

Ectodermal Dysplasias 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


NATIONAL FOUNDATION FOR
ECTODERMAL DYSPLASIAS

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](#) and [Privacy Policy](#) and have read the [Consumer Health Data Privacy Notice](#). *

[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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Registration

Progress bar: Terms & Conditions (active), 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”.

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Registration

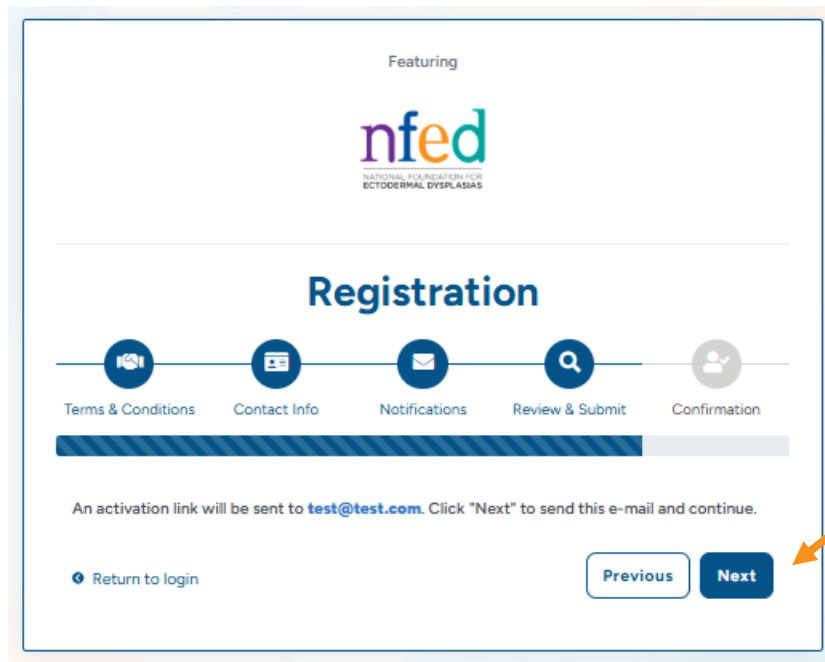
Progress bar: Terms & Conditions, Contact Info, Notifications (active), Review & Submit, Confirmation

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 image shows a registration progress bar with five steps: Terms & Conditions, Contact Info, Notifications, Review & Submit, and Confirmation. The progress bar is currently at the 'Review & Submit' step. 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 right, there are two buttons: 'Previous' and 'Next'. An orange arrow points to the 'Next' button.

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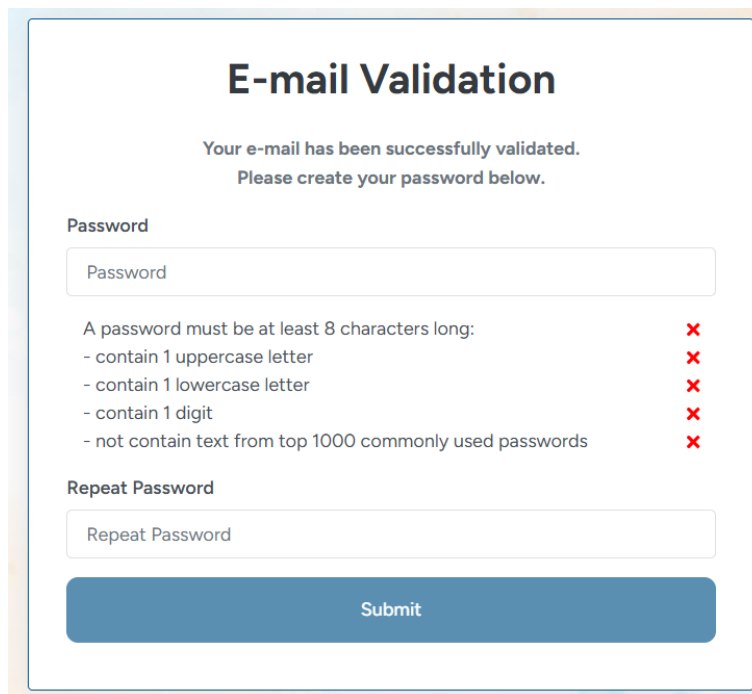
Registration

Terms & Conditions Contact Info Notifications Review & Submit Confirmation

An activation link will be sent to **test@test.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”.



