



CLOVES Syndrome Registry Participant User Guide

Register for an Account

- **Step 1:** Select the appropriate Account Type. If you need more information to help you choose, click “Not sure? Help me choose”.
 - If **you** have a diagnosis of CLOVES Syndrome, select **Participant Account**.
 - If you are entering information for **someone else** who has CLOVES Syndrome, select **Caregiver Account**.
 - If you are entering information for a CLOVES Syndrome **patient who has passed away**, select **Caregiver Account**.

A screenshot of the CLOVES Syndrome Registry registration page. At the top, it says "Featuring" above the CLOVES SYNDROME COMMUNITY logo. Below the logo is a horizontal line, followed by the heading "Select Account Type". There are two white rectangular boxes with rounded corners. The left box contains the text "I have a rare disease, condition, and/or diagnosis." and "Participant Account" below it. The right box contains the text "I am a family member or guardian of someone with a rare disease." and "Caregiver Account" below it. At the bottom left of the white area is a blue back arrow icon followed by the text "Return to login". At the bottom right is the text "Not sure? Help me choose.".

- **Step 2:** Read the Terms and Conditions and Privacy Policy and attest to the statements provided. When you are finished with this page, click “Next”.

Featuring
CLOVES
SYNDROME COMMUNITY

Caregiver 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.

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

Featuring
CLOVES
SYNDROME COMMUNITY

Caregiver Registration

Terms & Conditions Contact Info Notifications Review & Submit Confirmation

Country of Residence *

First Name * Last Name *

E-mail *

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

Step 4: Select whether you are interested in being contacted by NORD regarding available studies. When you are finished with this page, click “Next”.

The screenshot shows the 'Caregiver Registration' form for the 'Featuring CLOVES SYNDROME COMMUNITY'. The progress bar indicates that the 'Review & Submit' step is currently active. The form contains the following elements:

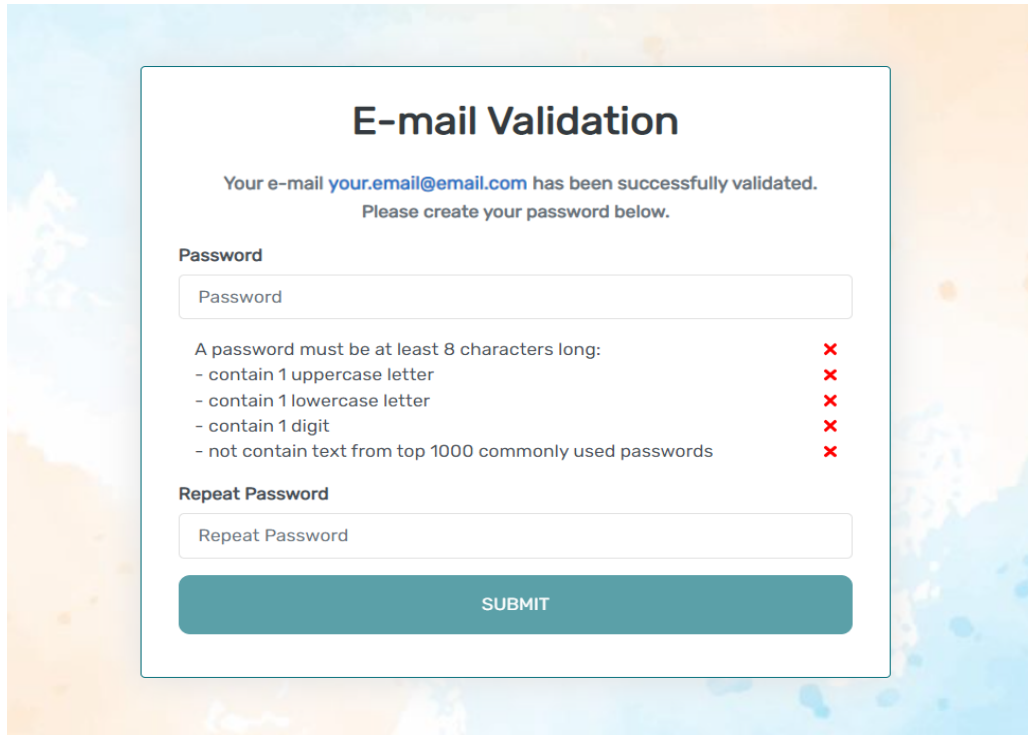
- Logo: Featuring CLOVES SYNDROME COMMUNITY
- Section Header: Caregiver Registration
- Progress Bar: Shows five steps: Terms & Conditions, Contact Info, Notifications, Review & Submit (active), and Confirmation.
- Text: I am interested in NORD contacting me regarding available studies. *
- Radio Buttons: Yes No
- Link: [Return to login](#)
- Buttons: [Previous](#) and [Next](#)

