



# CCHS NETWORK

FAMILY • FOUNDATION • SCIENCE

## 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



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## 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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## Registration

Terms & Conditions   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

Terms & Conditions   Contact Info   Notifications   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.

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## 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.

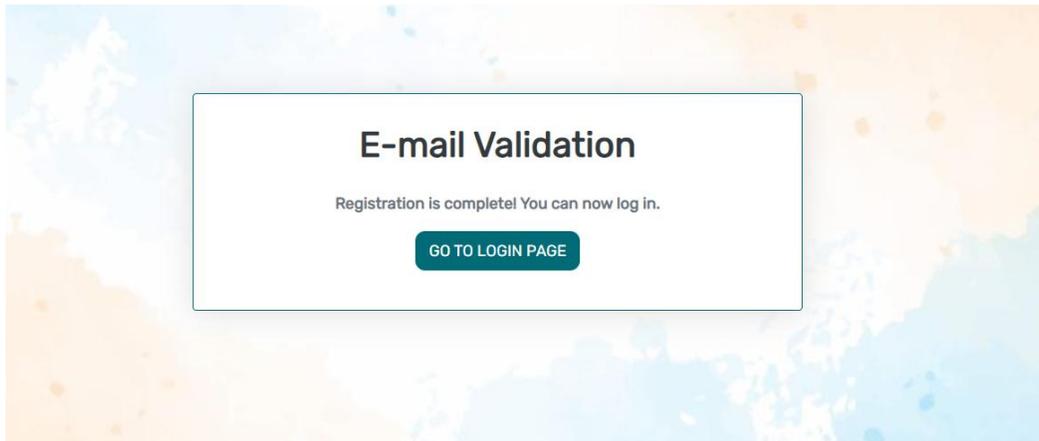
**Password**

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.

**IAMRARE<sup>®</sup>**  
LOGIN

e-mail

password 

Keep me logged in

**➔ LOGIN**

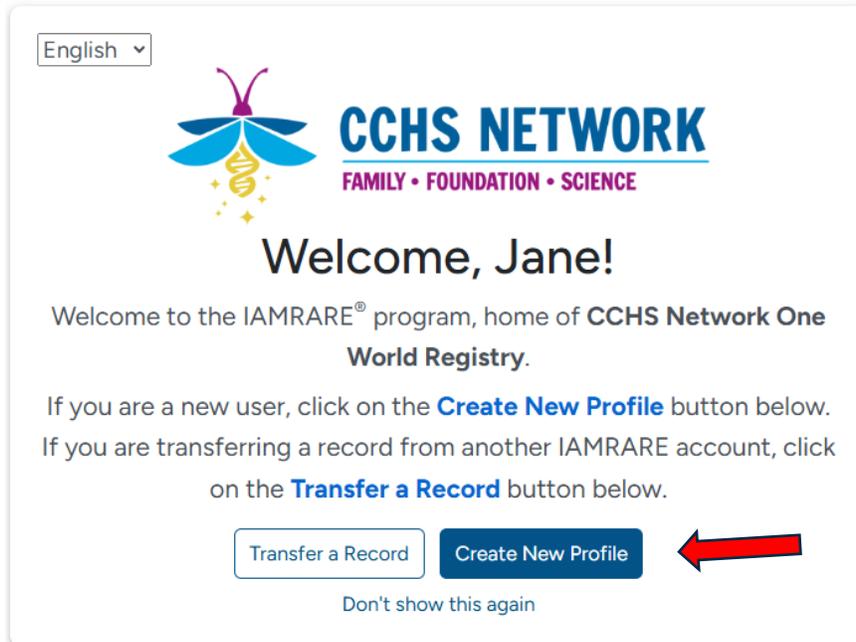
 Forgot Password **+** Create an Account

By logging in, you agree to NORD's [Privacy Policy](#) & [Terms and Conditions](#)

