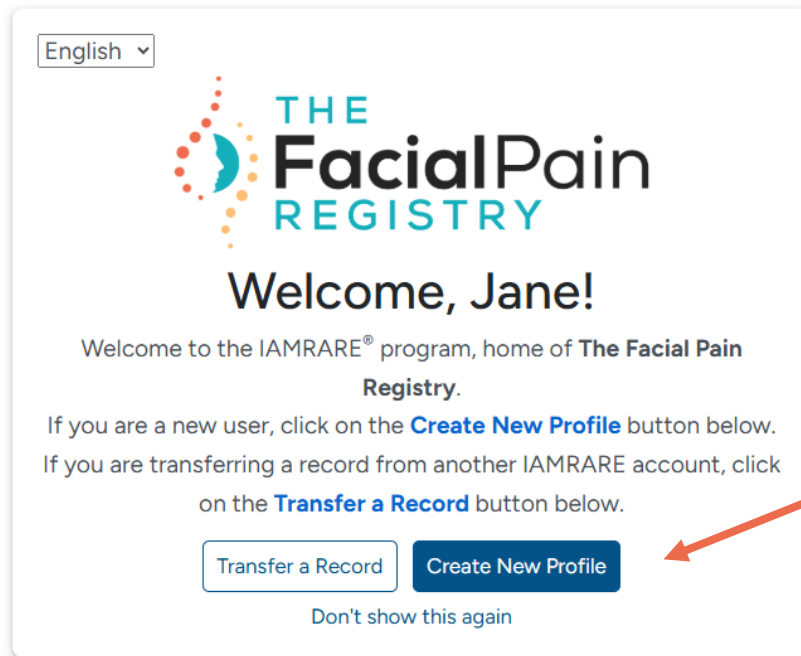


- Step 7: Log in using your new e-mail and password.


A screenshot of the IAMRARE login page. The page has a light blue and orange watercolor background. The login form is a white rectangle with the following elements: the "IAMRARE®" logo at the top, the word "LOGIN" below it, an "e-mail" input field, a "password" input field with a toggle eye icon, a "Keep me logged in" checkbox, a large dark teal "LOGIN" button, "Forgot Password" and "Create an Account" links, a privacy/terms notice, and the "Featuring THE FacialPain REGISTRY" logo at the bottom.

Add a Participant

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



English ▾

 **THE FacialPain REGISTRY**

Welcome, Jane!

Welcome to the IAMRARE® program, home of **The Facial Pain Registry**.

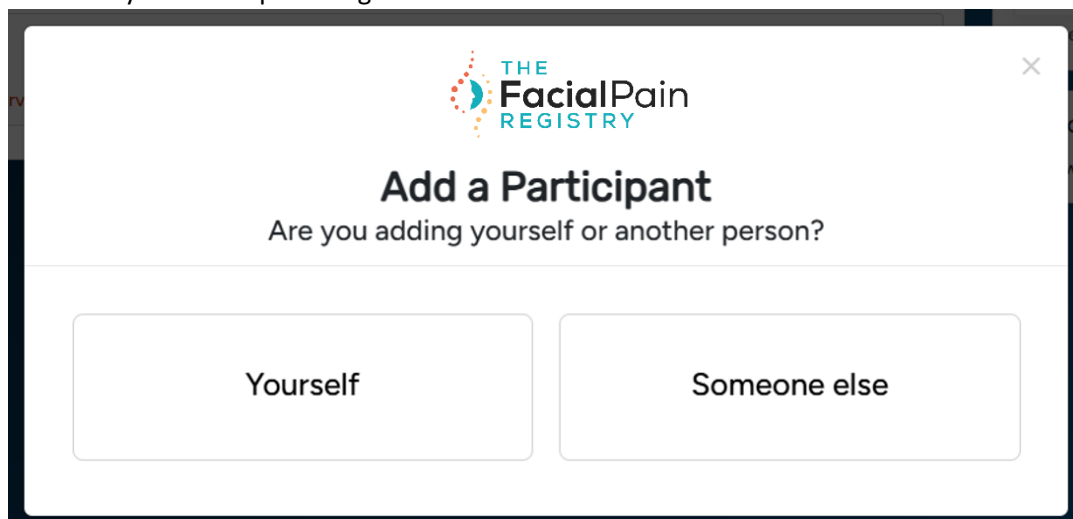
If you are a new user, click on the **Create New Profile** button below.


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.



 **THE FacialPain REGISTRY**

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.”