- Step 5: Select “Next” so that an activation link is sent to your e-mail to complete registration.

This screenshot shows the 'Caregiver Registration' form at the 'Review & Submit' step. The progress bar is now fully filled, indicating that all previous steps are complete. The form contains the following elements:

- Logo: Featuring CLOVES SYNDROME COMMUNITY
- Section Header: Caregiver Registration
- Progress Bar: Shows five steps: Terms & Conditions, Contact Info, Notifications, Review & Submit (active), and Confirmation.
- Text: An activation link will be sent to [your.email@email.com](#). Click "Next" to send this e-mail and continue.
- Link: [Return to login](#)
- Buttons: [Previous](#) and [Next](#). A green arrow points to the 'Next' button.

- Step 6: 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.

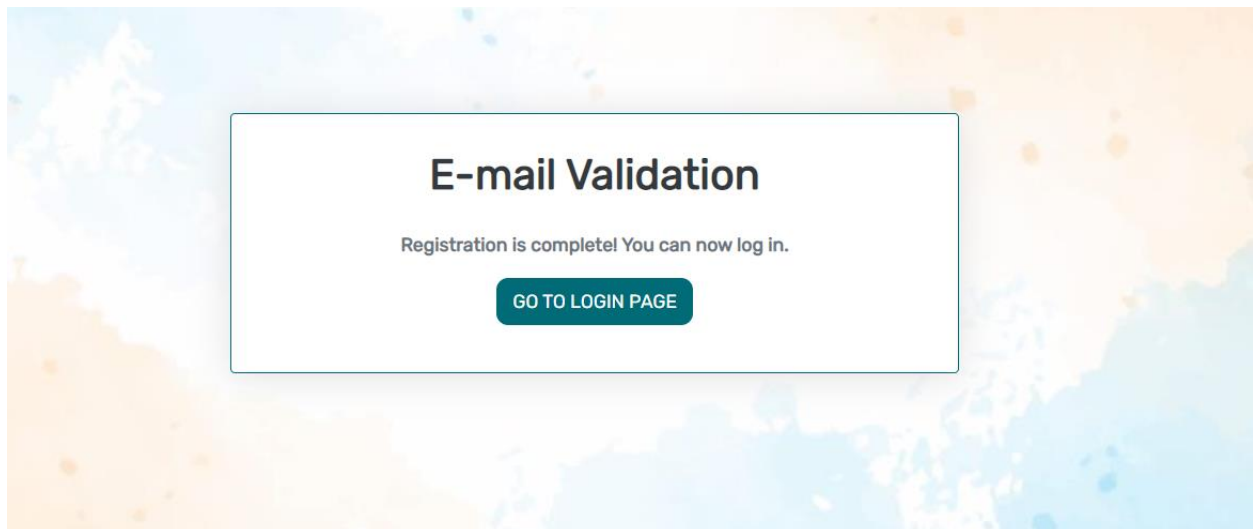
Password

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 7: Your validation is now complete. Select “Go to Login Page”.

