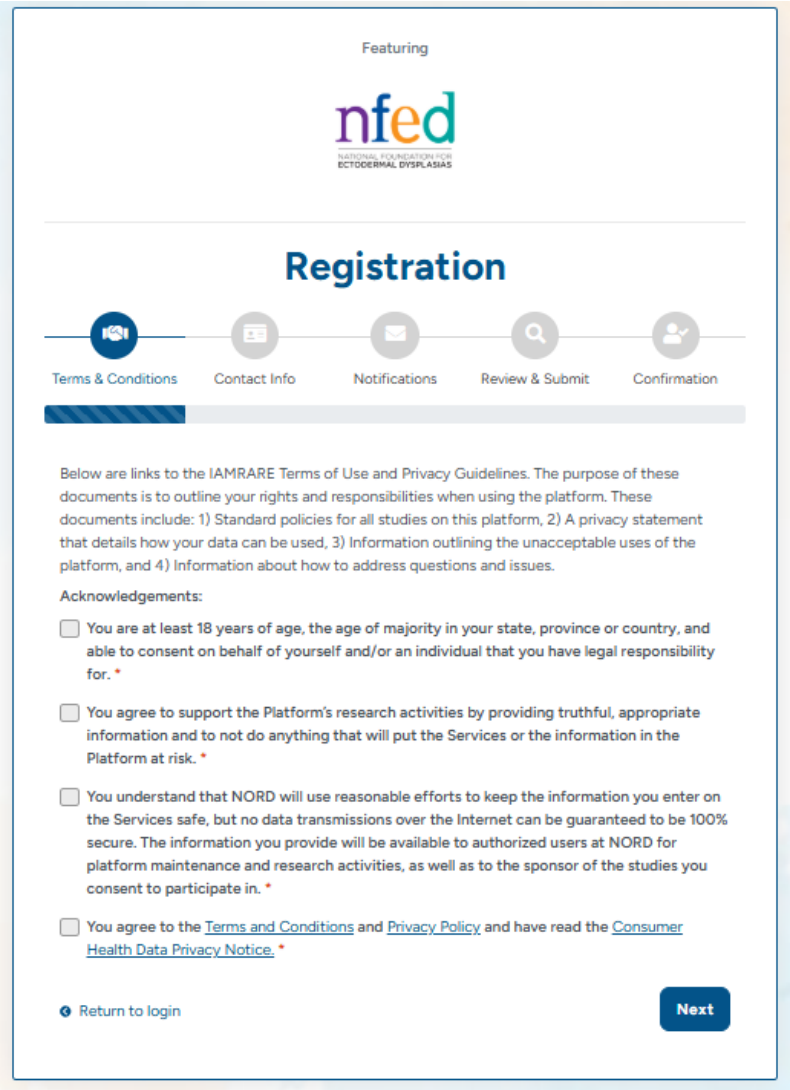
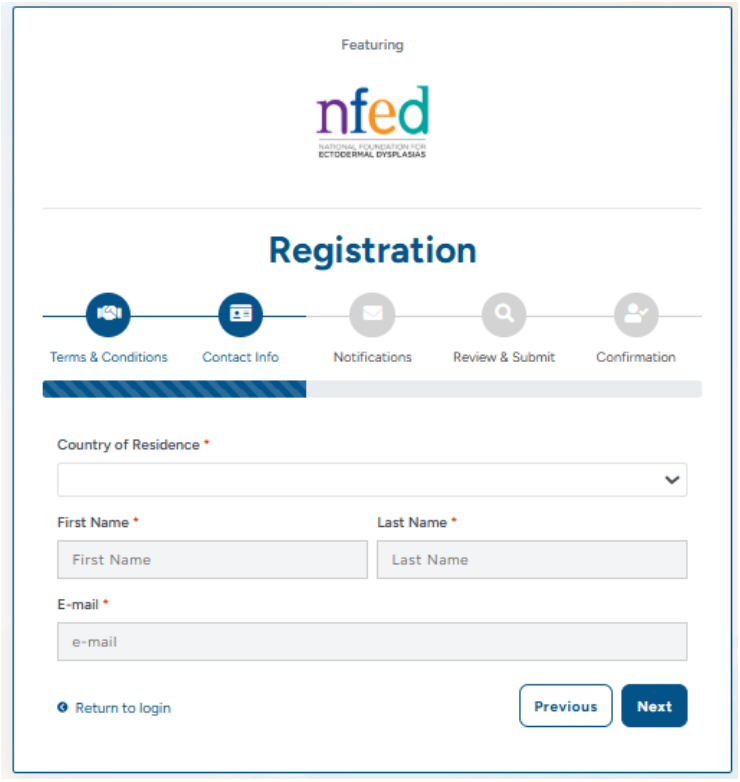
Ectodermal Dysplasias Registry Participant User Guide

Register for an Account

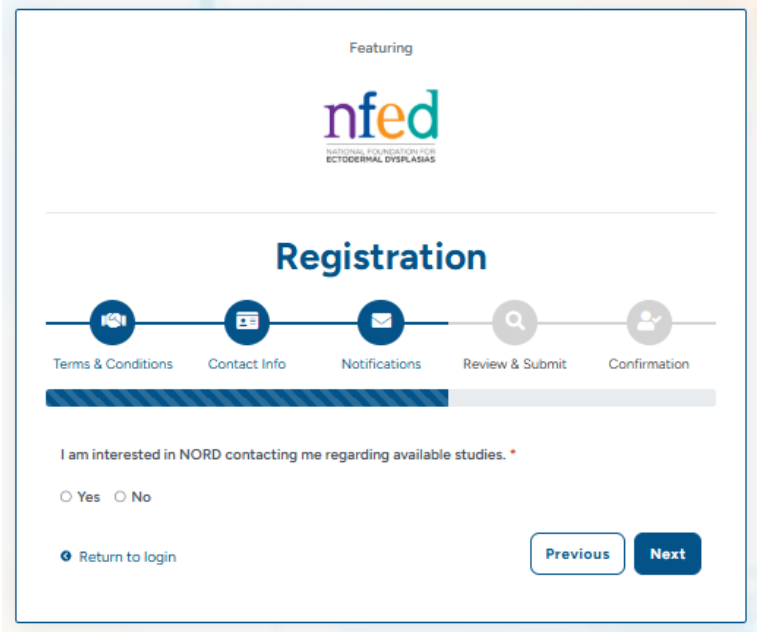
- Step 1: Read the Terms and Conditions and Privacy Policy and attest to the statements provided. When you are finished with this page, click “Next”.



