



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

VHL Alliance

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

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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

VHL Alliance
Registration

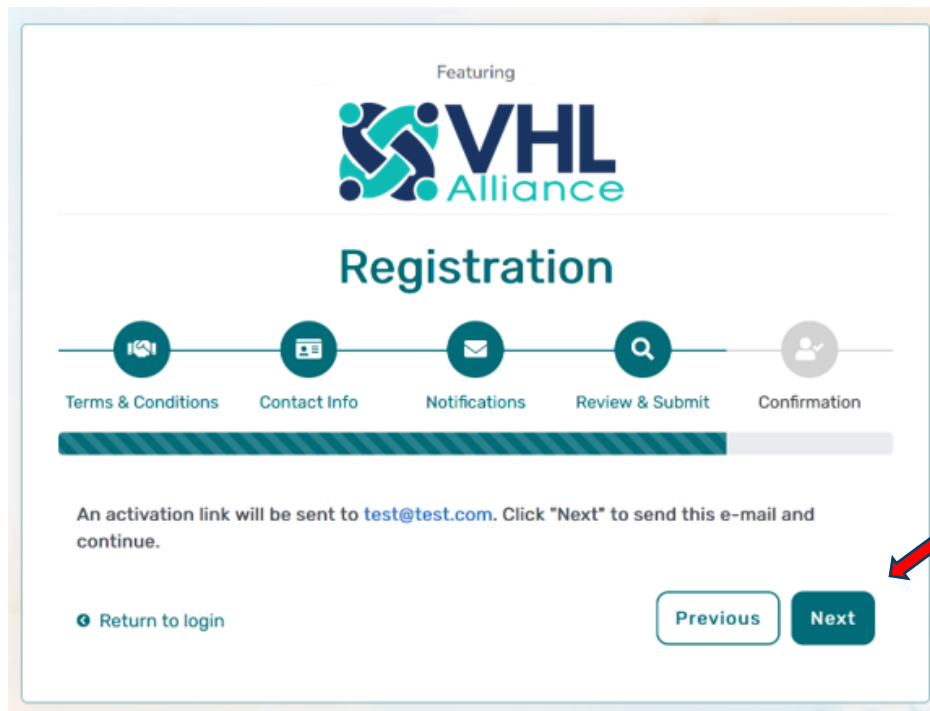
Progress bar: Terms & Conditions, Contact Info, Notifications (active), Review & Submit, Confirmation

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.



Featuring

VHL Alliance

Registration

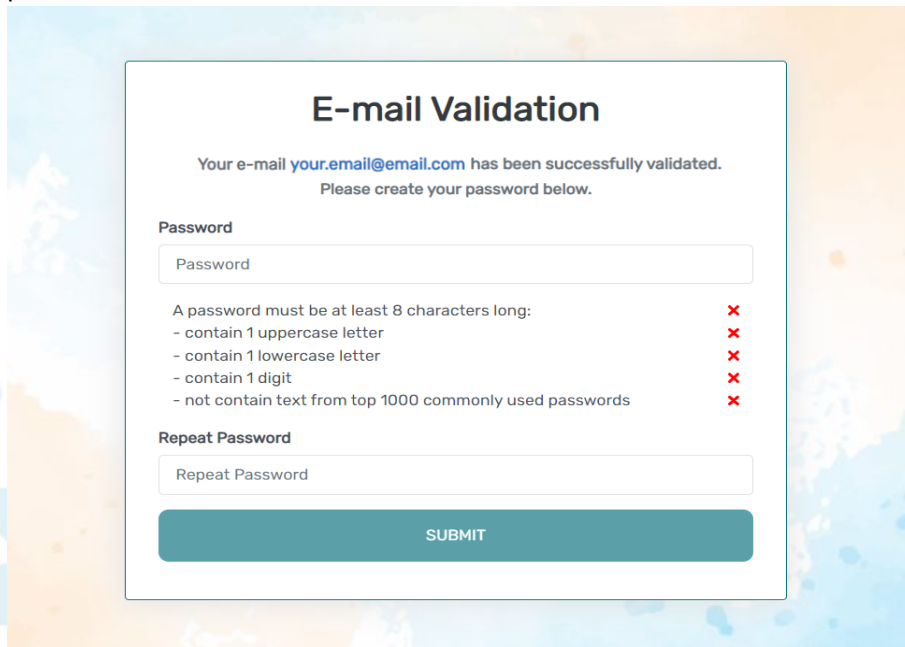
Terms & Conditions Contact Info Notifications Review & Submit Confirmation

An activation link will be sent to test@test.com. Click “Next” to send this e-mail and continue.

