



## CLOVES Syndrome 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”.

A screenshot of the CLOVES SYNDROME COMMUNITY registration page. At the top, it says "Featuring" above the CLOVES SYNDROME COMMUNITY logo. Below the logo is the word "Registration" in a large, bold, blue font. Underneath is a progress bar with five steps: "Terms & Conditions" (active, highlighted in blue), "Contact Info", "Notifications", "Review & Submit", and "Confirmation". Below the progress bar is a paragraph of text explaining the purpose of the documents and listing four items: 1) Standard policies for all studies, 2) A privacy statement, 3) Information on unacceptable uses, and 4) Information on addressing questions. This is followed by a section titled "Acknowledgements:" with four checkboxes and their corresponding statements. The first checkbox is selected. At the bottom left is a link "Return to login" and at the bottom right is a blue button labeled "Next".

Featuring

**CLOVES**  
SYNDROME COMMUNITY

### 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  
**CLOVES**  
SYNDROME COMMUNITY

## 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”.

Featuring  
**CLOVES**  
SYNDROME COMMUNITY

## Registration


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



Featuring

**CLOVES**  
SYNDROME COMMUNITY

## Registration

Terms & Conditions   Contact Info   Notifications   Review & Submit   Confirmation

An activation link will be sent to [test@test.com](mailto: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”.

## E-mail Validation

Your e-mail [your.email@email.com](mailto:your.email@email.com) has been successfully validated.  
Please create your password below.

