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".

1779 MASSACHUSETTS AVENUE NW, SUITE 500
WASHINGTON, DC 20036
T 202-588-5700 ▪ F 202-588-5701

55 KENOSIA AVENUE
DANBURY, CT 06810
T 203-744-0100 ▪ F 203-263-9938

1900 CROWN COLONY DRIVE, SUITE 310
QUINCY, MA 02169
T 617-249-7300 ▪ F 617-249-7301

rarediseases.org ▪ orphan@rarediseases.org

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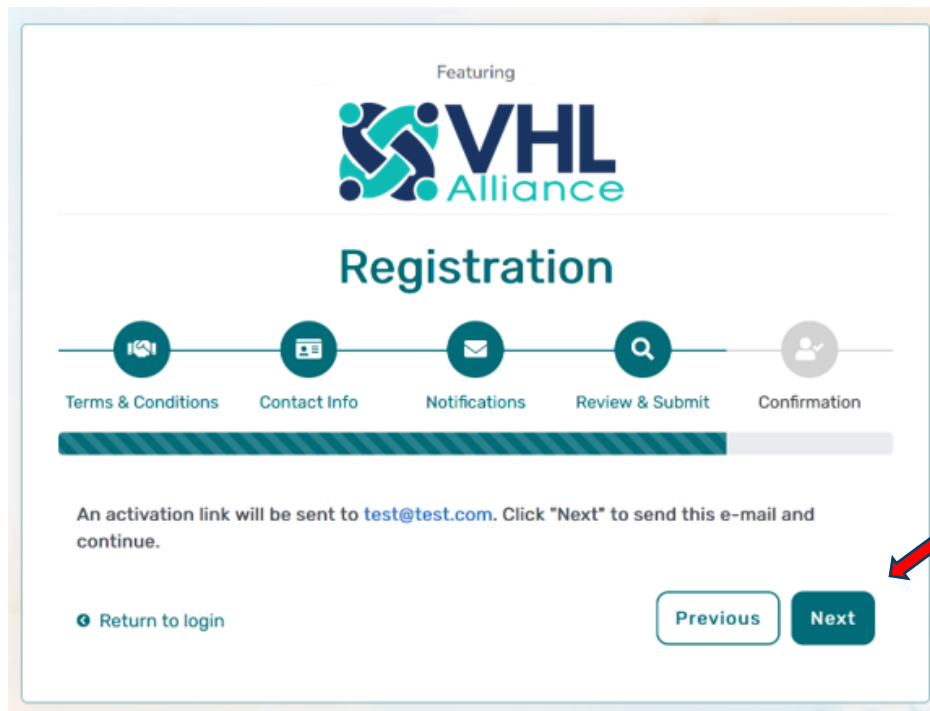
- Step 4: Select "Next" so that an activation link is sent to your e-mail to complete registration.