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

A red arrow points to the "Next" button.

- 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.

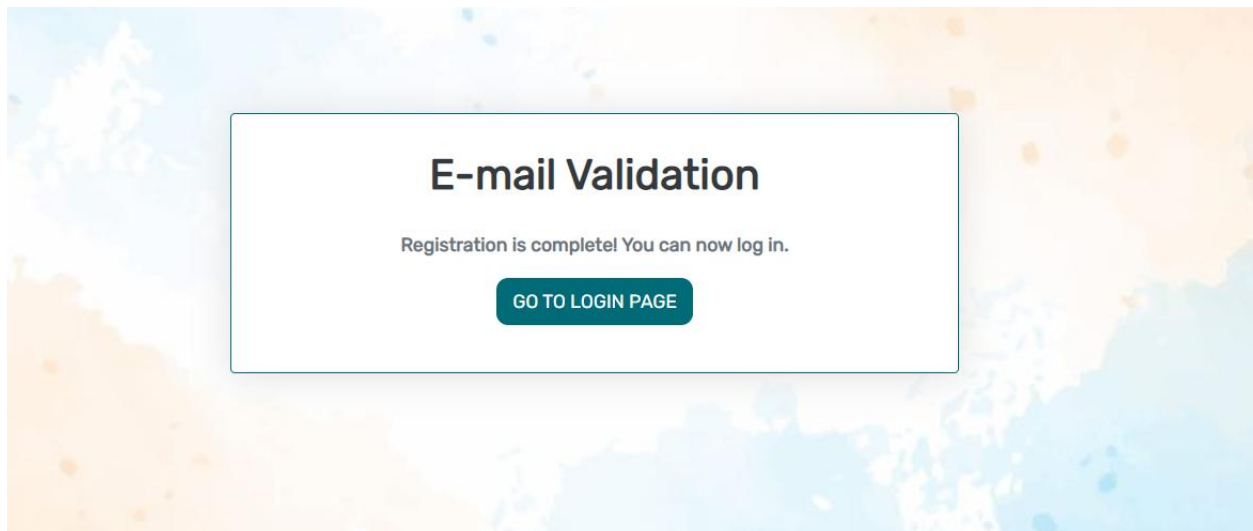
Password

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 background is white with a large, abstract, light blue pattern on the left side. At the top, the text "IAMRARE®" is displayed in a large, bold, black font. Below it, the word "LOGIN" is centered in a smaller, black font. There are two input fields: the first is labeled "e-mail" and the second is labeled "password". The password field has a small eye icon to its right. Below the input fields is a checkbox labeled "Keep me logged in". At the bottom of the form is a large, dark teal button with the text "LOGIN" in white, uppercase letters. Below the button are two smaller buttons: "Forgot Password" with a warning icon and "Create an Account" with a plus icon. At the very bottom, there is a line of text: "By logging in, you agree to NORD's [Privacy Policy](#) & [Terms and Conditions](#)". Below this text is a logo for "Featuring VHL Alliance" with the VHL logo in blue and green.

Add a Participant

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




Welcome to the IAMRARE® program where the **MyVHL: Patient Natural History Study** is located!

Would you like to register a participant to join the **MyVHL: Patient Natural History Study**?