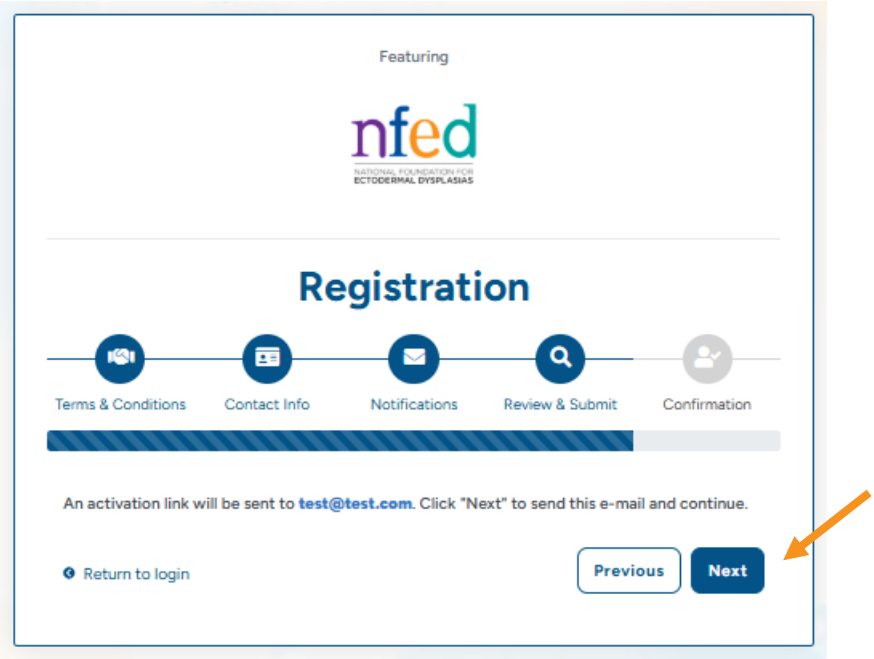
- Step 2: Enter your personal information in the spaces provided. When you are finished with this page, click “Next”.



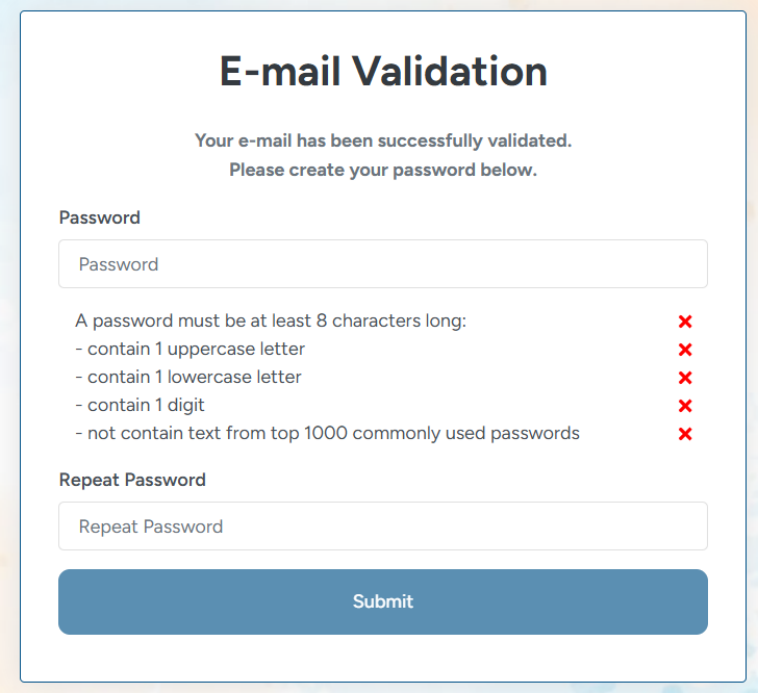
- Step 3: Select whether you are interested in being contacted by NORD regarding available studies. When you are finished with this page, click “Next”.



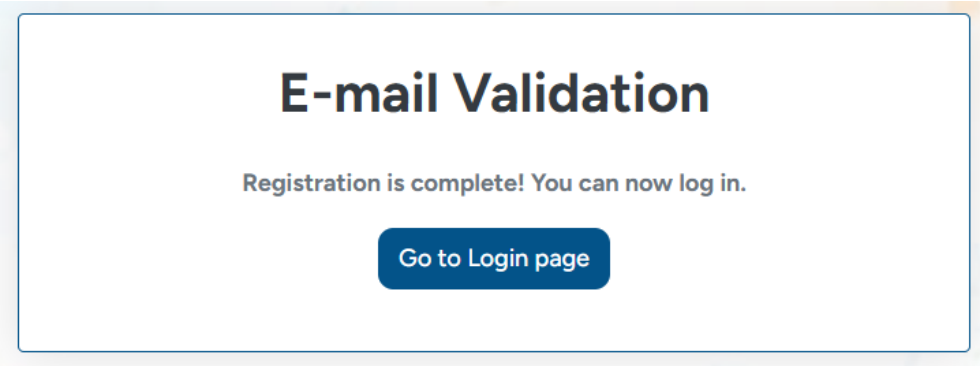
- Step 4: Select “Next” so that an activation link is sent to your e-mail to complete registration.