Featuring
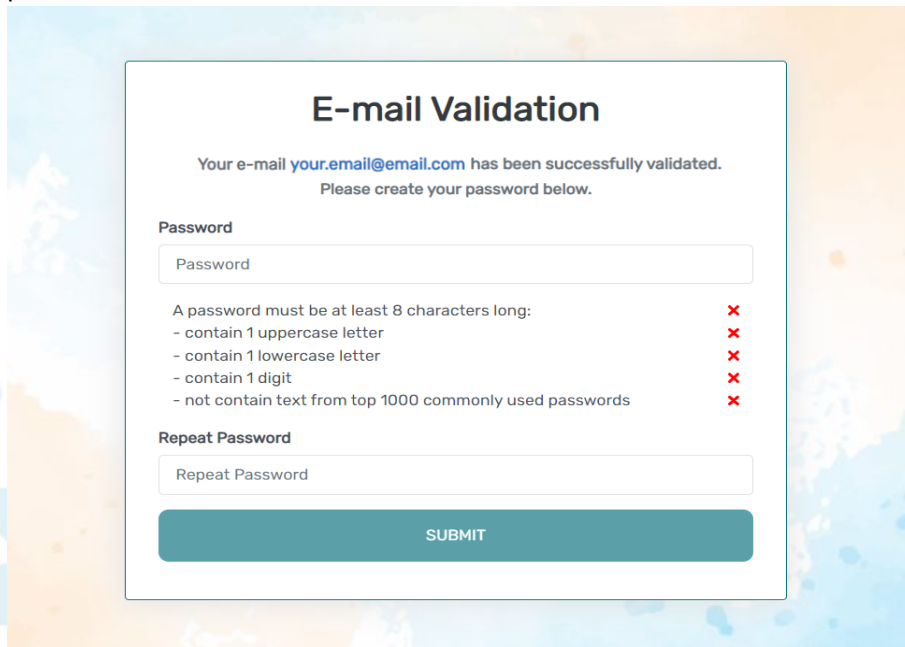
VHL Alliance

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".

E-mail Validation

Your e-mail your.email@email.com has been successfully validated.
Please create your password below.
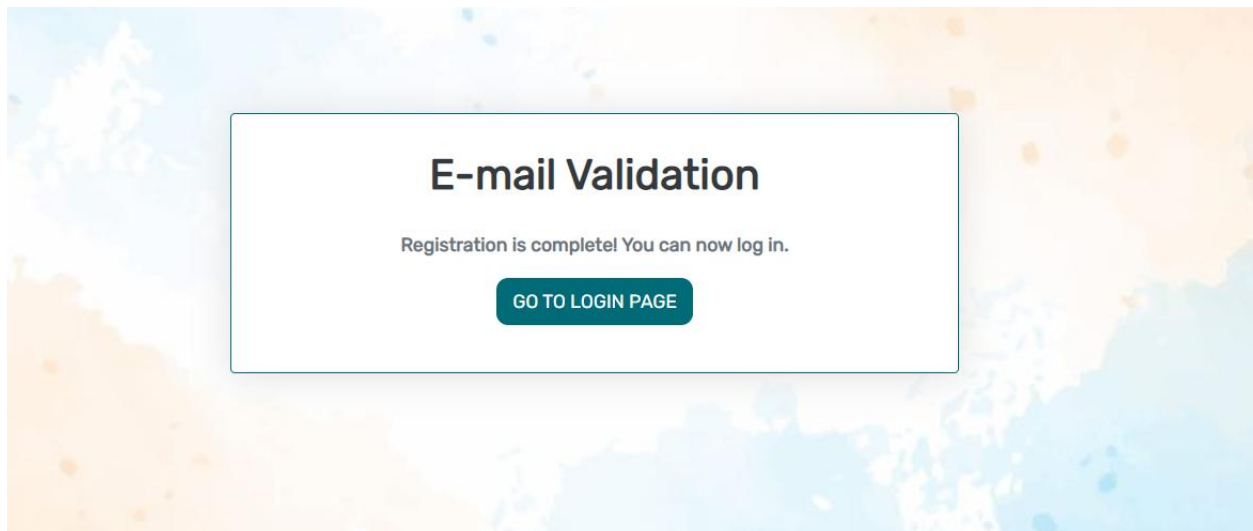
Password

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.