The image shows the 'E-mail Validation' screen. It states: 'Your e-mail has been successfully validated. Please create your password below.' There are two password input fields: 'Password' and 'Repeat Password'. Below the 'Password' field, there are five 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', 'contain 1 digit', and 'not contain text from top 1000 commonly used passwords'. At the bottom, there is a blue 'Submit' button.

E-mail Validation

Your e-mail has been successfully validated.
Please create your password below.

Password

Password

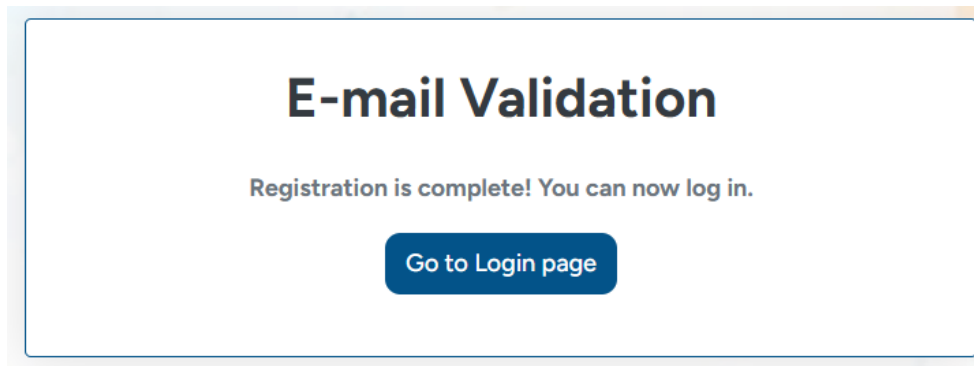
A password must be at least 8 characters long: ✗
- contain 1 uppercase letter ✗
- contain 1 lowercase letter ✗
- contain 1 digit ✗
- not contain text from top 1000 commonly used passwords ✗