[Don't show this again](#)

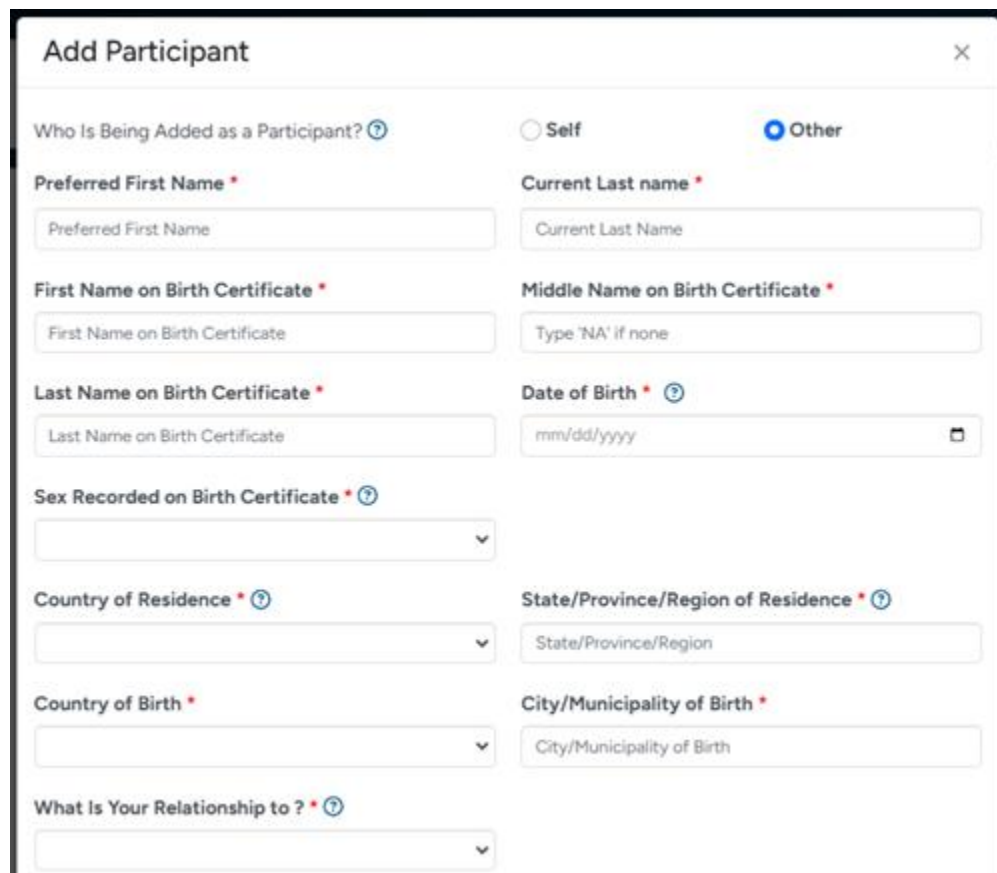
- Step 2: Select who you will be providing information about.



Add a Participant

Are you adding yourself or another person?

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



The 'Add Participant' form is a web-based interface for entering participant details. It features a title bar with a close button (X) and a question mark icon. The form is organized into two columns. The left column contains fields for 'Preferred First Name', 'First Name on Birth Certificate', 'Last Name on Birth Certificate', 'Sex Recorded on Birth Certificate' (a dropdown menu), 'Country of Residence' (a dropdown menu), 'Country of Birth' (a dropdown menu), and 'What Is Your Relationship to?' (a dropdown menu). The right column contains radio buttons for 'Self' and 'Other' (selected), 'Current Last name', 'Middle Name on Birth Certificate' (with a note 'Type NA if none'), 'Date of Birth' (with a date picker icon), 'State/Province/Region of Residence' (a dropdown menu), and 'City/Municipality of Birth' (a dropdown menu). All text input fields have placeholder text. Red asterisks indicate required fields.

Add Participant [X]

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 * ⓘ [Calendar Icon]