Add a Participant

- Step 1: To start, click Yes, register new participant.
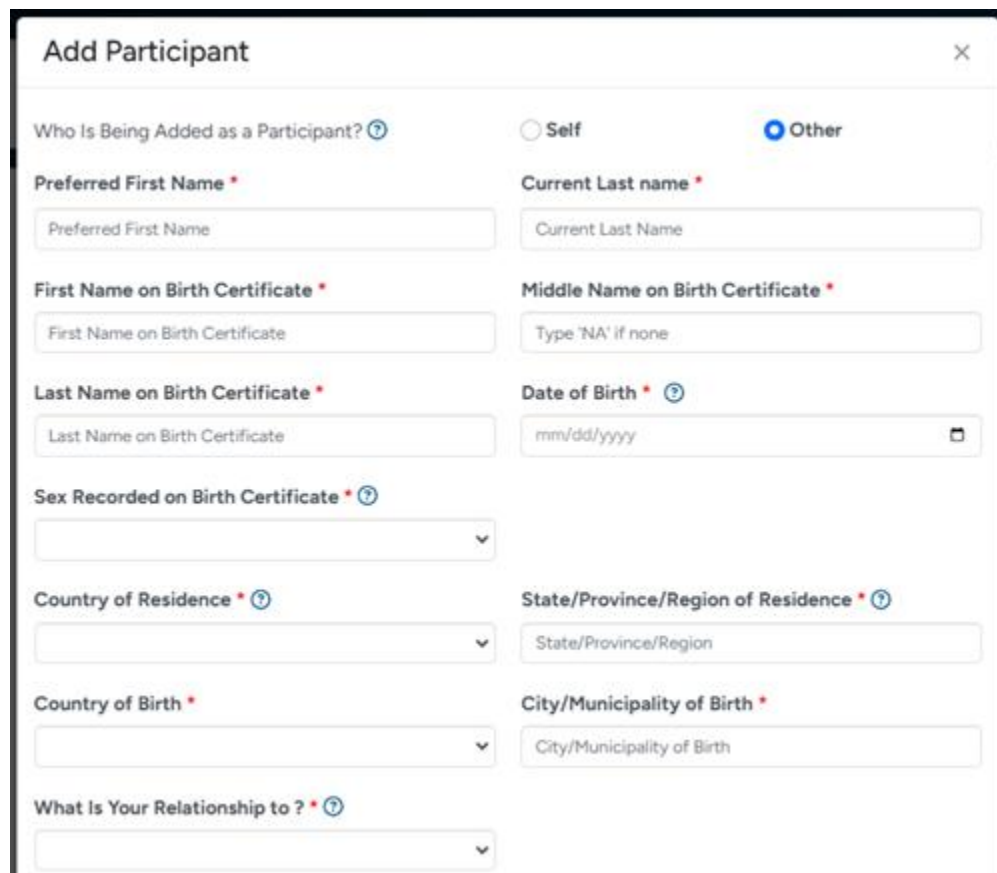
- Step 2: Select who you will be providing information about.

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

Consent to the Study
- Step 1: Click on "Yes, complete consent for this participant."
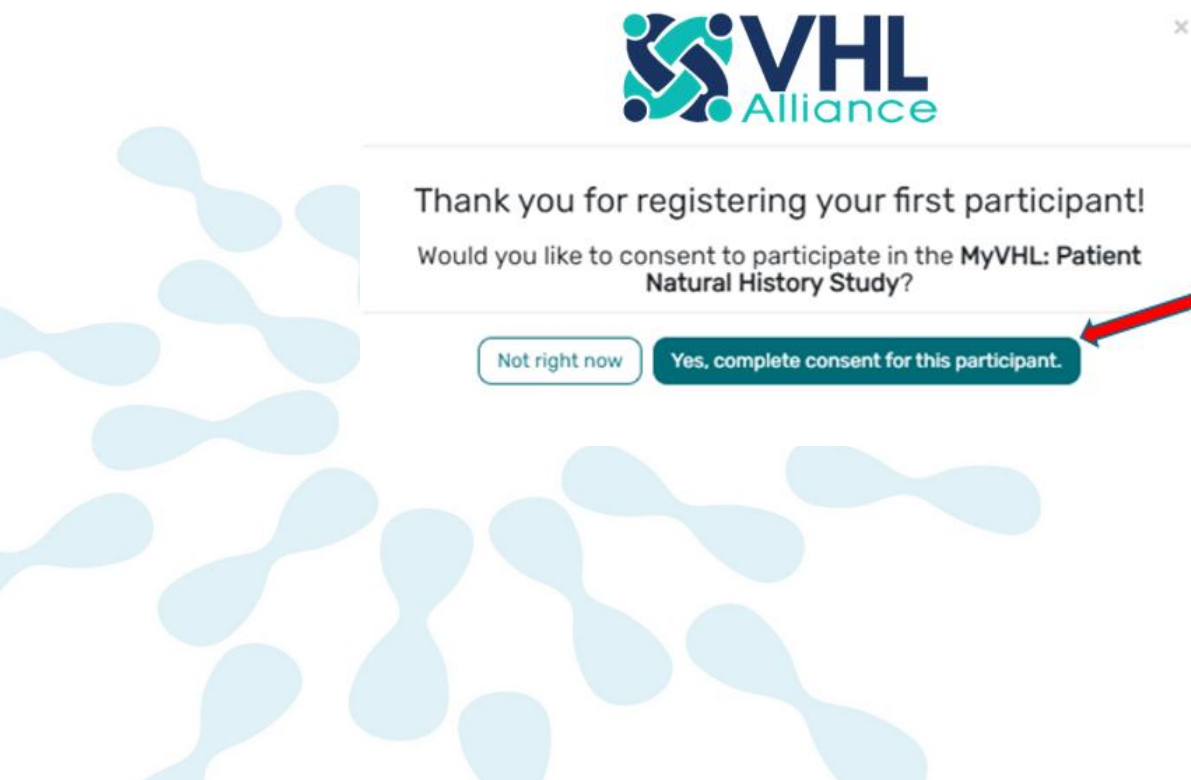
- Step 2: Scroll down and read through the consent form thoroughly. Once you finish each page, click the "Next" button. Once you reach the Authorization form, read through the statements thoroughly. If you are comfortable consenting to participate in the study, please read each statement and authorize your consent. After checking the boxes, click "Next."