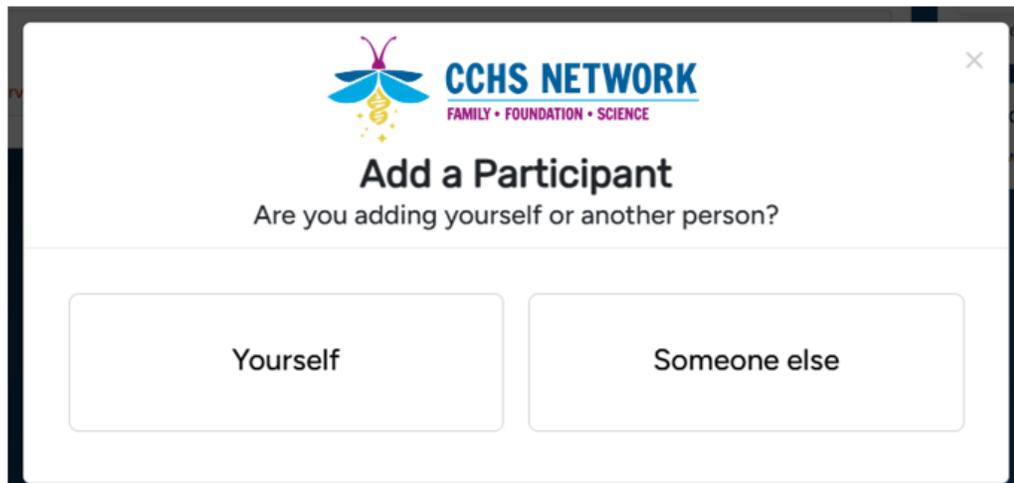


## Add a Participant

- 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.

### 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."



**CCHS NETWORK**  
CASTING A LIGHT IN THE DARK

Thank you for registering your first participant!

Would you like to consent to participate in **CCHS Network One World 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.”

## Consent to CCHS Network One World Registry

Answered 0/1 questions

### Consent Overview

Those eligible to participate in our study include:

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

Next

## Consent to CCHS Network One World Registry

Answered 1/8 questions

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

Consent to Participate in the CCHS Network One World Registry and to Allow Data to be Shared for Future Research

Title: CCHS Network One World Registry

Principal Investigator: Dr. Michelle Whalen, RN, DNP, NNP-BC, CNE

Phone: (781) 956-0754

Email: [oneworldregistry@cchsnetwork.org](mailto:oneworldregistry@cchsnetwork.org)

Sponsor: CCHS Network

#### Key Information

You are invited to take part in a research study for individuals with CCHS on behalf of the person in your care. We hope that this form will help you decide whether 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 be able to better describe individuals who have CCHS looking at the changes and stages of the disease over a person's lifetime. This study will help to inform best practices, management guidelines, and future recommendations of care. This research will also help to identify individuals who may want to participate in other research studies or clinical trials related to CCHS in the future.

If you choose to participate on behalf of the participant, you will be asked to complete survey questions annually using the online site. This will take approximately 1-2 hours.

You may experience the following risks, discomforts or inconveniences from participating:

As with any information you provide electronically, there is a risk that your privacy could be compromised if the data is inappropriately disclosed or misused. The CCHS Network One World Registry surveys will ask questions about the impact of CCHS on your daily life, economic status, mood, and other topics that could potentially be unpleasant or upsetting.

Previous

Next

**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 CCHS Network One World 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 CCHS Network One World 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 CCHS Network One World Registry for the purposes described above under Study Aims.

Previous

Next

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

## Consent to CCHS Network One World 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 CCHS Network One World Registry

Select Opt-Ins for this study

- Interest in hearing about other studies from **CCHS Network**
- 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 **CCHS Network**
- Interest in signing up for a **CCHS Network** newsletter

**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.

The screenshot shows the IAMRARE user interface. At the top, there is a navigation bar with 'Home', 'Help', 'Settings', and a user profile 'Hi, Jane!'. Below this, a greeting 'Good Afternoon, Jane!' is displayed along with 'Member since Apr 02, 2025' and an '+ Add Participant' button. The main content area is divided into three sections: 'Participants', 'Shortcuts', and 'Notifications'. The 'Participants' section shows a list with one entry for 'Jane Smith', born '5-May-2000', with '20 pending surveys'. A red arrow points to a chevron icon on the right of this entry. The 'Shortcuts' section contains two buttons: 'Request Transfer' and 'Consent/Opt-Ins'. The 'Notifications' section shows '0' notifications.

- Step 2: Click on the appropriate study.

This screenshot shows the 'Enrolled Studies' page for Jane Smith. It features a 'Back to participant list' link, a dropdown menu for 'Jane Smith', and a 'Search Studies' button. The 'Enrolled Studies' section contains a card for 'CCHS Network One World Registry', which is marked as 'Consented' and has '20 pending surveys'. A red arrow points to the study card. To the right, there are 'Shortcuts' for 'Request Transfer' and 'Consent/Opt-Ins', and a 'Notifications (0)' section.