THE
FacialPain
REGISTRY

Thank you for registering your first participant!
Would you like to consent to participate in **The Facial Pain 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 Facial Pain Registry

Answered 0/1 questions

Consent Overview

Those eligible to participate in our study include:

Participant: An individual who has experienced neuropathic facial pain 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 neuropathic facial pain, defined as a spouse, parent, sibling, offspring, close relative, close friend, guardian and/or significant other of the individual and who had knowledge of 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 who is unable to contribute their own data. I am currently their caregiver.

☐ They were a patient with neuropathic facial pain and have since passed away. I participated in their medical care.

Next

Consent to The Facial Pain Registry

Answered 1/7 questions

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

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

Title: Facial Pain Registry

Principal Investigator: Melissa Baumbick, CEO

Co-Principal Investigator: Brandi Underwood, Manager of Development, Research, and Advocacy

Phone: 800-923-3608

E-mail: registry@facepain.org

Sponsor: Facial Pain Association

Key Information

You are invited to take part in a research study for individuals with neuropathic facial pain 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 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:

We are doing this research to better understand the experiences of those living with and affected by neuropathic facial pain.

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Consent to The Facial Pain Registry

Answered 7/7 questions

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 Facial Pain Registry 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.

Previous Next

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

Consent to The Facial Pain Registry

Answered 7/7 questions

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".

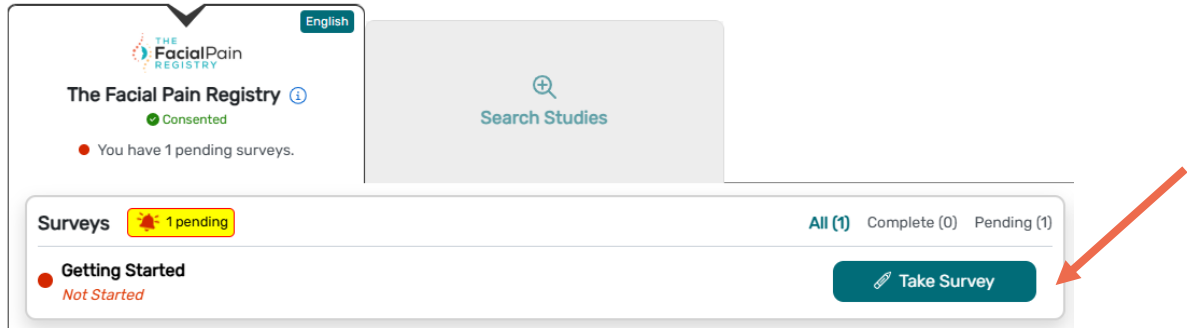
Opt-Ins for The Facial Pain Registry

Select Opt-Ins for this study

- ☐ Interest in hearing about other studies from Facial Pain Association
- ☐ 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 Facial Pain Association
- ☐ Interest in learning about upcoming events such as webinars and conferences
- ☐ Interest in learning more about neuropathic facial pain educational programs and resources from Facial Pain Association
- ☐ Interest in support services offered from Facial Pain Association
- ☐ Interest in learning ways to support Facial Pain Association
- ☐ Interest in receiving news and updates from Facial Pain Association