Sex Recorded on Birth Certificate * ⓘ

Country of Residence * ⓘ

State/Province/Region of Residence * ⓘ

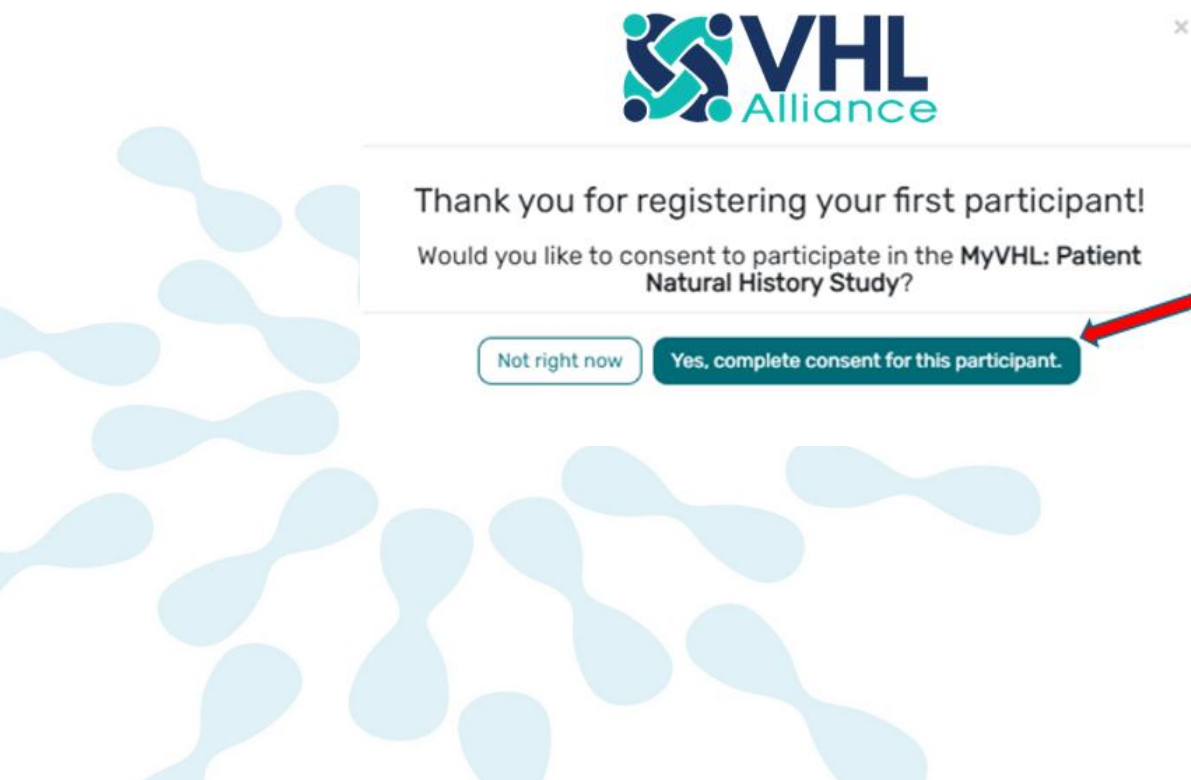
Country of Birth *

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.”

Jane Smith

Consent to MyVHL: Patient Natural History Study

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 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 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

Jane Smith

Consent to MyVHL: Patient Natural History Study

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

Jane Smith

Consent to MyVHL: Patient Natural History Study

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 MyVHL: Patient Natural History Study 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 MyVHL: Patient Natural History Study have been answered to my satisfaction, and I understand the purpose of the registry and the risks of participation.

[Previous](#) [Next](#)

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

Jane Smith

Consent to MyVHL: Patient Natural History Study

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 MyVHL: Patient Natural History Study