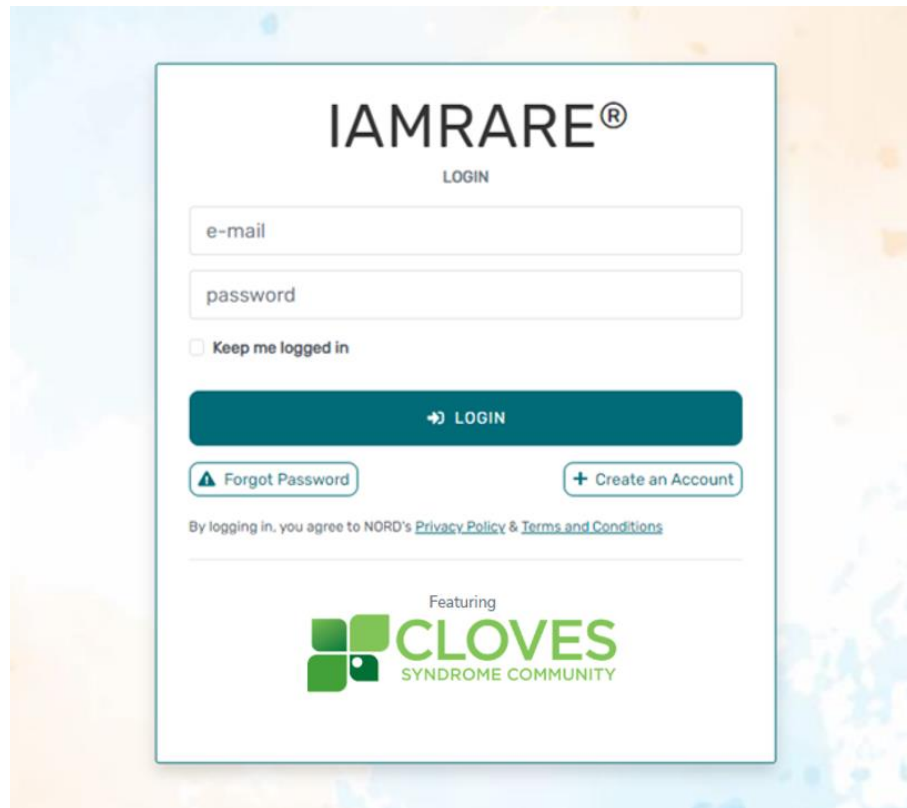


E-mail Validation

Registration is complete! You can now log in.

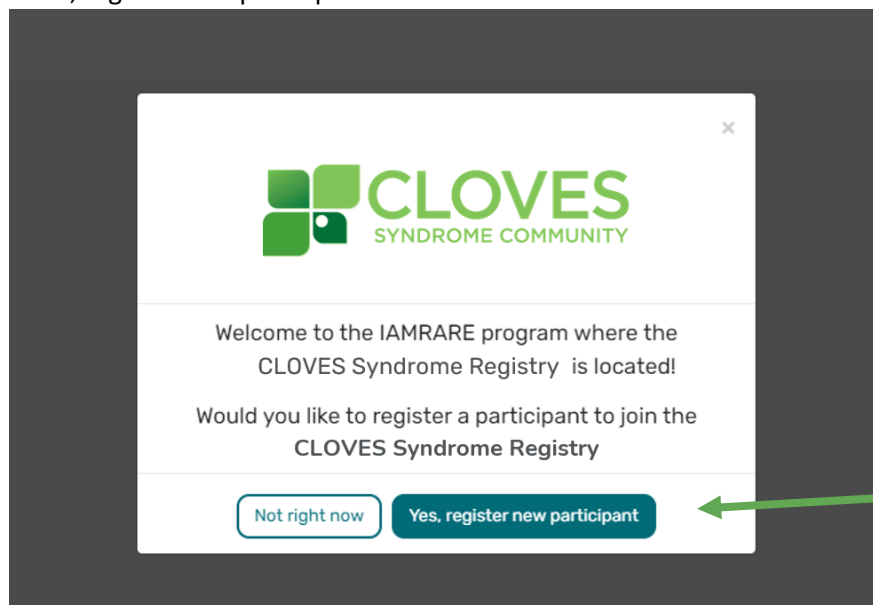
GO TO LOGIN PAGE

- Step 8: Log in using your new e-mail and password.



Add a Participant

- Step 1: To start, click Yes, register new participant.



- Step 2: Fill out the Participant’s information.

Add Participant ✕

Acknowledgement*

By checking this box, you acknowledge that information collected on this platform will only be used for research purposes by NORD and in ways that will not reveal who you are. Federal or state laws may require us to show information to university or government officials (or sponsors) who are responsible for monitoring the safety of any studies running on this platform. You will not be identified in any publications.