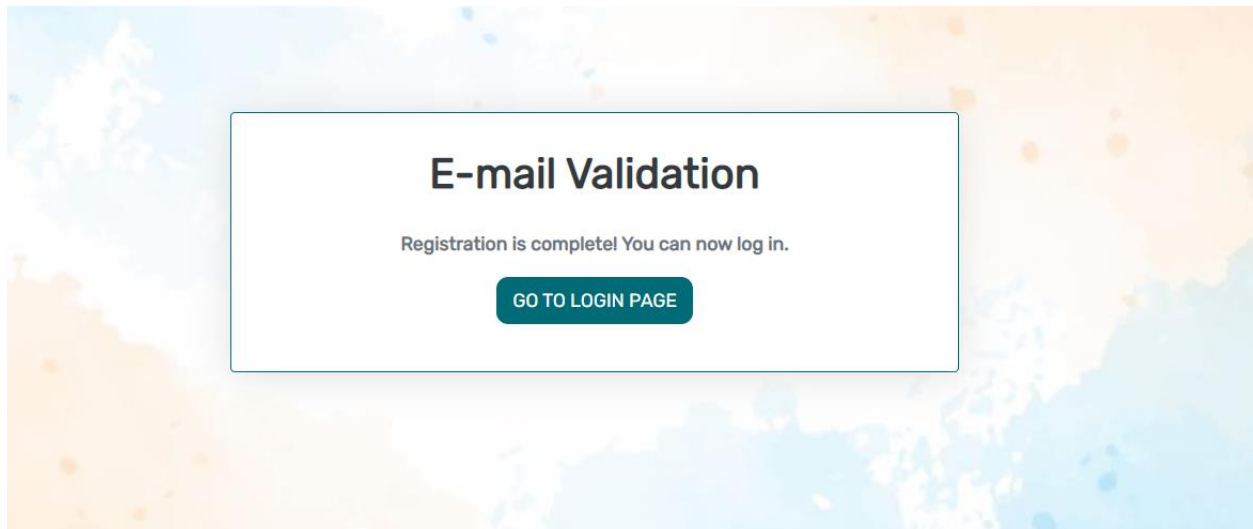
**Password**

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 ✗

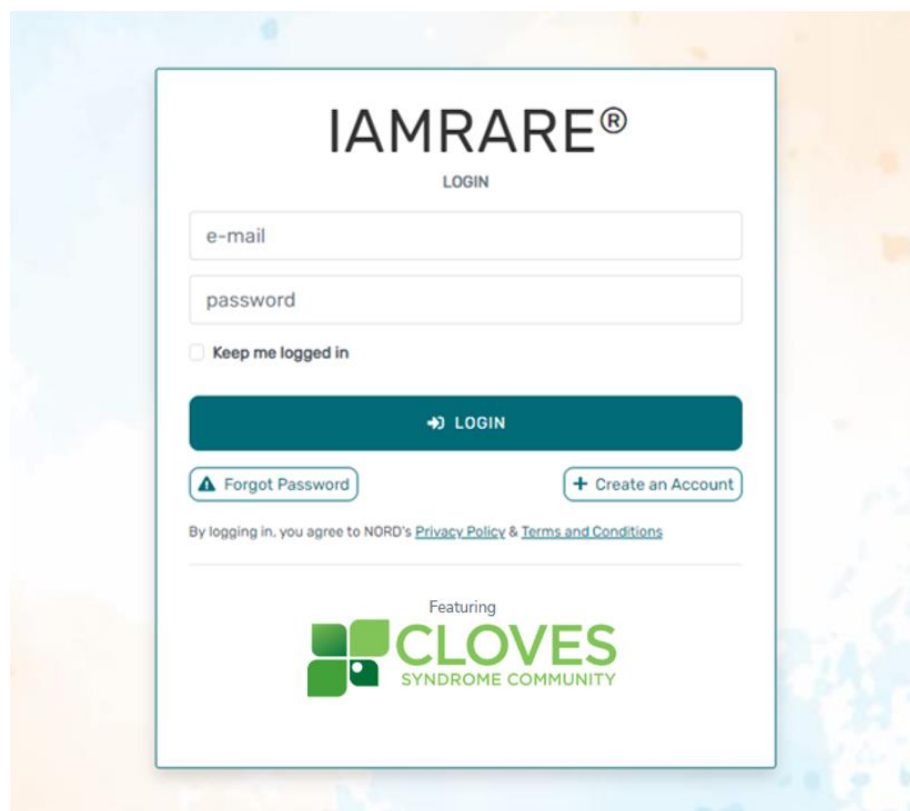
**Repeat Password**

[SUBMIT](#)

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

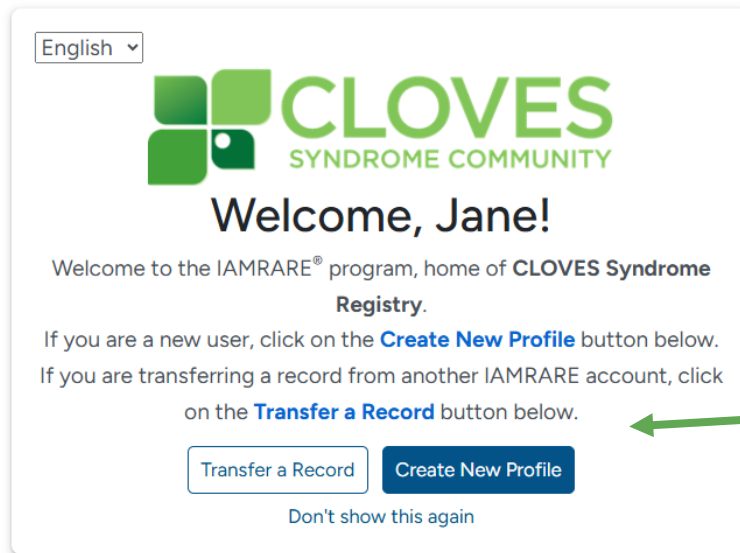


- Step 7: Log in using your new e-mail and password.

A screenshot of the IAMRARE login page. The page has a light blue and orange abstract background. The login form is a white rectangle with a thin blue border. At the top of the form is the "IAMRARE®" logo in black. Below the logo is the word "LOGIN" in a smaller, black, uppercase font. The form contains two input fields: "e-mail" and "password", both with placeholder text. Below these fields is a checkbox labeled "Keep me logged in". A large, dark teal button with a white right-pointing arrow and the word "LOGIN" is positioned below the checkbox. Underneath the button are two smaller buttons: "Forgot Password" (with a warning icon) and "Create an Account" (with a plus icon). Below these buttons is a line of text: "By logging in, you agree to NORD's [Privacy Policy](#) & [Terms and Conditions](#)". At the bottom of the form, it says "Featuring" above the "CLOVES SYNDROME COMMUNITY" logo, which consists of three green squares of varying shades and the text "CLOVES SYNDROME COMMUNITY" in green.