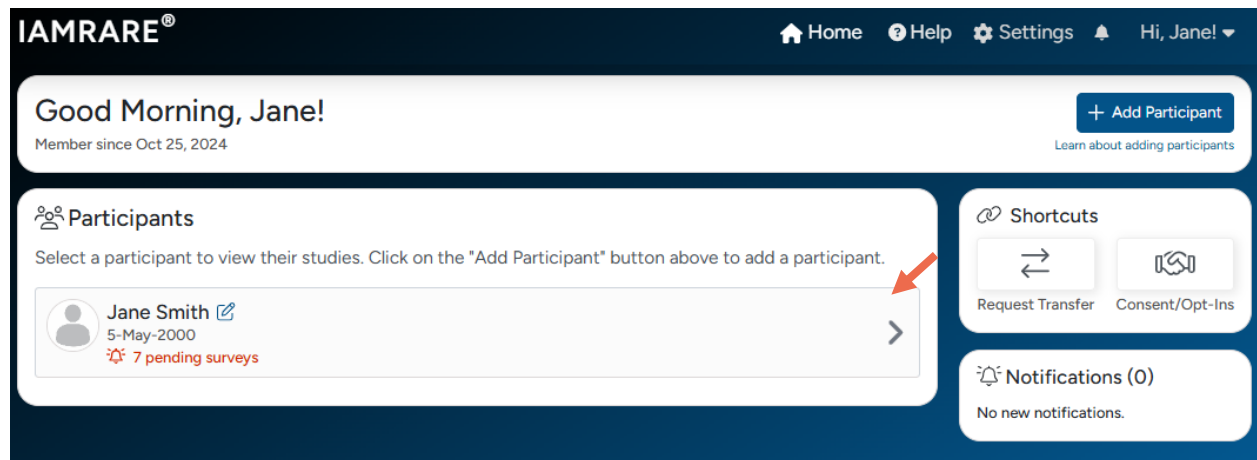
Save and Review

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

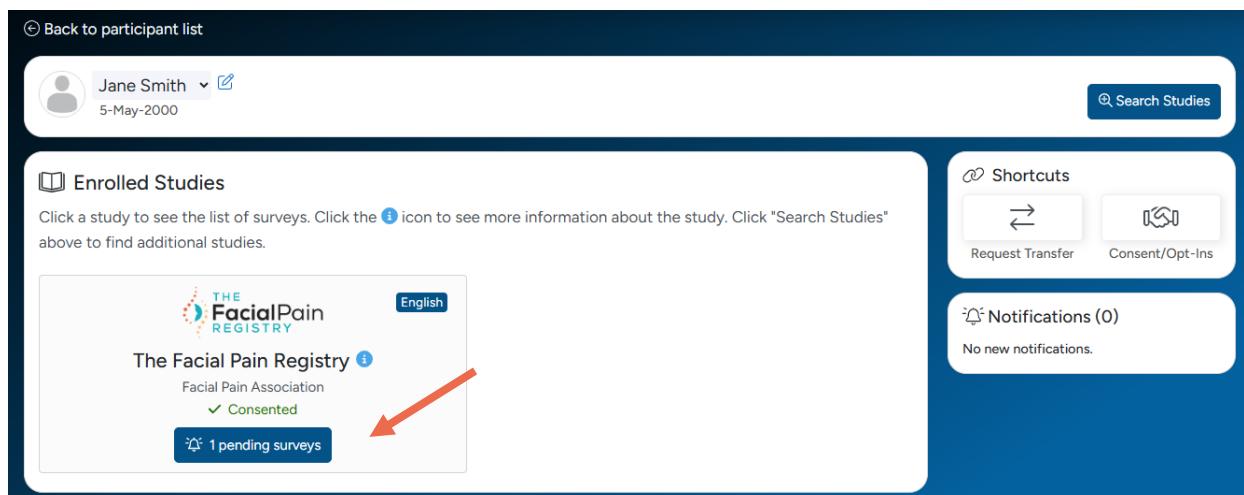


Taking Surveys

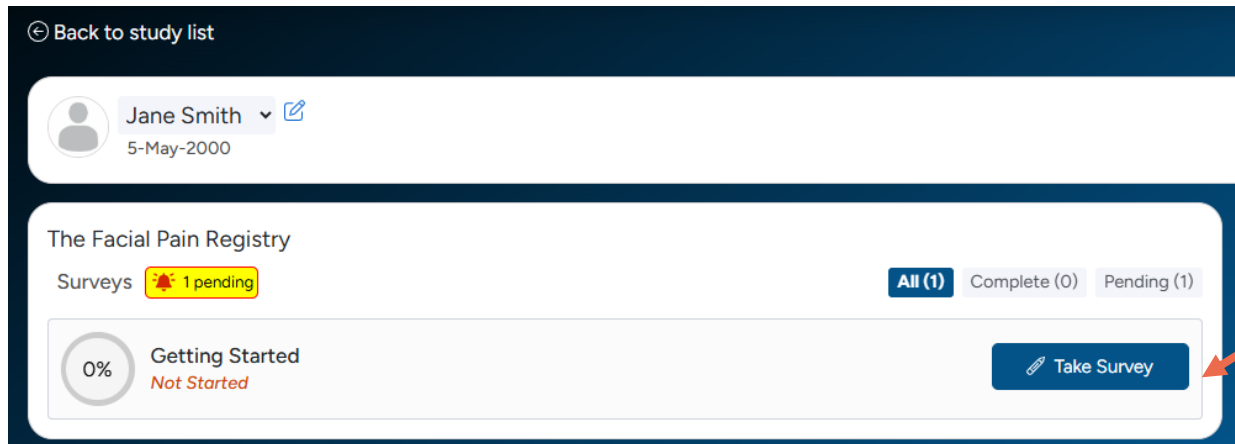
- Step 1: Click on your Participant.