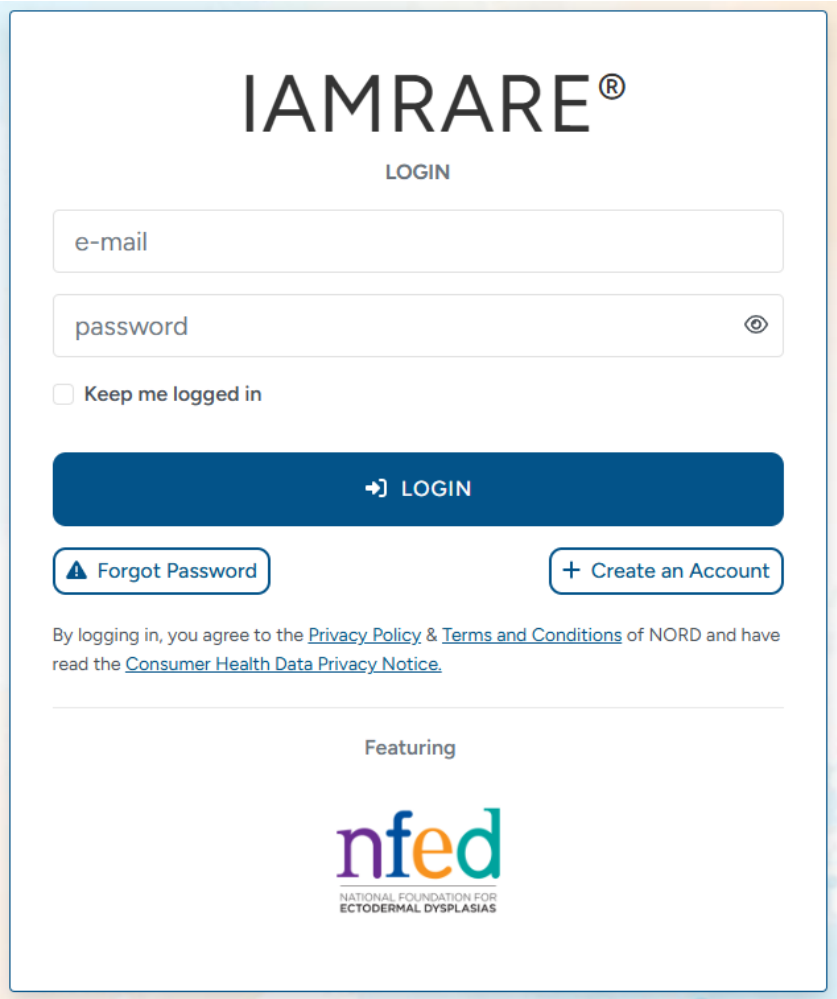
- Step 5: Click the link you are sent via e-mail. Please check your Spam folder if you do not see the e-mail. You will be taken to the following screen in a new tab within your browser. Set your password and click “Submit”.



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

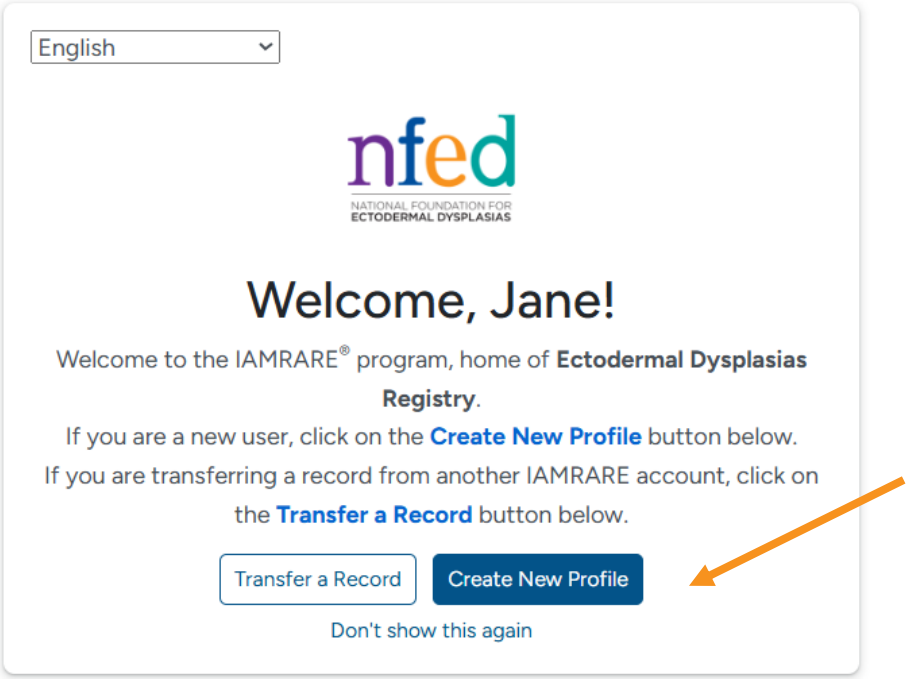


- Step 7: Log in using your new e-mail and password.