Repeat Password

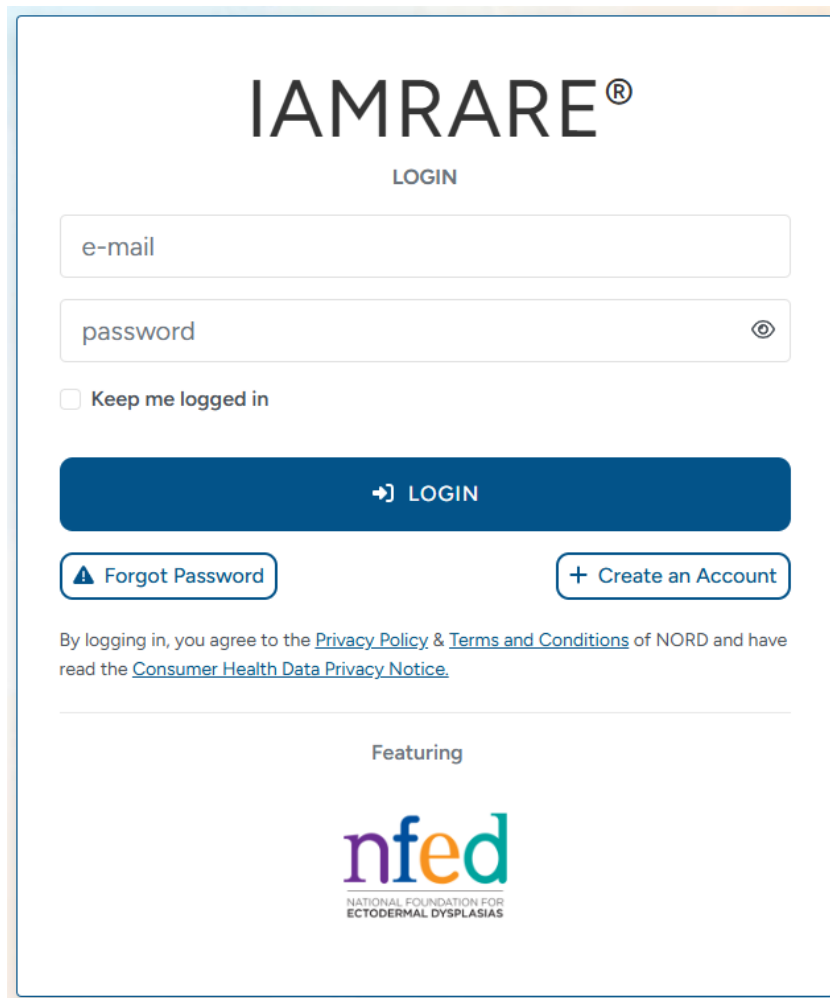
Repeat Password

[Submit](#)

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

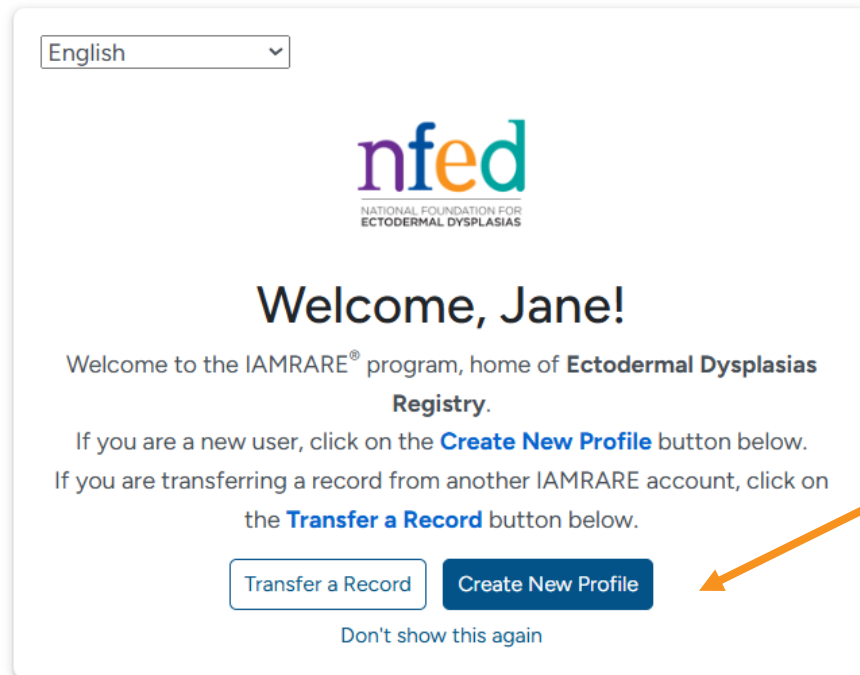


- Step 7: Log in using your new e-mail and password.

A login page for IAMRARE. At the top, the text "IAMRARE®" is displayed in a large, black, sans-serif font, with "LOGIN" in a smaller font directly below it. There are two input fields: the first is labeled "e-mail" and the second is labeled "password" with a small eye icon to its right. Below the password field is a checkbox labeled "Keep me logged in". A large, dark blue button with white text and a right-pointing arrow icon says "LOGIN". Below this button are two smaller buttons: "Forgot Password" with a warning triangle icon and "Create an Account" with a plus icon. A line of text below these buttons states: "By logging in, you agree to the [Privacy Policy](#) & [Terms and Conditions](#) of NORD and have read the [Consumer Health Data Privacy Notice](#)." At the bottom, the word "Featuring" is centered above the "nfed" logo, which consists of the letters "n", "f", and "e" in purple, blue, and orange respectively, followed by "d" in green. Below the logo, the text "NATIONAL FOUNDATION FOR ECTODERMAL DYSPLASIAS" is written in a small, black, sans-serif font.