## Add a Participant

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



English ▾

**CLOVES**  
SYNDROME COMMUNITY

**Welcome, Jane!**

Welcome to the IAMRARE® program, home of **CLOVES Syndrome Registry**.

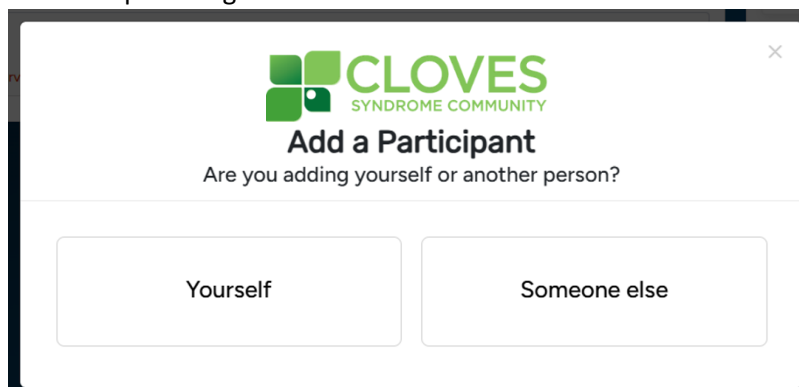
If you are a new user, click on the [Create New Profile](#) button below.

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.