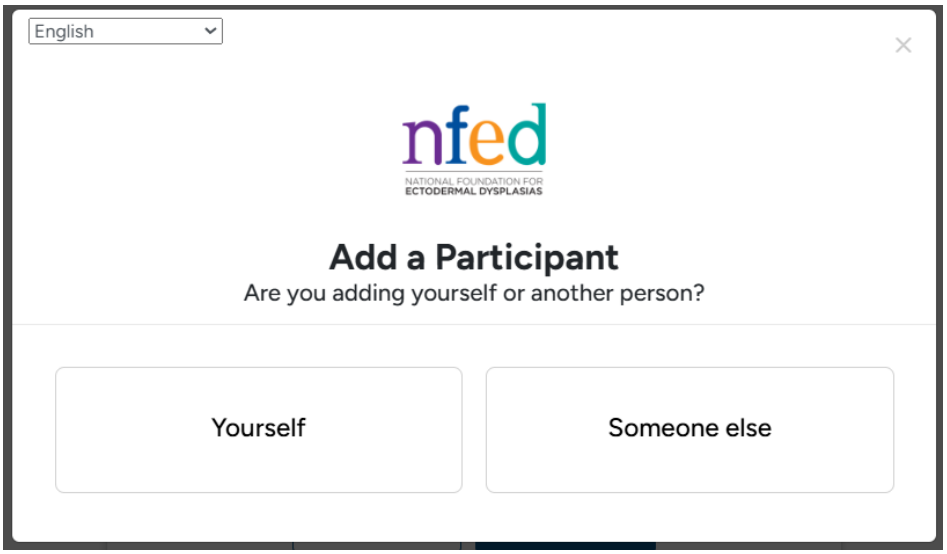


Add a Participant

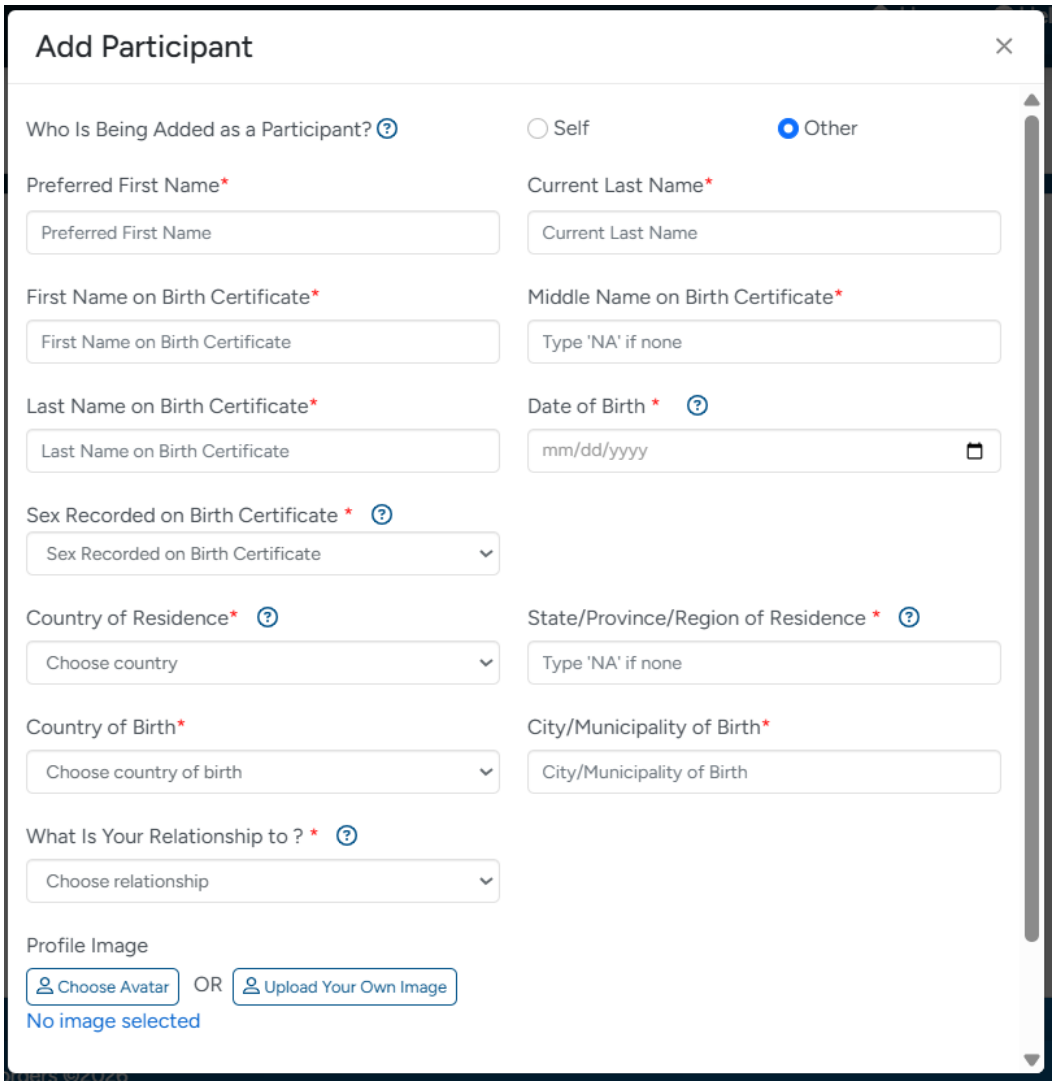
- Step 1: To start, click Create New Profile.



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



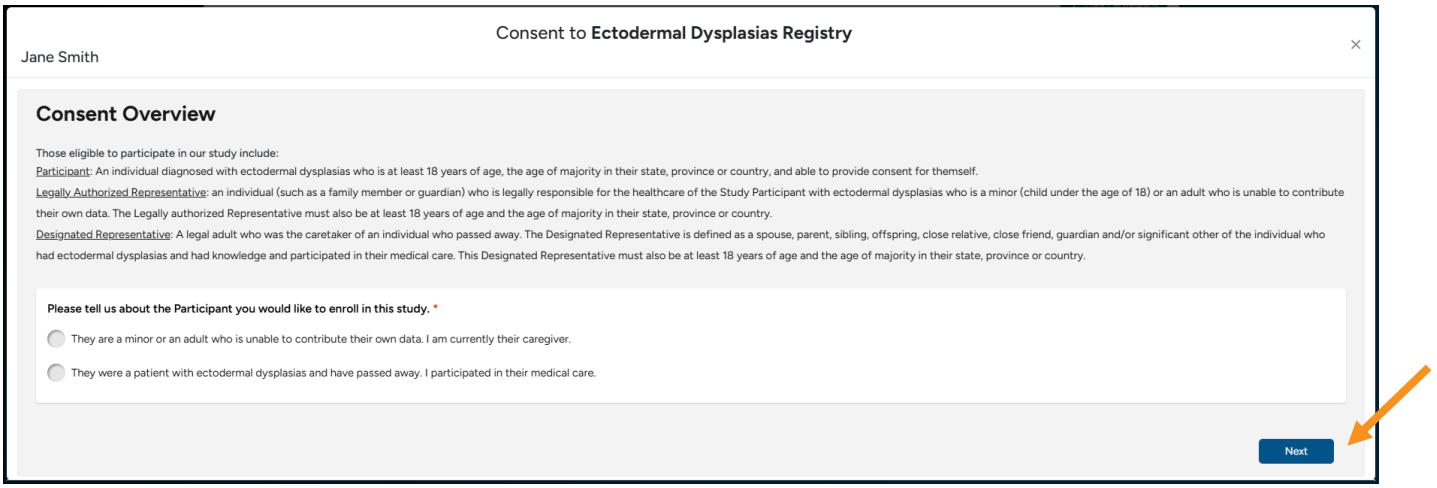
- Step 3: Fill out the Participant's information.