Add a Participant

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



English ▼

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Welcome, Jane!

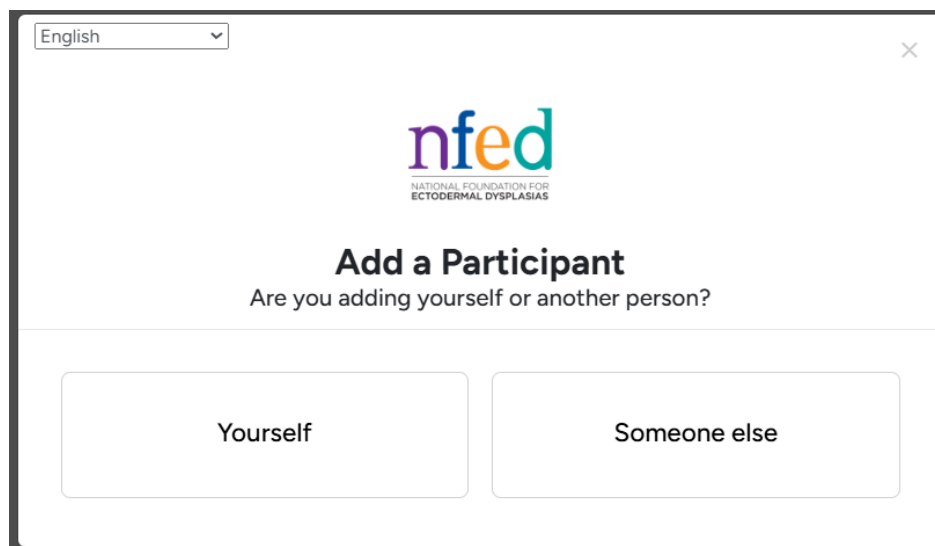
Welcome to the IAMRARE® program, home of **Ectodermal Dysplasias Registry**.

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.



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

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? * ?

Profile Image

OR

No image selected

Consent to the Study

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



NATIONAL FOUNDATION FOR
ECTODERMAL DYSPLASIAS

Thank you for registering your first participant!

Would you like to consent to participate in **Ectodermal Dysplasias 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.”

Jane Smith

Consent to Ectodermal Dysplasias Registry

Consent Overview

Those eligible to participate in our study include:
Participant: An individual diagnosed with ectodermal dysplasias 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 with ectodermal dysplasias who 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. 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 ectodermal dysplasias and had knowledge and participated in their medical care. This Designated Representative 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 ectodermal dysplasias and have passed away. I participated in their medical care.

Next

Jane Smith

Consent to Ectodermal Dysplasias Registry

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

Consent to Participate in the National Foundation for Ectodermal Dysplasias (NFED) Natural History Registry Study (Ectodermal Dysplasias Registry) and to Allow Your Data to be Shared for Future Research

Title: National Foundation for Ectodermal Dysplasias (NFED) Natural History Registry Study (Ectodermal Dysplasias Registry)

Principal Investigators:
Beau D. Meyer, DDS, MPH Associate Professor Ohio State University College of Dentistry Division of Pediatric Dentistry Columbus, OH
Clayton J. Butcher, M.D. University of Missouri Health Care Associate Professor Internal Medicine and Pediatrics Internal Medicine & Pediatrics Program Director 1000 W. Nifong Blvd Bldg 3 Ste 130 Columbia, MO 65203

Sponsor: National Foundation for Ectodermal Dysplasias

Study Staff: Mary Fete

Phone: 618-566-2020

E-mail: registry@NFED.org

Key Information
You are invited to take part in a research study for people with ectodermal dysplasias on behalf of the person in your care who is not able or no longer 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 contact information is listed above.
Things you should know:
We are doing this research to learn as much as possible about the various ectodermal dysplasia syndromes so that more information is available to inform early diagnosis of the conditions, treatments for the conditions and potentially,

Previous

Next

Consent to Ectodermal Dysplasias Registry

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 the Ectodermal Dysplasias 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.