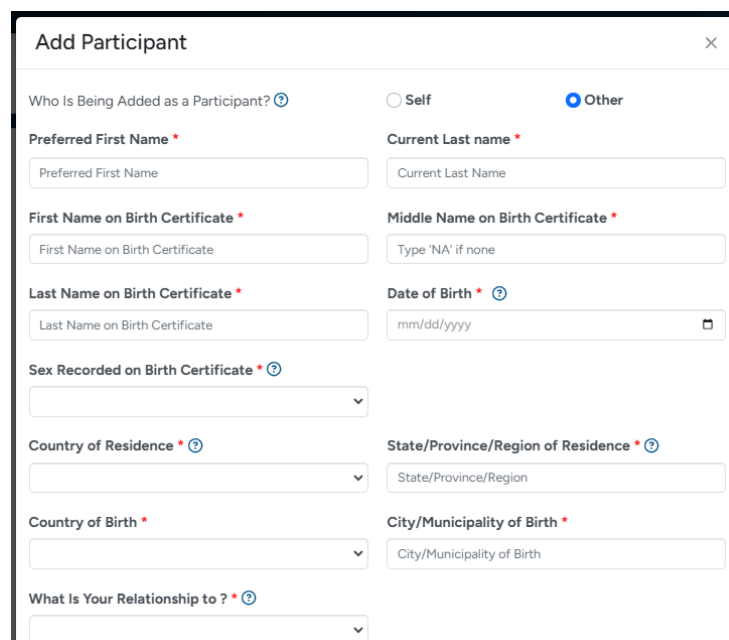
**CLOVES**  
SYNDROME COMMUNITY

**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 \*** ⓘ

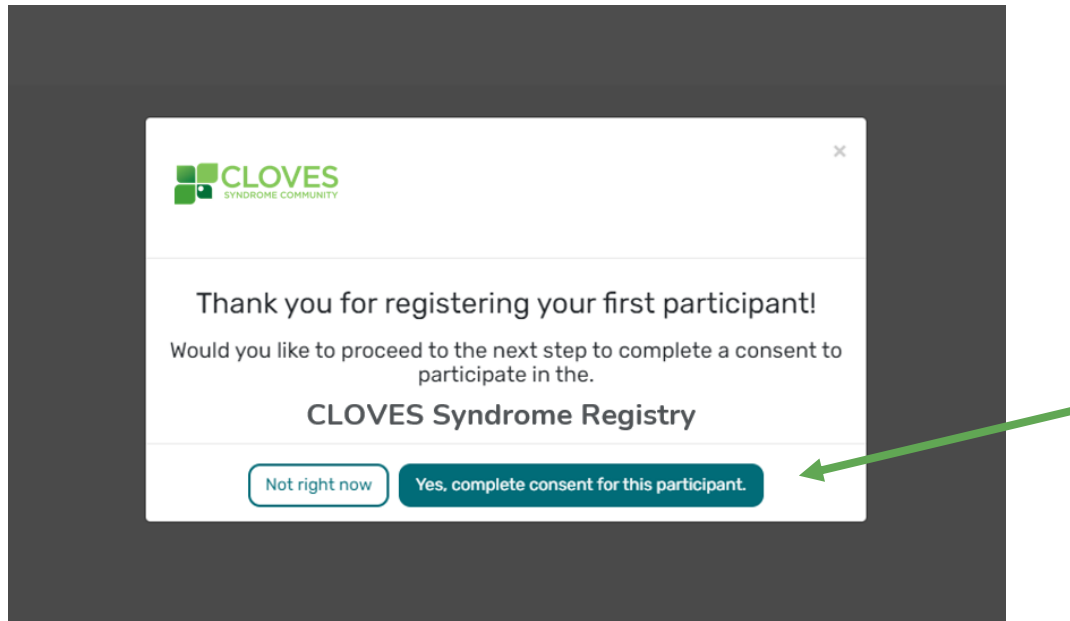
**Country of Residence \*** ⓘ  **State/Province/Region of Residence \*** ⓘ

**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.”



- 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.”

Back to participant list

### Consent to CLOVES Syndrome Registry

Jane Smith

#### Consent Overview

Those eligible to participate in our study include:

Participant: An individual diagnosed with CLOVES Syndrome 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 CLOVES Syndrome, defined as a spouse, parent, sibling, offspring, close relative, close friend, guardian and/or significant other of the individual who had CLOVES Syndrome 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 CLOVES Syndrome. I participated in their medical care.

Next

Consent to CLOVES Syndrome Registry

Jane Smith

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

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

Title: CLOVES Syndrome Registry

Principal Investigator: Lauren Beauregard, Executive Director

Phone: 833-425-6837

Email: [registry@clovessyndrome.org](mailto:registry@clovessyndrome.org)

Sponsor: CLOVES Syndrome Community

Key Information

You are invited to take part in a research study for individuals with CLOVES Syndrome on behalf of the person in your care. 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.

Previous

Next

Consent to CLOVES Syndrome 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:

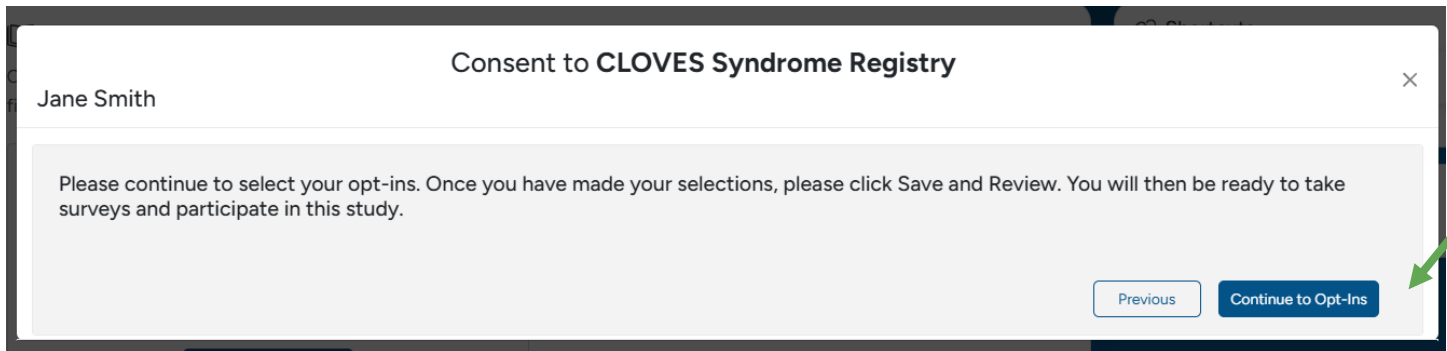
- That you have read the consent form and have no further questions about the registry and the Study Participant's participation;
- That you wish to provide the Study Participant's personal data to the registry for the purposes of the Study;
- That you allow for this data to be used for future research;
- 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 CLOVES Syndrome 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.