- Step 2: Click on the appropriate study.

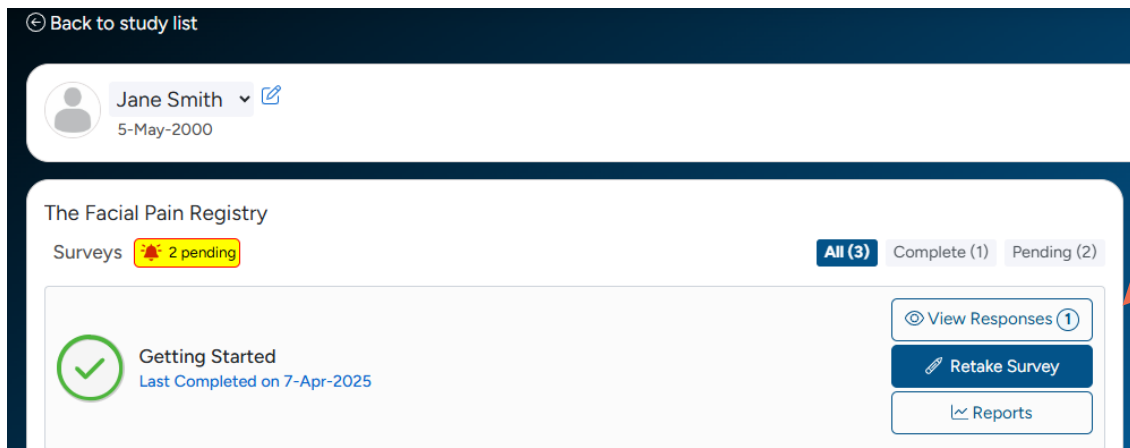


- Step 3: Click “Take Survey” for an available survey.



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.



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 **i** icon to see more information about the study. Click "Search Studies" above to find additional studies.

Shortcuts

- Request Transfer
- Consent/Opt-Ins

An orange arrow points to the 'Consent/Opt-Ins' shortcut button.

Back to study list

Jane Smith 5-May-2000

Consents/Opt-Ins

Study Name	Consent Status	Consented On	Actions
The Facial Pain Registry	✓ Consented	7-Apr-2025	View Consent Revoke Opt-Ins

Two orange arrows point to the 'View Consent', 'Revoke', and 'Opt-Ins' buttons in the Actions column.

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

An orange arrow points to the 'Settings' link in the top navigation bar.

- Step 2: Select Dark Mode.

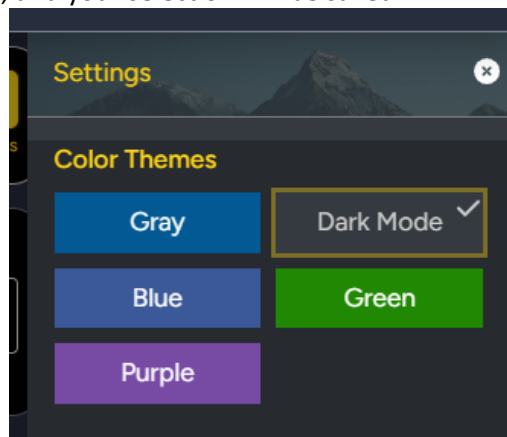
Settings

Color Themes

- Gray ✓
- Dark Mode
- Blue
- Green
- Purple

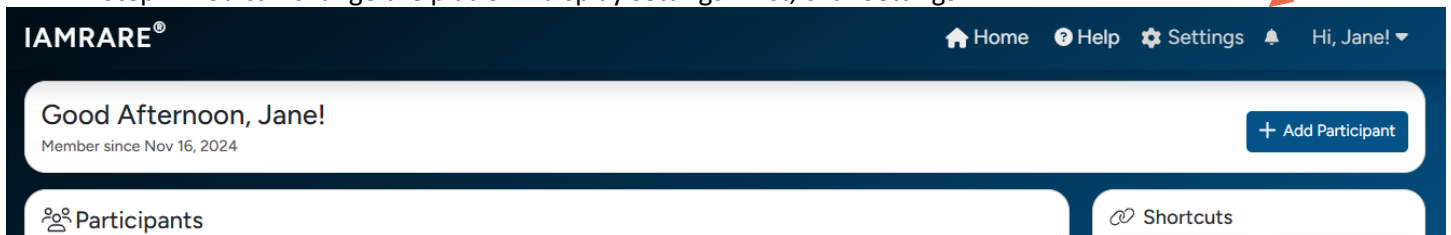
An orange arrow points to the 'Dark Mode' option.