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

This screenshot shows the 'Getting Started' survey progress page for Jane Smith. It includes a 'Back to study list' link, a dropdown for 'Jane Smith', and a title 'CCHS Network One World Registry'. Below the title, it shows 'Surveys' with '20 pending' in a yellow box and a filter for 'All (20)'. A progress indicator shows '0%' and 'Not Started'. A 'Take Survey' button is located at the bottom right. A red arrow points to this button.

## 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.

The screenshot shows a user profile for Jane Smith (5-May-2000) at the top. Below is the 'CCHS Network One World Registry' section. It displays 'Surveys' with a status of '18 pending'. There are two tabs: 'All (20)' (selected) and 'Complete (2)'. Under the 'Complete (2)' tab, two survey items are listed: 'Getting Started' and 'Participant Profile', both completed on 2-Apr-2025. For each survey, there are two buttons: 'View Responses' (with a circled '1') and 'Reports'. Red arrows point from the survey titles to these buttons.

## 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.

The screenshot shows the 'Enrolled Studies' page for Jane Smith. At the top left is a 'Back to participant list' link. The user profile is shown. A 'Search Studies' button is at the top right. Below the header is the 'Enrolled Studies' section with instructions. To the right is a 'Shortcuts' section with two buttons: 'Request Transfer' and 'Consent/Opt-Ins'. Red arrows point to the user profile and the 'Consent/Opt-Ins' button.

- Step 2: 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 'Consents/Opt-Ins' page for Jane Smith. At the top left is a 'Back to study list' link. The user profile is shown. Below is a table with the following data:

Study Name	Consent Status	Consented On	Actions
CCHS Network One World Registry	✓ Consented	2-Apr-2025	View Consent Revoke Opt-Ins

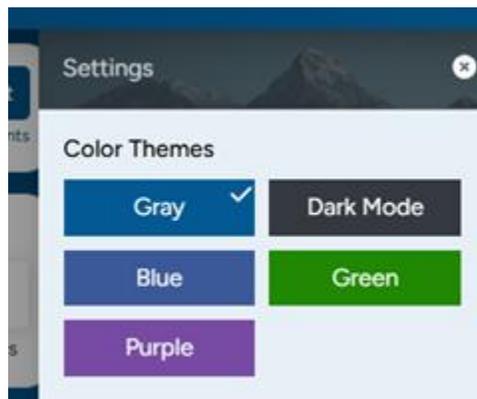
Red arrows point to the 'View Consent', 'Revoke', and 'Opt-Ins' buttons in the Actions column.

## Dark Mode Settings

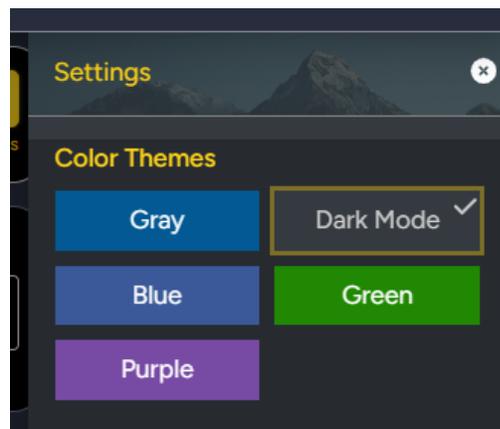
- Step 1: You can view the platform in Dark Mode. First, click Settings.



- Step 2: Select Dark Mode.



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

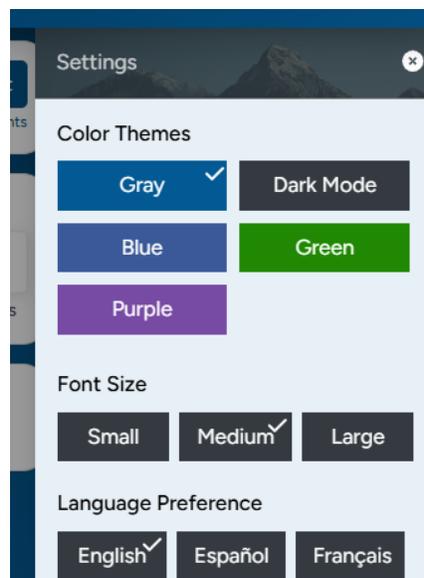


## Display Settings

- 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 ([cchsnowregistry.iamrare.org](https://cchsnowregistry.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.