Consent to **MyVHL: Patient Natural History Study**

Jane Smith

Consent Overview

Those eligible to participate in our study include:

Participant: An individual diagnosed with VHL who is at least 18 years of age, the age of majority in their state, province or country, and able to provide consent for themself.

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 VHL, defined as a spouse, parent, sibling, offspring, close relative, close friend, guardian and/or significant other of the individual who had VHL 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 VHL. I participated in their medical care.

Next

Consent to **MyVHL: Patient Natural History Study**

Jane Smith

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

Title: MyVHL: Patient Natural History Study

Principal Investigator: Joshua Mann, MPH

Phone: 800-767-4845 x710

E-mail: josh.mann@vhl.org

Sponsor: VHL Alliance

Key Information

You are invited to take part in a research study for individuals with VHL 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 help researchers understand more about VHL and how we might intervene and make a difference.

If you choose to participate on behalf of the participant, you will be asked to answer a series of questions about the participant's experience living with VHL. This will take approximately several hours, depending on their medical history.

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

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".
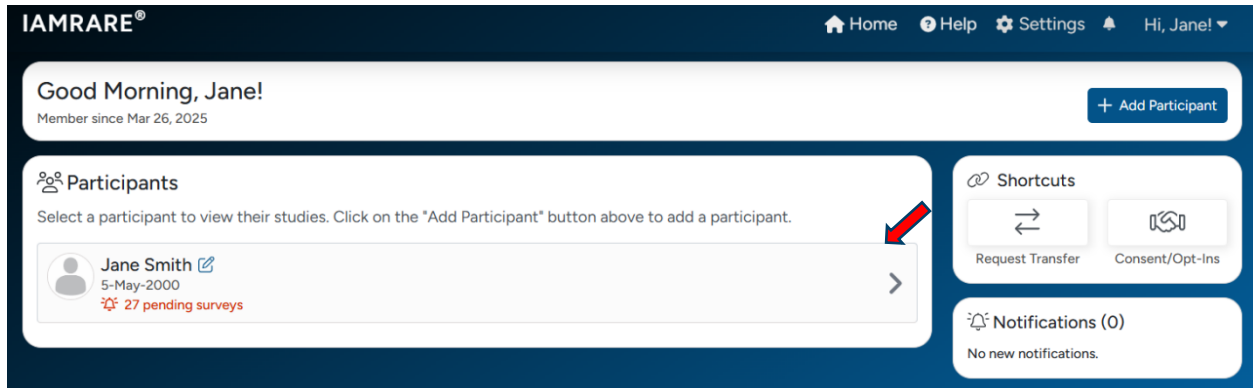
Taking Surveys