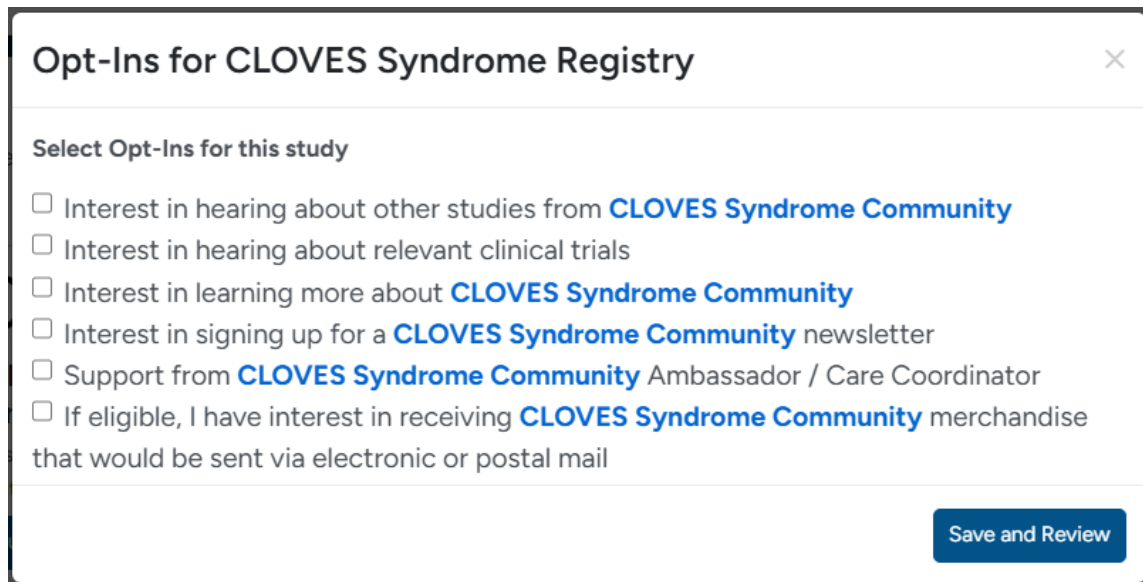
Previous

Next

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



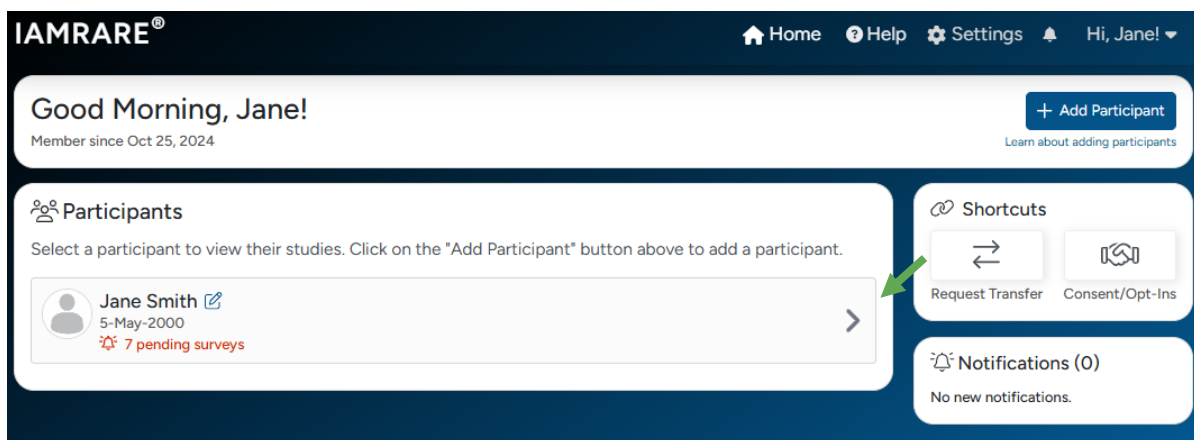
- Step 4: Once you click “Continue to Opt-Ins” read through the opt-ins thoroughly. If you would like to receive information about the topic, check the box, and click “Save and Review”.