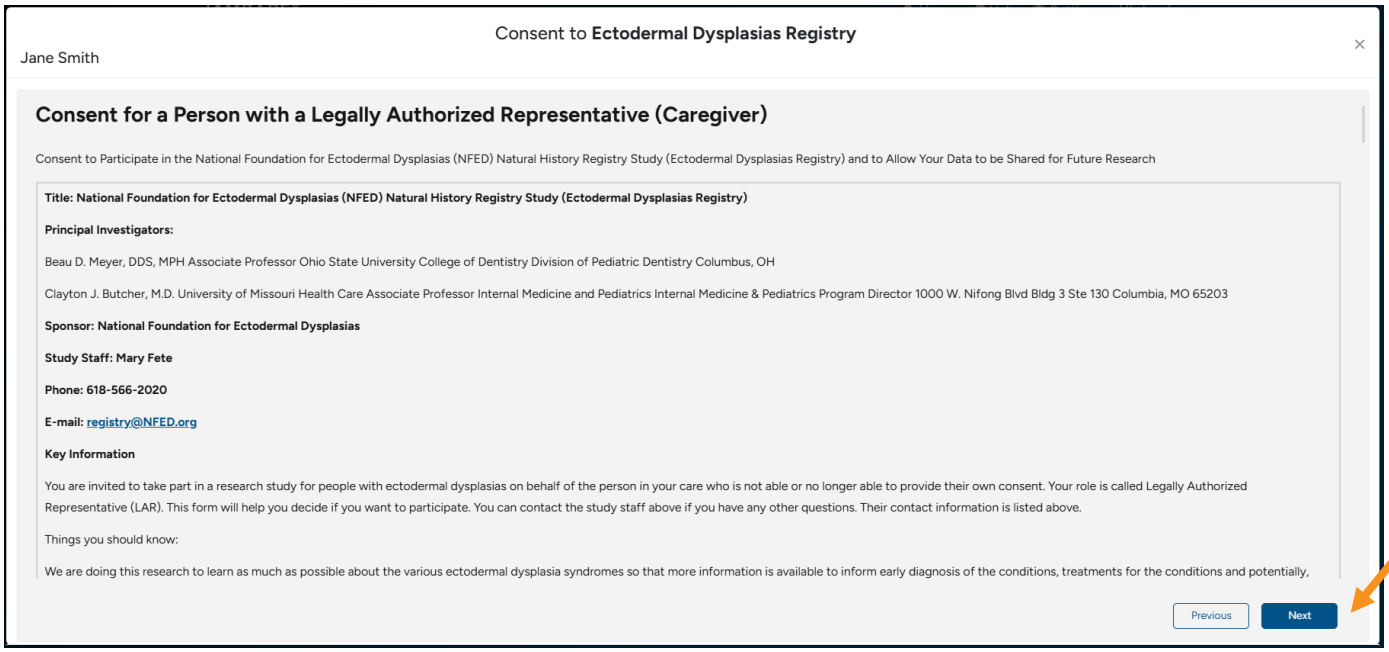


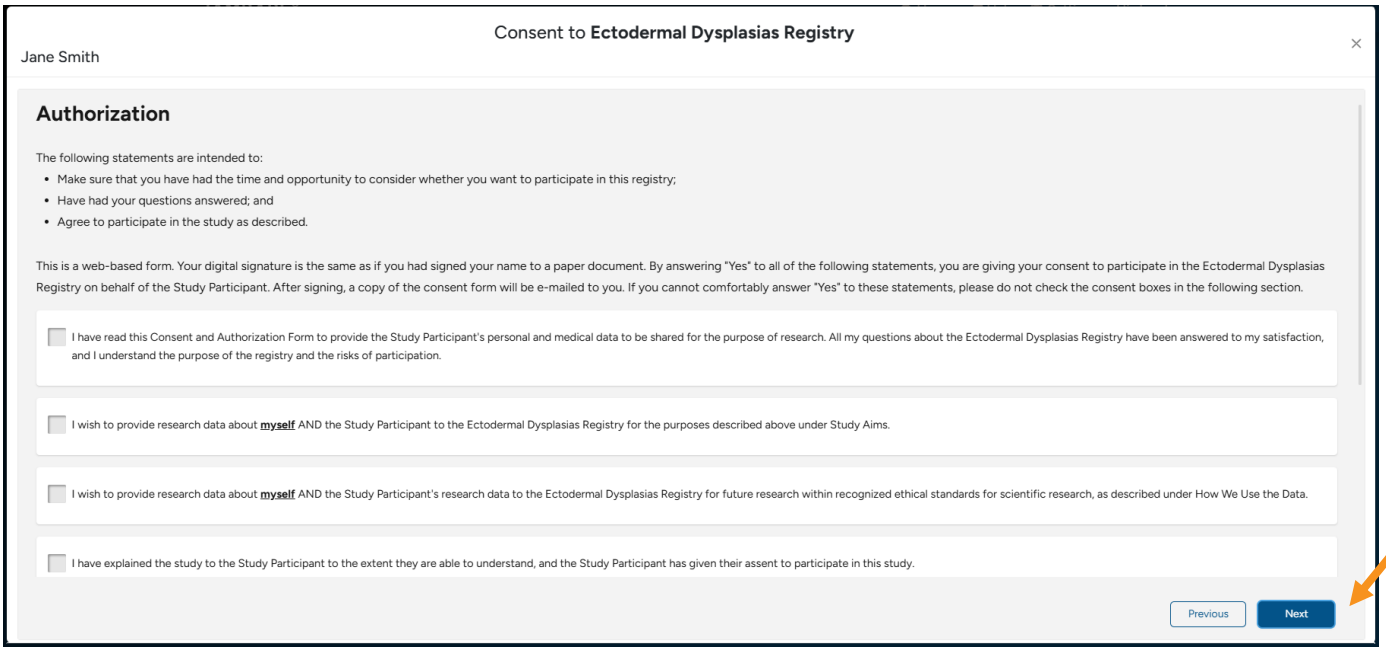
Consent to the Study

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

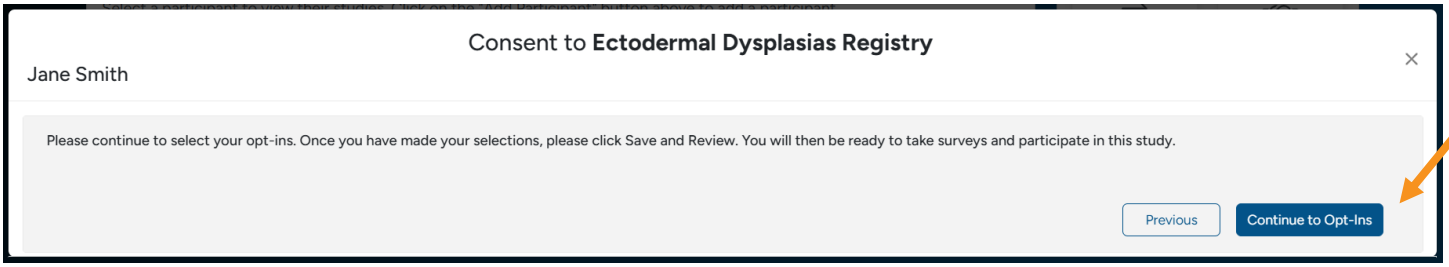
- Step 2: Scroll down and read through the consent form thoroughly. Once you finish each page, click the “Next” button. Once you reach the Authorization form, read through the statements thoroughly. If you are comfortable consenting to participate in the study, please