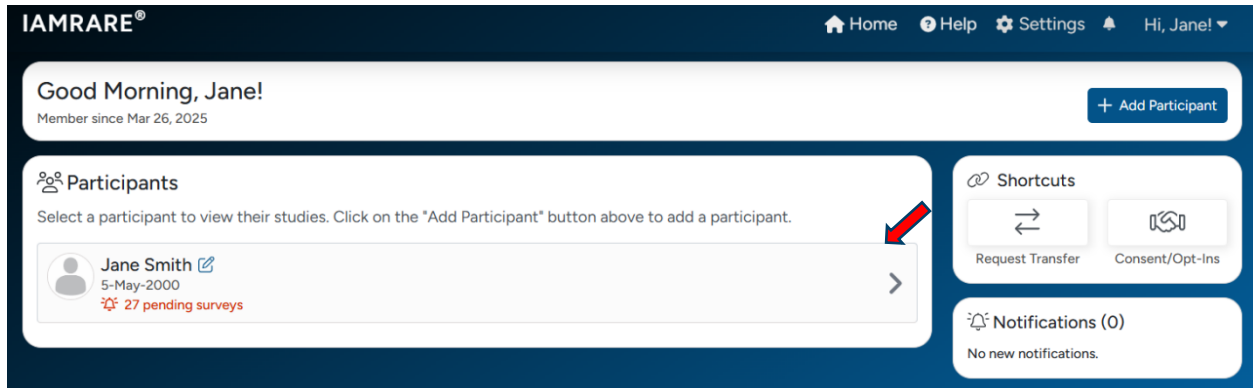
Select Opt-Ins for this study

- ☐ Interest in hearing about other studies from **VHL Alliance**
- ☐ Interest in hearing about relevant clinical trials
- ☐ Interest in donating specimens or DNA (biobanking) for future research

[Save and Review](#)

Taking Surveys

- Step 1: Click on your Participant.



IAMRARE® Home Help Settings Hi, Jane! ▼

Good Morning, Jane!
Member since Mar 26, 2025 [+ Add Participant](#)

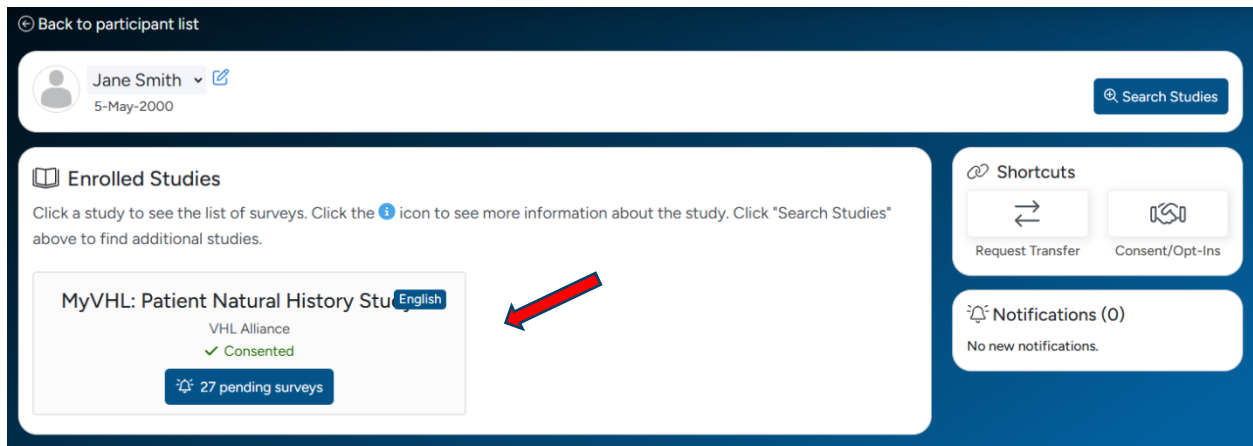
Participants
Select a participant to view their studies. Click on the "Add Participant" button above to add a participant.

Jane Smith
5-May-2000
🔔 27 pending surveys

Shortcuts
[Request Transfer](#) [Consent/Opt-Ins](#)

Notifications (0)
No new notifications.

- Step 2: Click on the appropriate study.



[← Back to participant list](#)

Jane Smith
5-May-2000 [🔍 Search Studies](#)