For Researchers

### Drive Research

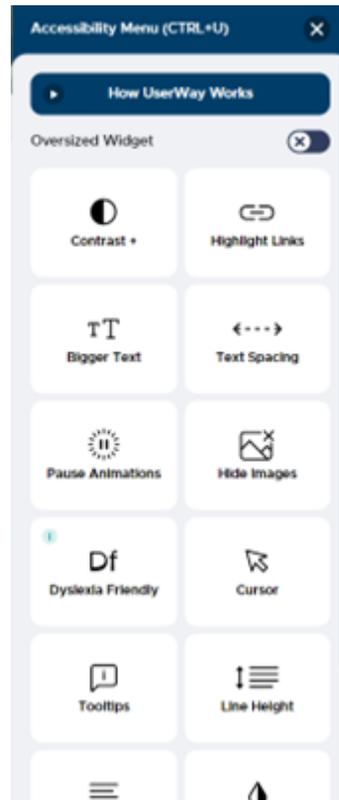
This is a unique rare disease patient registry. Are you interested in using our data to further your rare disease research?



For Patients

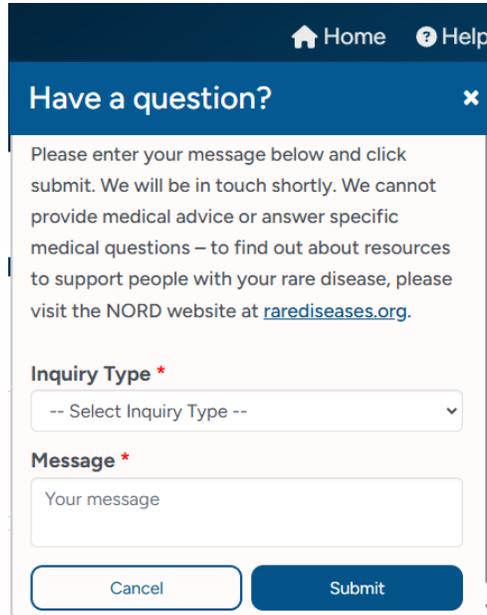
### Get Involved

Information collected during this study may be used to help provide opportunities for patients and researchers to collaborate in the rare disease community.



## Need Assistance?

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



Home Help

### Have a question?

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).

**Inquiry Type \***

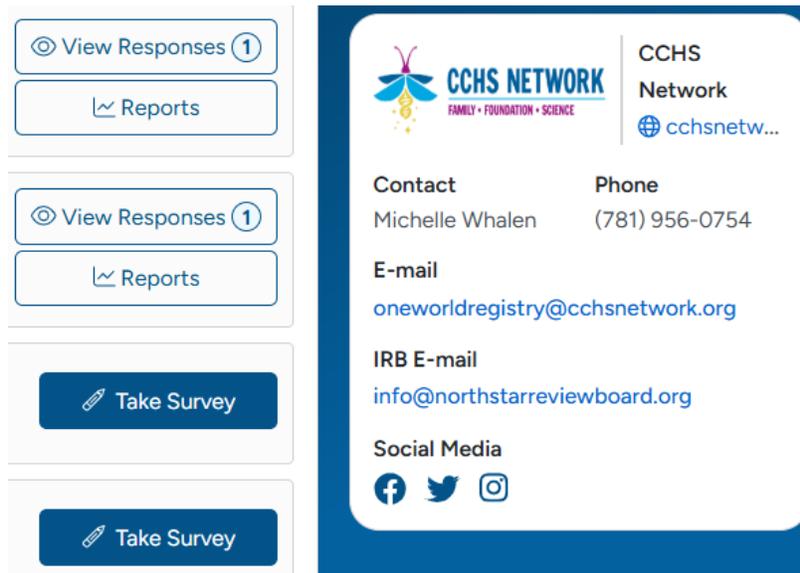
-- Select Inquiry Type --

**Message \***

Your message

Cancel 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.



View Responses 1

Reports

View Responses 1

Reports

Take Survey

Take Survey

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CCHS Network  
cchsnet...

**Contact**  
Michelle Whalen

**Phone**  
(781) 956-0754

**E-mail**  
[oneworldregistry@cchsnetwork.org](mailto:oneworldregistry@cchsnetwork.org)

**IRB E-mail**  
[info@northstarreviewboard.org](mailto:info@northstarreviewboard.org)

**Social Media**

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