read each statement and authorize your consent. After checking the boxes, click “Next.”



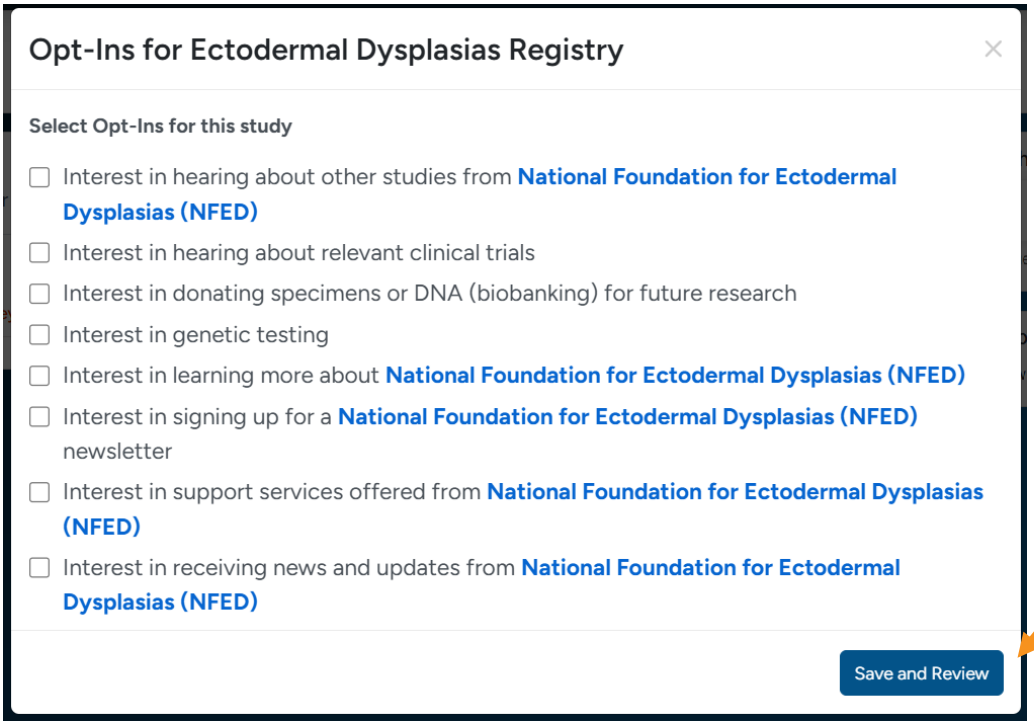




- Step 3: Once you click “Next” and reach the Thank You page, click “Continue to Opt-Ins”.



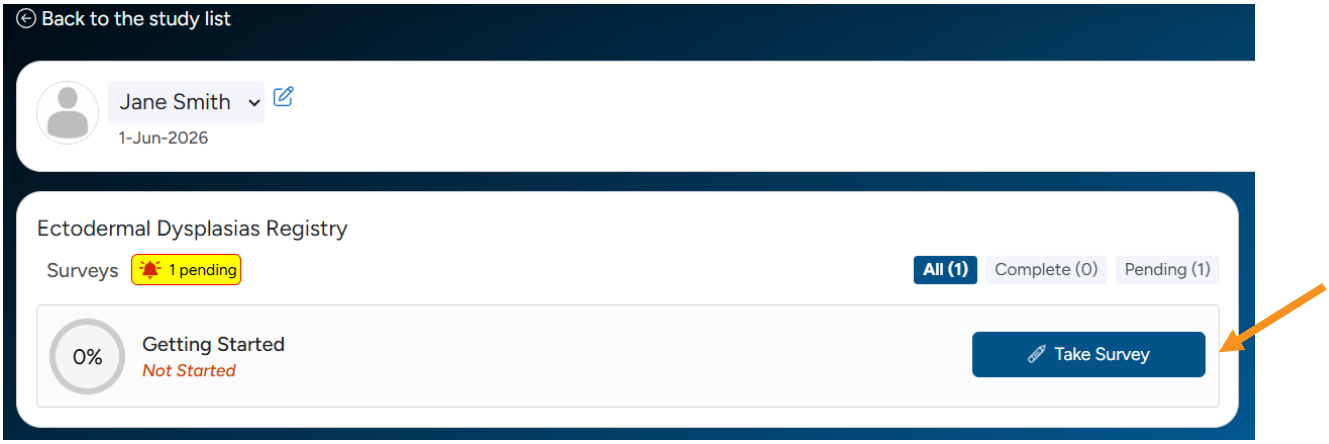
- Step 4: Once you click “Continue to Opt-Ins” read through the opt-ins thoroughly. If you would like to receive information about the topic, check the box, and click “Save and Review”.