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

## Taking Surveys

- Step 1: Click on your Participant.





- Step 2: Click on the appropriate study.

Back to participant list

Jane Smith 5-May-2000 [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.

**CLOVES SYNDROME COMMUNITY** English

**CLOVES Syndrome Registry**

CLOVES Syndrome Community

✓ 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-2000

**CLOVES Syndrome Registry**

Surveys **All (1)** Complete (0) Pending (1)

0% **CLOVES Syndrome Health History** *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 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.

Back to study list

Jane Smith 5-May-2000

**CLOVES Syndrome Registry**

Surveys **All (6)** Complete (1) Pending (5)

**CLOVES Syndrome Health History** *Completed on 28-Mar-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”.

The screenshot shows the IAMRARE interface. At the top, there's a header with a 'Back to participant list' link and a user profile for Jane Smith (5-May-2000). Below this is a 'Search Studies' button. The main content area is divided into two sections. The first section, 'Enrolled Studies', has a green arrow pointing to its title. It contains a description and a 'Search Studies' button. The second section, 'Consents/Opt-Ins', has a green arrow pointing to its title. It contains a table with columns: Study Name, Consent Status, Consented On, and Actions. The table has one row for 'CLOVES Syndrome Registry' with a 'Consented' status and a date of '28-Mar-2025'. The Actions column for this row has three buttons: 'View Consent', 'Revoke', and 'Opt-Ins'. A green arrow points to the 'Opt-Ins' button.

Back to participant list

Jane Smith 5-May-2000

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.

Shortcuts

Request Transfer

Consent/Opt-Ins

Back to study list

Jane Smith 5-May-2000

Consents/Opt-Ins

Study Name	Consent Status	Consented On	Actions
CLOVES Syndrome Registry	✓ Consented	28-Mar-2025	<a href="#">View Consent</a> <a href="#">Revoke</a> <a href="#">Opt-Ins</a>

## Dark Mode Settings

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

The screenshot shows the IAMRARE home page. At the top, there's a header with the IAMRARE logo and navigation links: Home, Help, Settings, and a user profile for Jane! (Hi, Jane!). Below this is a 'Good Afternoon, Jane!' greeting and a 'Member since Nov 16, 2024' note. There's an 'Add Participant' button. The main content area is divided into two sections: 'Participants' and 'Shortcuts'.

IAMRARE®

Home Help Settings Hi, Jane!

Good Afternoon, Jane!

Member since Nov 16, 2024

Add Participant

Participants

Shortcuts

- Step 2: Select Dark Mode.

The screenshot shows the 'Settings' dialog box. It has a title bar with 'Settings' and a close button. The main content area is titled 'Color Themes' and contains five buttons: 'Gray' (selected with a checkmark), 'Dark Mode', 'Blue', 'Green', and 'Purple'.