☐ 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 Ectodermal Dysplasias Registry have been answered to my satisfaction, and I understand the purpose of the registry and the risks of participation.

☐ I wish to provide research data about **myself** AND the Study Participant to the Ectodermal Dysplasias Registry for the purposes described above under Study Aims.

☐ I wish to provide research data about **myself** AND the Study Participant's research data to the Ectodermal Dysplasias Registry for future research within recognized ethical standards for scientific research, as described under How We Use the 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.

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

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

Consent to Ectodermal Dysplasias 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 Ectodermal Dysplasias Registry

Select Opt-Ins for this study

☐ Interest in hearing about other studies from **National Foundation for Ectodermal Dysplasias (NFED)**

☐ 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 **National Foundation for Ectodermal Dysplasias (NFED)**

☐ Interest in signing up for a **National Foundation for Ectodermal Dysplasias (NFED)** newsletter

☐ Interest in support services offered from **National Foundation for Ectodermal Dysplasias (NFED)**

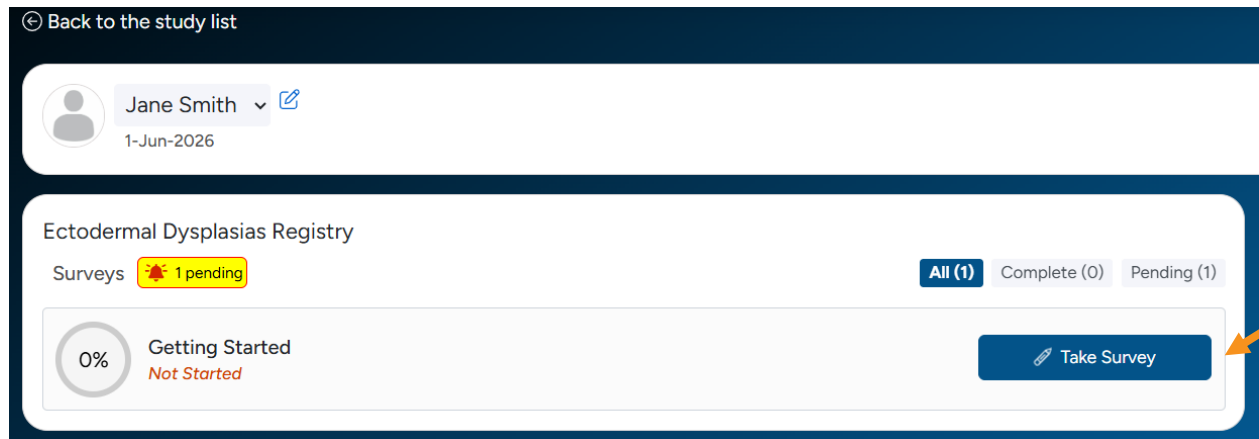
☐ Interest in receiving news and updates from **National Foundation for Ectodermal Dysplasias (NFED)**

[Save and Review](#)