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

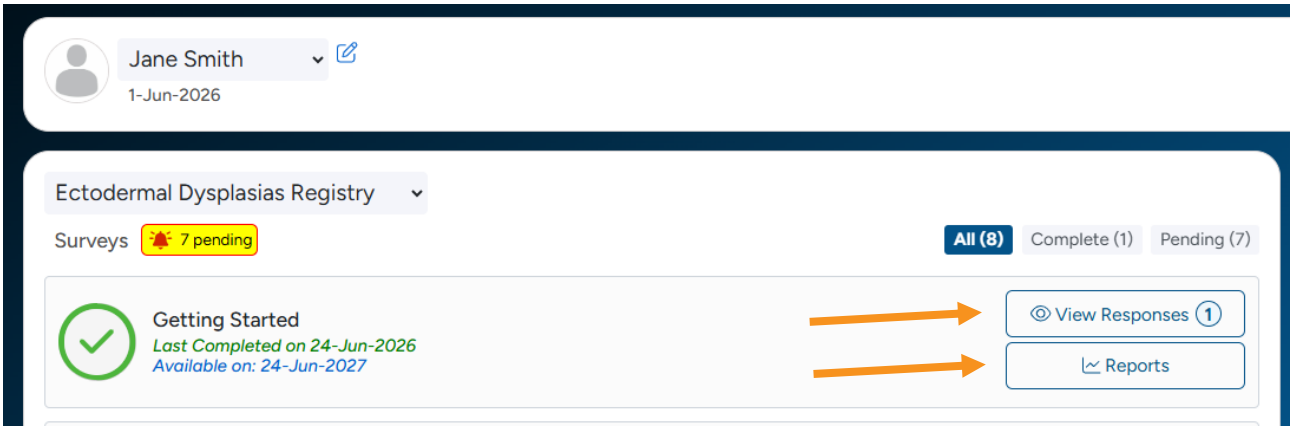
Taking Surveys

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



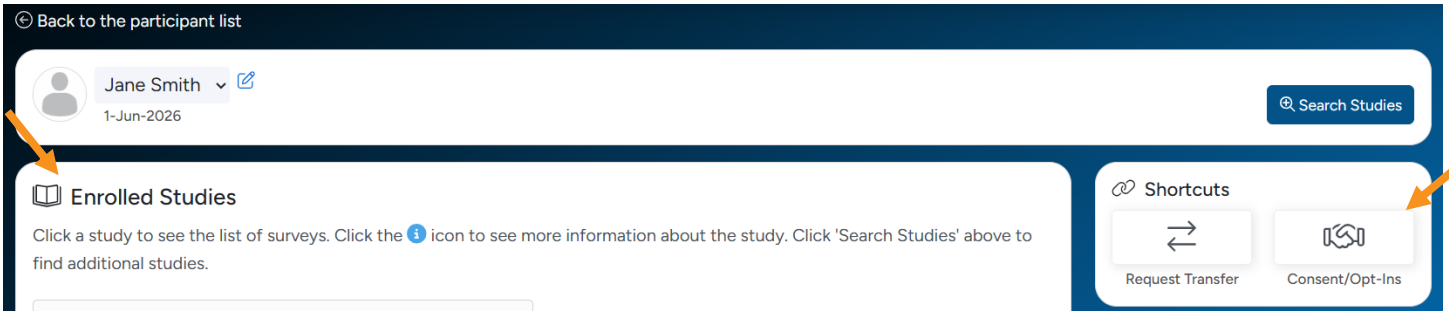
View Responses and Reports

- 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.

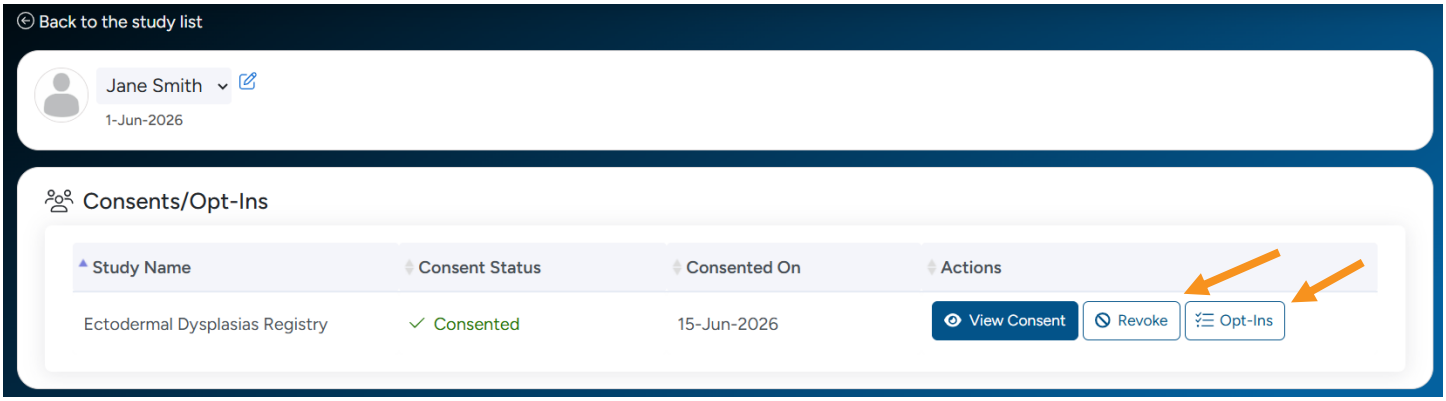


View Consent and Opt-Ins

- 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.