- Step 1: Click on your Participant.
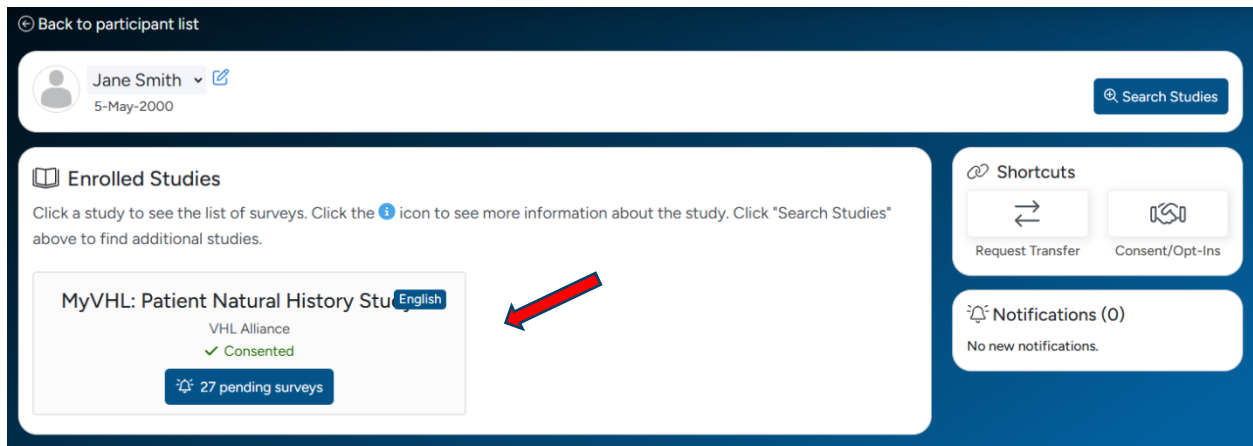
- Step 2: Click on the appropriate study.
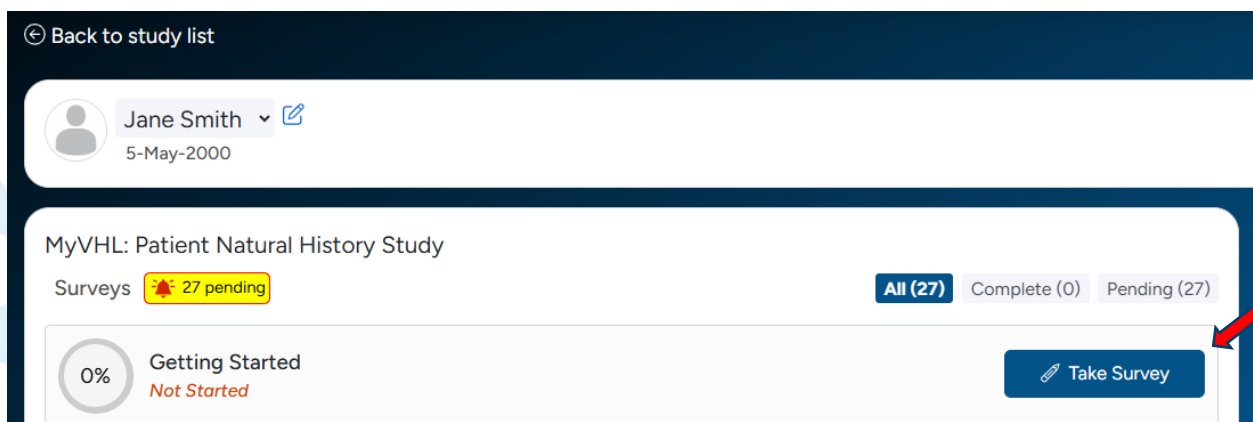
- Step 3: Click "Take Survey" for an available survey.