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

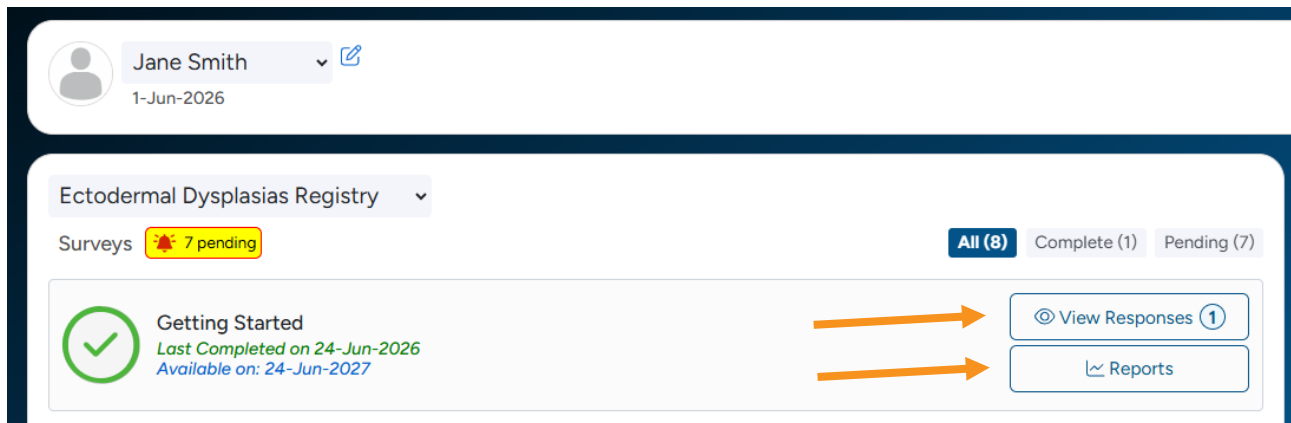
Taking Surveys

- Step 1: Click "Take Survey" for an available survey.



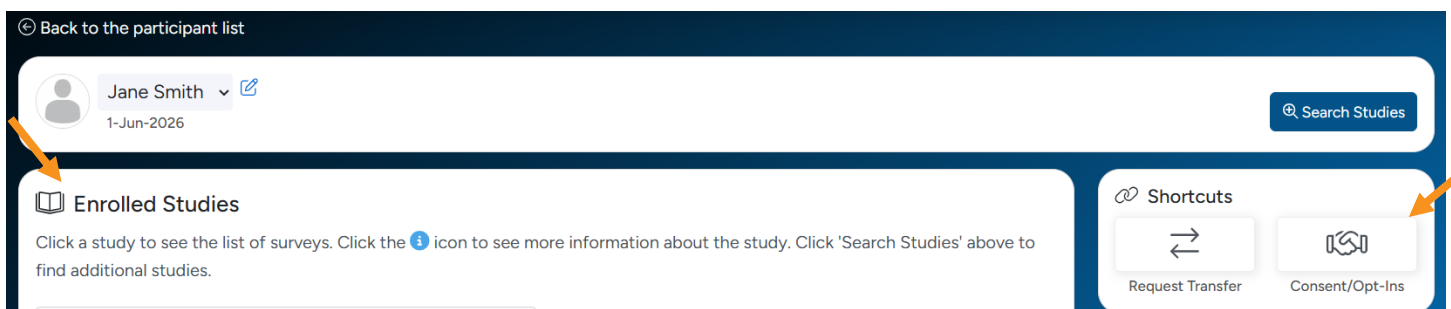
View Responses and Reports

- 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.



- 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 1-Jun-2026

Consents/Opt-Ins

Study Name	Consent Status	Consented On	Actions
Ectodermal Dysplasias Registry	✓ Consented	15-Jun-2026	View Consent Revoke Opt-Ins