Settings

Color Themes

Gray ✓

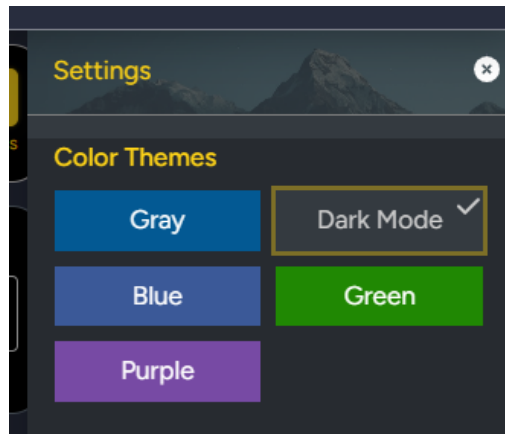
Dark Mode

Blue

Green

Purple

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

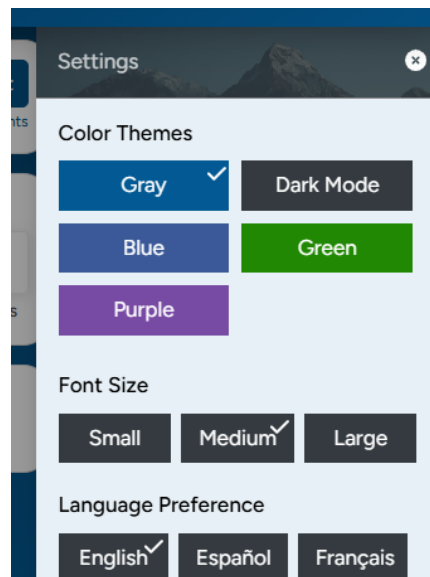


## Display Settings

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



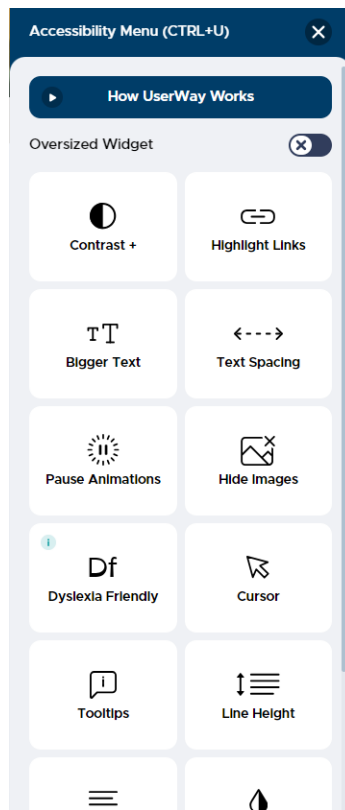
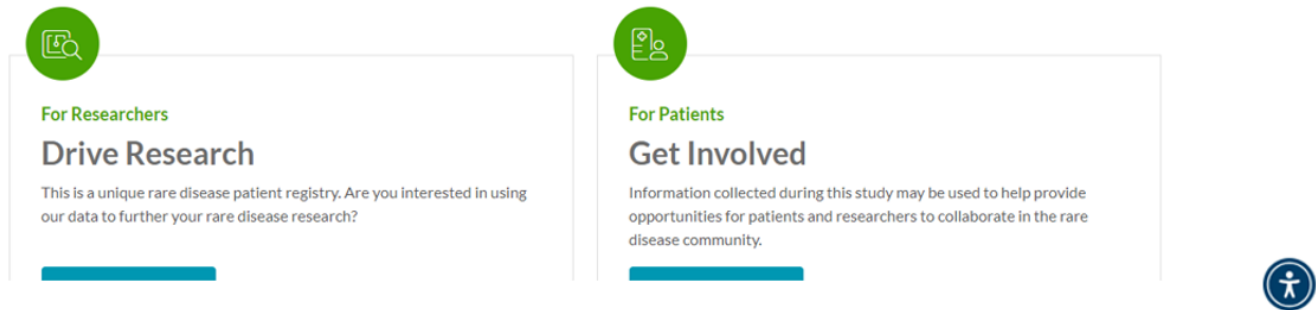
- Step 2: Select a color theme, a font size, or language preference.



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

## Microsite Visibility

- Step 1: You can change how you view the microsite [insert URL] 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.

The screenshot shows a mobile application interface with a dark blue header containing 'Home' and 'Help' icons. Below the header is a white modal window titled 'Have a question?' with a close button (X). The modal contains the following 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](http://rarediseases.org).' Below this text is a dropdown menu labeled 'Inquiry Type \*' with the placeholder '-- Select Inquiry Type --'. Underneath is a text input field labeled 'Message \*' with the placeholder '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 screenshot shows a contact information card for the 'CLOVES Syndrome Community'. The card has a blue header with the CLOVES logo (a green square with a white 'C') and the text 'CLOVES SYNDROME COMMUNITY'. To the right of the logo is the text 'CLOVES Syndrome Community' and a link 'clovessyndro...'. Below the header, the card is divided into sections: 'Contact' with 'Lauren Beauregard', 'Phone' with '833-425-6837', 'E-mail' with 'registry@clovessyndrome.org', 'IRB E-mail' with 'info@northstarreviewboard.org', and 'Social Media' with icons for Facebook, Twitter, and Instagram.