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".
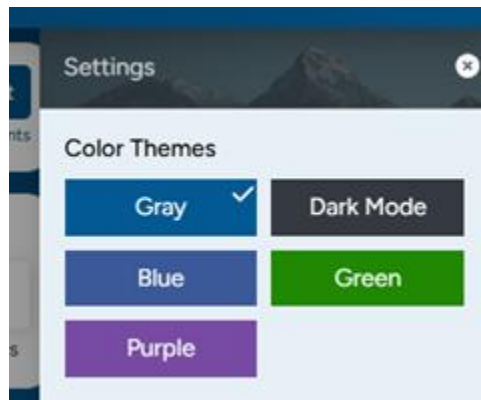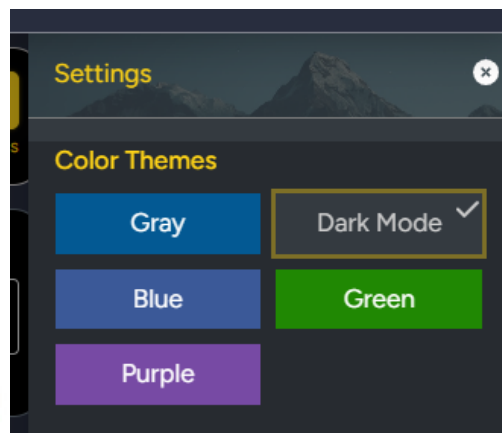
Dark Mode Settings

- 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.
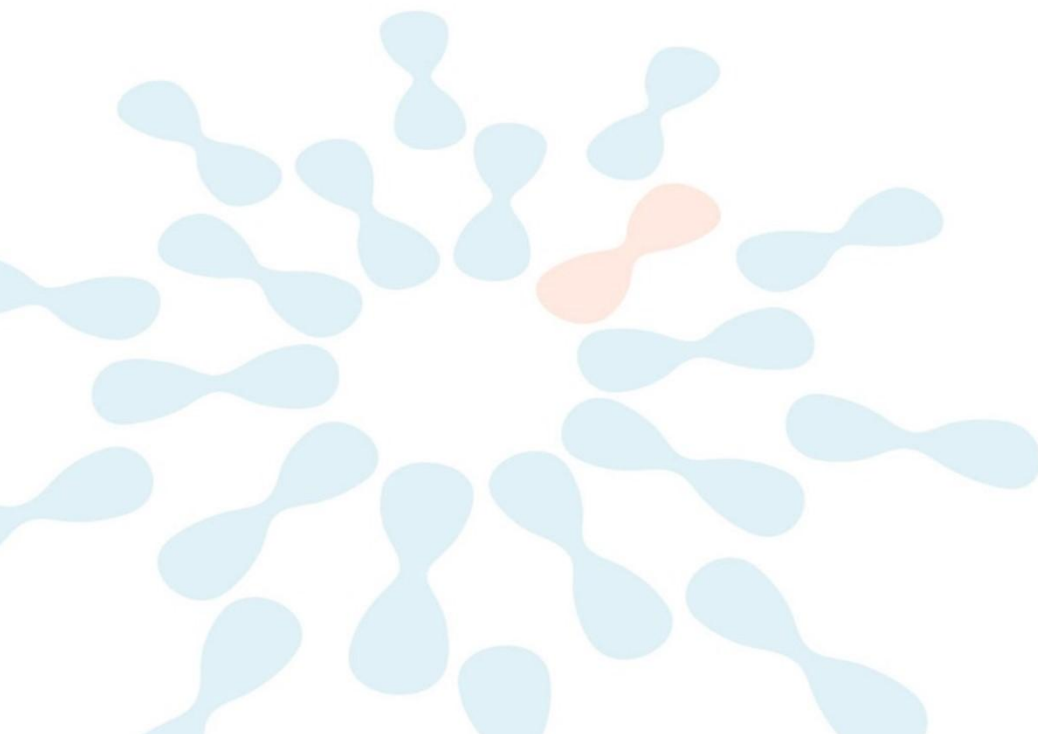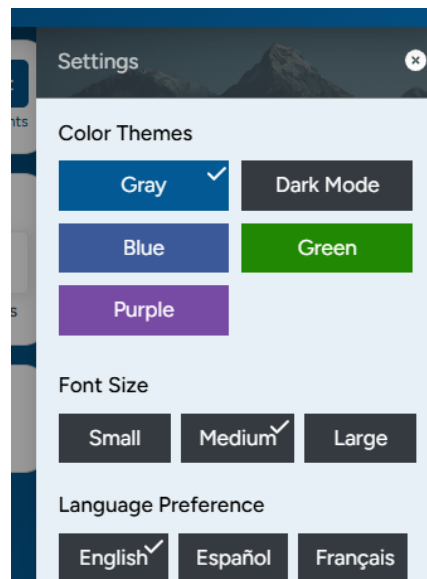
Display Settings