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 of Residence *

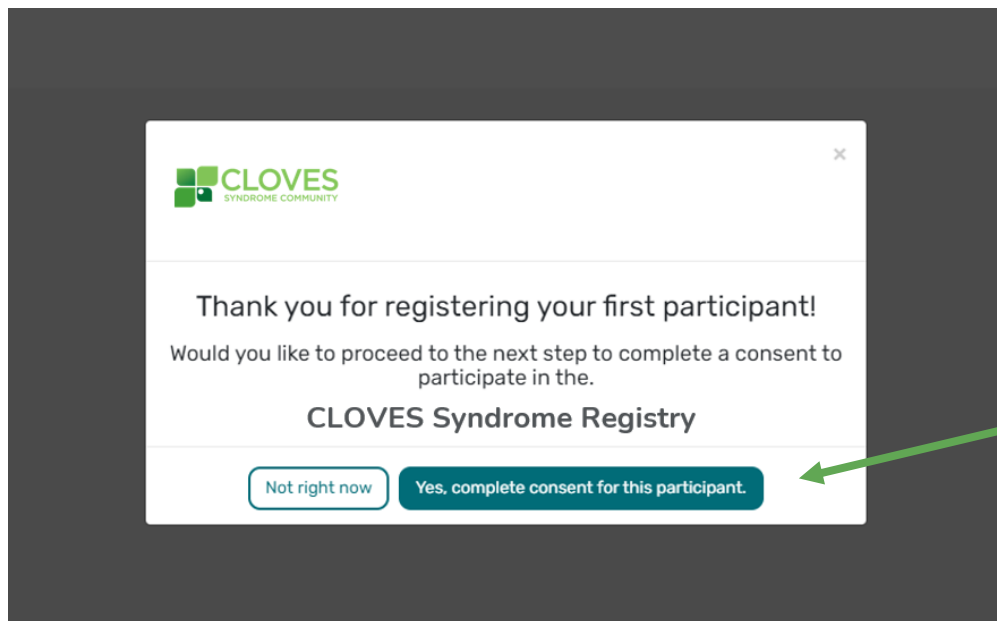
Country of Birth * ▼

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.”

Consent to CLOVES Syndrome Registry



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.

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 Rare Disease. I participated in their medical care.

Next



Consent to CLOVES Syndrome Registry



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

Title: CLOVES Syndrome Registry

Principal Investigator: Kristen Davis, Executive Director

Phone: 833-425-6837

Email: 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.

Things you should know:

We are doing this research to learn more about CLOVES Syndrome, its complications and disease progression.

If you choose to participate on behalf of the participant, you will be asked to complete surveys about the person with CLOVES Syndrome. This will take approximately 30 minutes.

Putting the Study Participant's data in the registry does not put you or them at any risk of physical harm. There is a risk that their privacy could be compromised if the data you provide online is inappropriately disclosed or misused. The registry is designed to make the chance of this happening very small. The registry surveys may ask questions that you or the Study Participant may find unpleasant or uncomfortable. These questions ask about the impact of CLOVES Syndrome on daily life, economic status, or mood.

Participating in our study may not help the Study Participant directly, but your time and information may help others with CLOVES Syndrome in the future. The direct benefits of participation are helping to:

- improve the quality of life for people living with CLOVES Syndrome;
- potentially informing future treatment options; and
- helping to learn about the disease.

It is up to you whether to participate in this study, and you can stop at any time. Please take time to read this entire form and ask questions before deciding whether to take part in this research project on behalf of the person in your care. As the guardian or legally authorized representative for the Study Participant, we encourage you to discuss the registry with the Study Participant to the extent compatible with their understanding. Detailed information about your participation in this study follows.

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Next



Consent to CLOVES Syndrome Registry



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.

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 CLOVES Syndrome 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 CLOVES Syndrome Registry for the purposes described above under Study Aims.