Dark Mode Settings

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

IAMRARE®

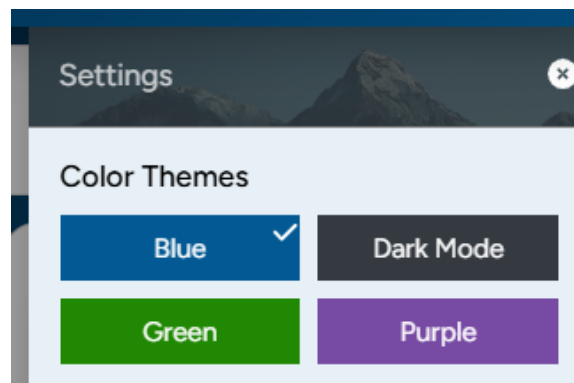
Home Help Settings Hi, Jane! ▼

Good Morning, Jane!
Member since Jun 15, 2026

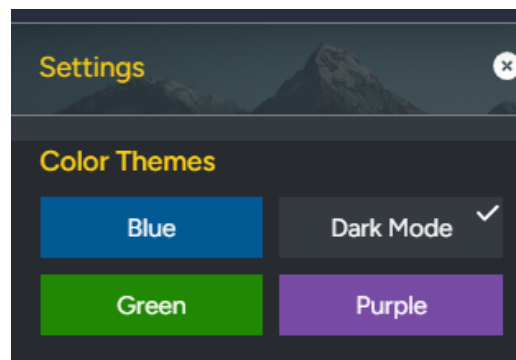
+ Add Participant

Participants Shortcuts

- Step 2: Select Dark Mode.



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

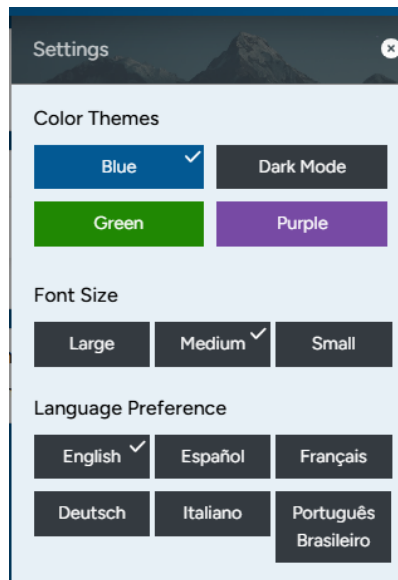


Display Settings

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



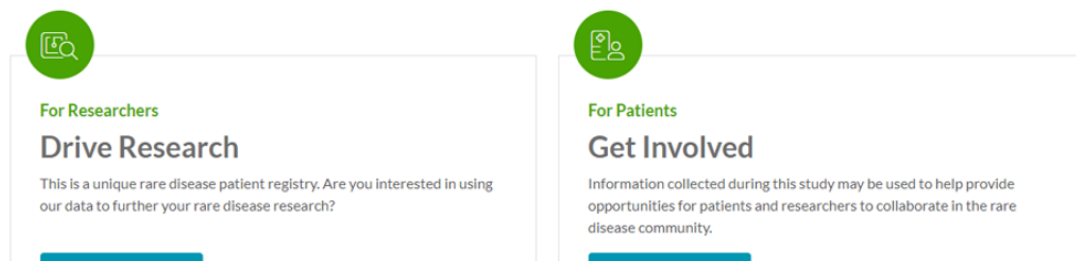
- Step 2: Select a color theme, a font size, or language preference.

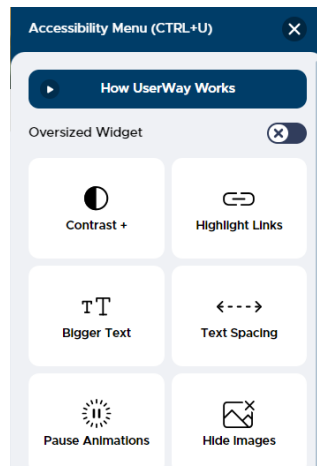


- Step 3: Exit the Settings menu, and your selection will be saved.

Microsite Visibility

- Step 1: You can change how you view the microsite (ectodermaldysplasiasregistry.iamrare.org) 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.





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.

 A "Have a question?" form with a close button. It includes a text area for a message, a dropdown menu for "Inquiry Type" with the placeholder "-- Select Inquiry Type --", and a text input for "Message" with the placeholder "Your message". At the bottom are "Cancel" and "Submit" buttons.

- You may also contact the study sponsor directly by using the contact information shown on your dashboard or the study website.

A contact information card for the National Foundation for Ectodermal Dysplasias (NFED). It features the NFED logo, the text "National Foundation for Ectodermal Dysplasias (NFED)", and contact details: "Contact NFED Study Staff", "E-mail info@NFED.org", and "Social Media" with Facebook and Instagram icons. To the left of the card are three buttons: "Responses 1", "Responses 1", and "e Survey".