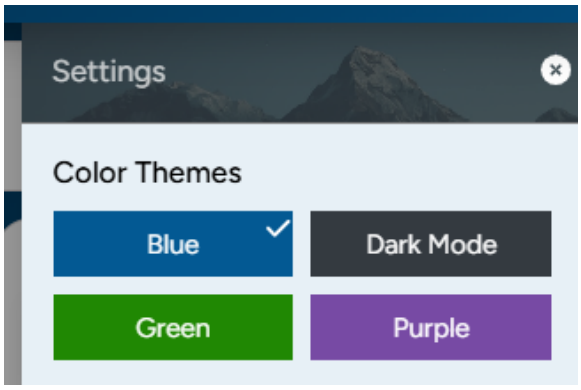
- Step 2: You may revoke your consent at any time by clicking “Revoke”. You may also edit your Opt-Ins by clicking “Opt-Ins”.



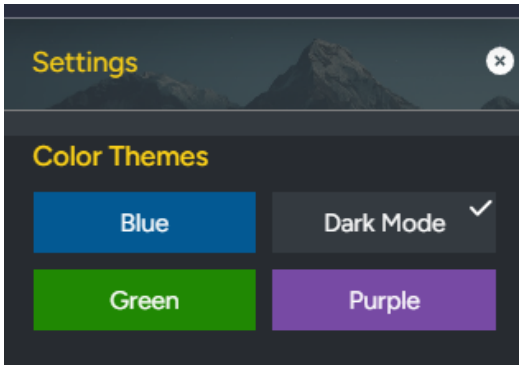
Dark Mode Settings

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

- Step 2: Select Dark Mode.



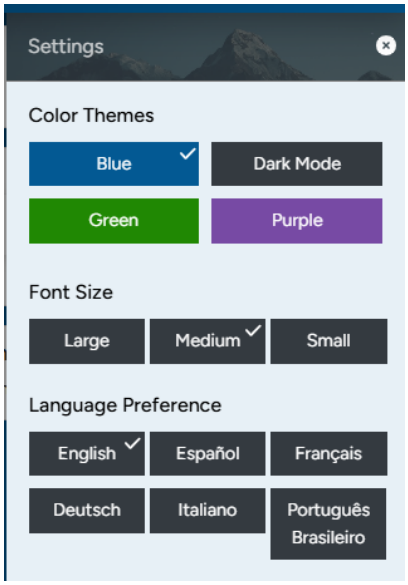
- Step 3: Exit the Settings menu, and your selection will be saved.



Display Settings

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

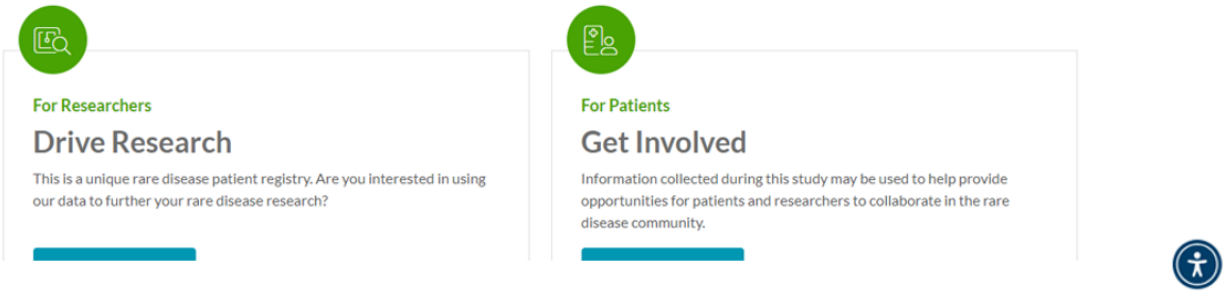
- Step 2: Select a color theme, a font size, or language preference.

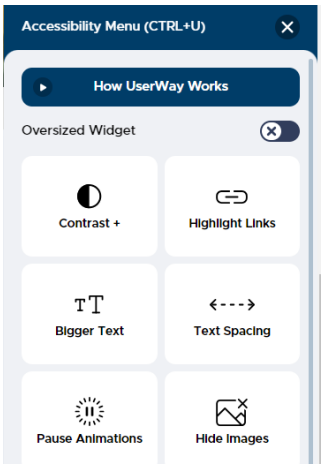


- Step 3: Exit the Settings menu, and your selection will be saved.

Microsite Visibility

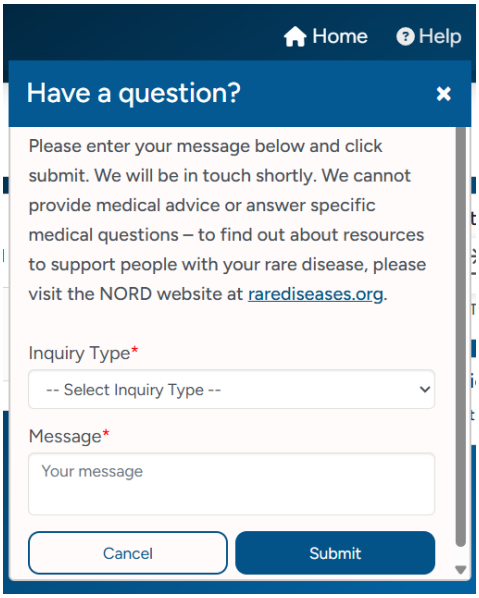
- Step 1: You can change how you view the microsite (ectodermaldysplasiasregistry.iamrare.org) using an Accessibility menu. Click the icon of a person at the bottom of the screen. You are able to change the settings such as the contrast, text sizing, and text spacing.





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.



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