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

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

Microsite Visibility

- Step 1: You can change how you view the microsite, https://databank.vhl.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.
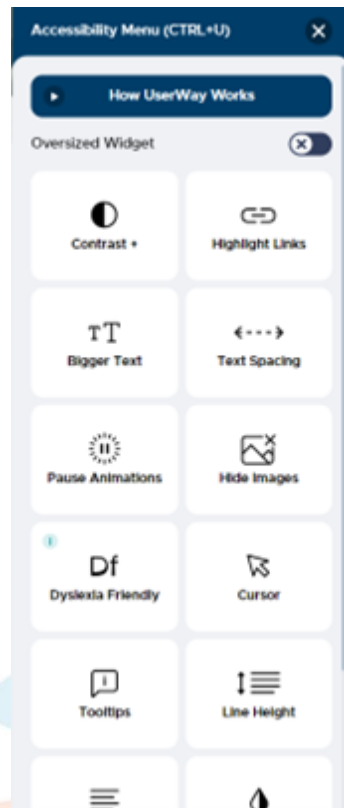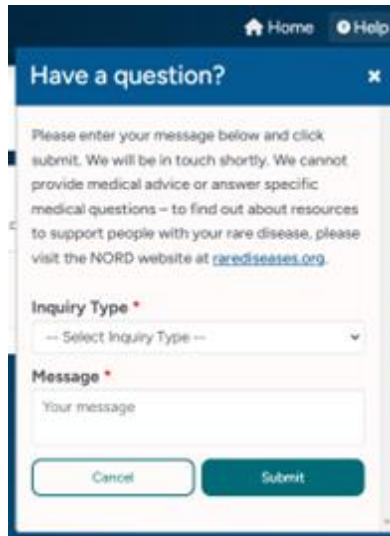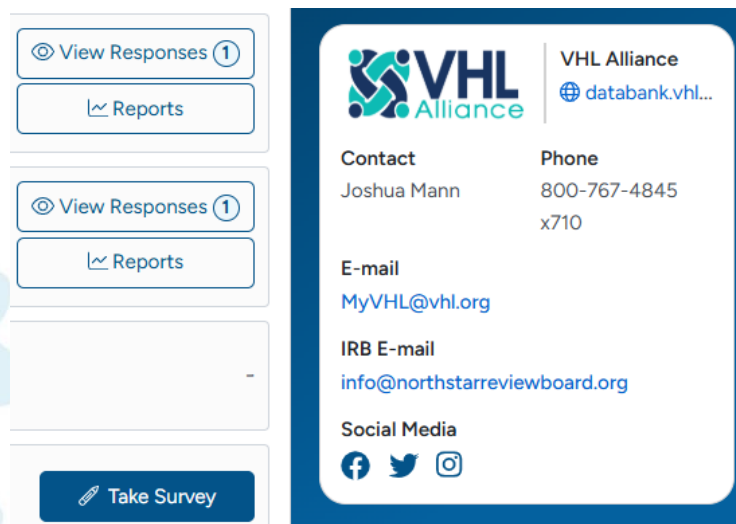
- Step 1: If you need help while using the platform, click Help.
- Step 2: Select an Inquiry Type and type a message.

- 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.