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

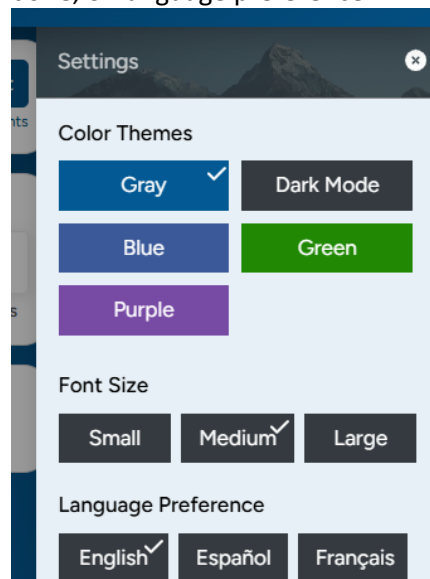


Display Settings

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



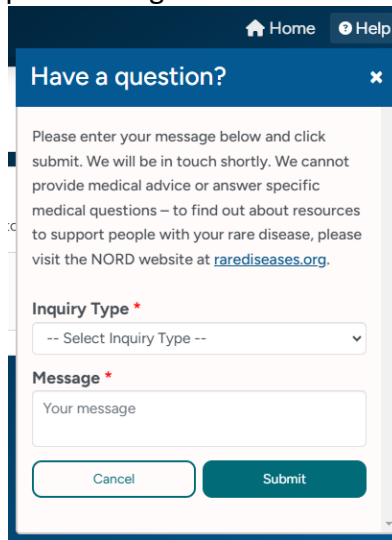
- Step 2: Select a color theme, a font size, or language preference.



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

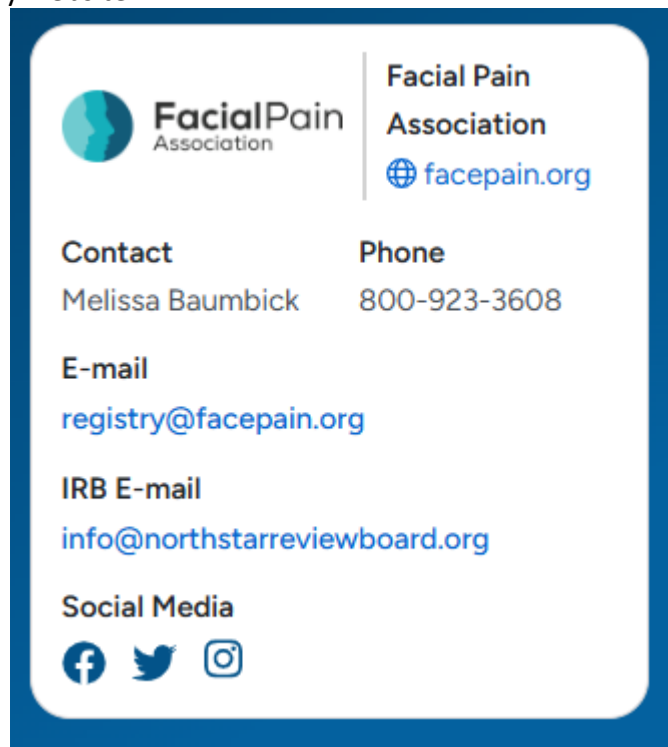
Need Assistance?

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



The screenshot shows a mobile application interface with a dark blue header containing 'Home' and 'Help' icons. Below the header is a white modal box titled 'Have a question?' with a close button (X). The modal 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 this text is a dropdown menu labeled 'Inquiry Type *' with the placeholder text '-- Select Inquiry Type --'. Underneath the dropdown is a text input field labeled 'Message *' with the placeholder text 'Your message'. At the bottom of the modal 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.



The image shows a contact information card for the Facial Pain Association. The card has a blue border and a white background. At the top left is the Facial Pain Association logo, which consists of a blue circle with a white profile of a face. To the right of the logo is the text 'FacialPain Association'. Further right is the text 'Facial Pain Association' and the website 'facepain.org' with a globe icon. Below this is a section titled 'Contact' with the name 'Melissa Baumbick' and a 'Phone' number '800-923-3608'. Underneath is an 'E-mail' address 'registry@facepain.org'. Below that is an 'IRB E-mail' address 'info@northstarreviewboard.org'. At the bottom is a 'Social Media' section with icons for Facebook, Twitter, and Instagram.