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

Previous

Next

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

Consent to CLOVES Syndrome Registry



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 CLOVES Syndrome Registry

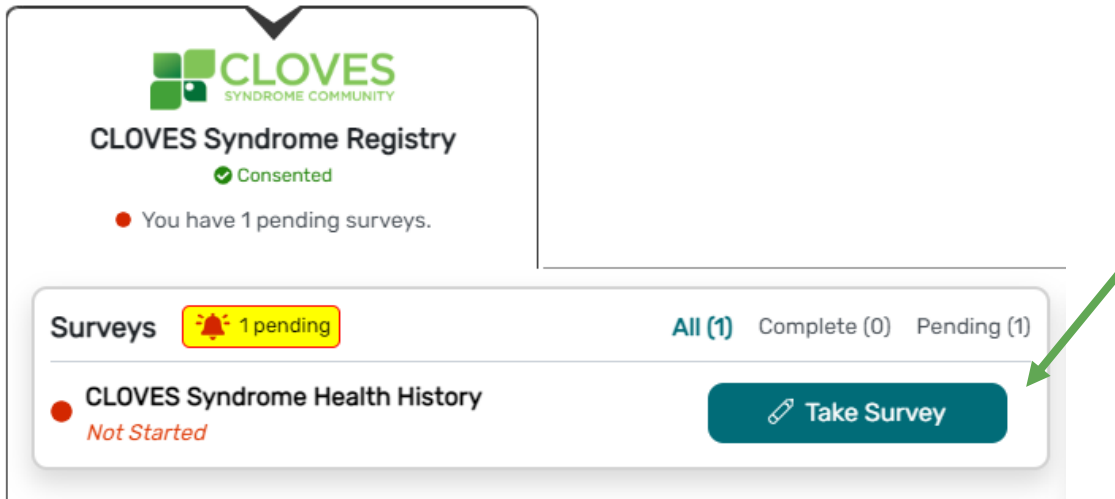


Select Opt-Ins for this study

- Interest in hearing about other studies from [CLOVES Syndrome Community](#)
- Interest in hearing about clinical trials you may be eligible for
- Interest in learning more about [CLOVES Syndrome Community](#)
- Interest in signing up for [CLOVES Syndrome Community's](#) newsletter
- Support from [CLOVES Syndrome Community](#) Ambassador / Care Coordinator
- If eligible, I have interest in receiving [CLOVES Syndrome Community's](#) merchandise that would be sent via electronic or postal mail

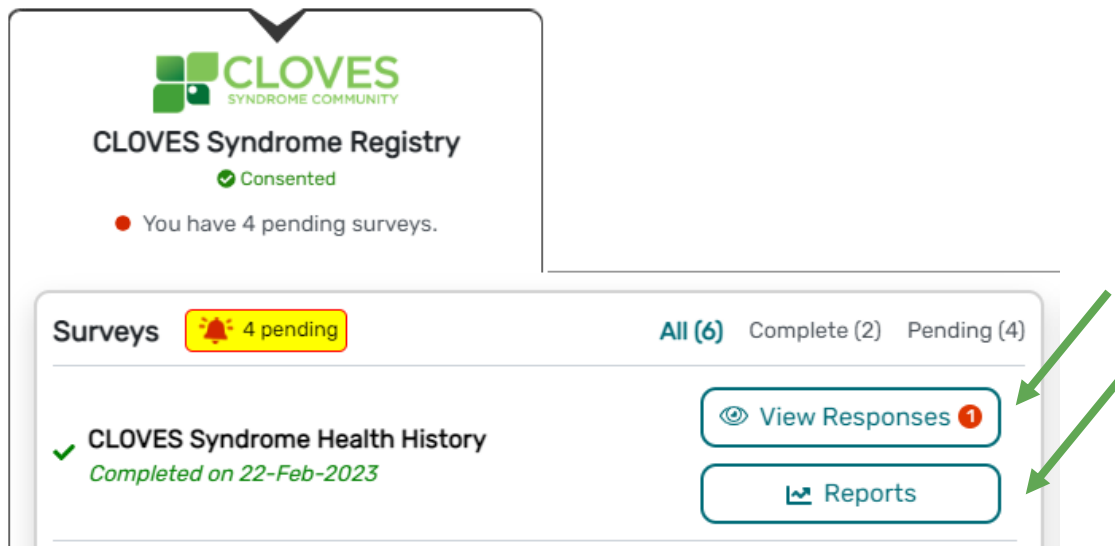
Save and Review

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



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. 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".