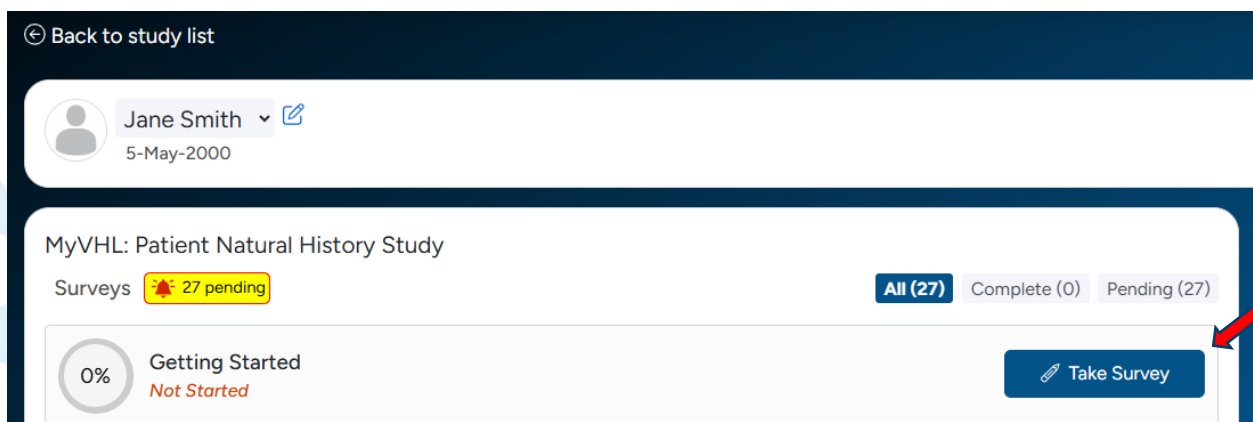
Enrolled Studies
Click a study to see the list of surveys. Click the icon to see more information about the study. Click "Search Studies" above to find additional studies.

MyVHL: Patient Natural History Study English
VHL Alliance
✓ Consented
[🔔 27 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

MyVHL: Patient Natural History Study

Surveys 🔔 27 pending All (27) Complete (0) Pending (27)

Getting Started
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.

The screenshot shows a user profile for Jane Smith (5-May-2000) at the top. Below is the study title "MyVHL: Patient Natural History Study". A "Surveys" section indicates "25 pending" with a clock icon. A summary bar shows "All (27)" surveys, with "Complete (2)" and "Pending (25)". Two survey cards are listed: "Getting Started" (Completed on 26-Mar-2025) and "Demographics" (Completed on 26-Mar-2025). Each card has a green checkmark icon and two buttons: "View Responses" (with a magnifying glass icon) and "Reports" (with a bar chart icon). Red arrows point to these buttons for both surveys.

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. It includes a "Back to participant list" link, a search bar, and a "Search Studies" button. Below the header, there's a section for "Enrolled Studies" with instructions. To the right, a "Shortcuts" section contains two buttons: "Request Transfer" and "Consent/Opt-Ins". A red arrow points to 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”.

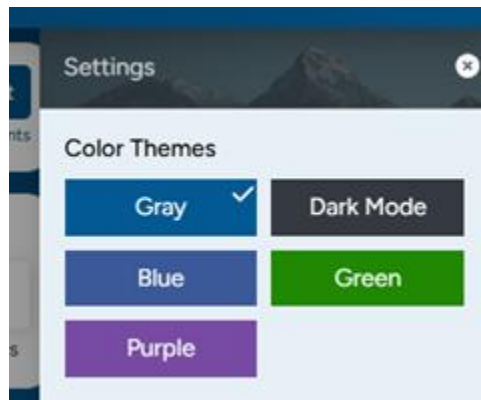
The screenshot shows the "Consents/Opt-Ins" page for Jane Smith. It features a table with columns: "Study Name", "Consent Status", "Consented On", and "Actions". The table lists the "MyVHL: Patient Natural History Study" with a "Consented" status and a date of "26-Mar-2025". The "Actions" column contains three buttons: "View Consent", "Revoke", and "Opt-Ins". Red arrows point to the "Revoke" and "Opt-Ins" buttons.

Dark Mode Settings

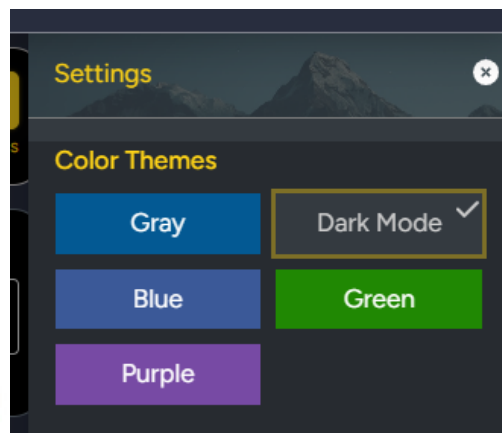
- Step 1: You can view the platform in Dark Mode. First, click Settings.



- Step 2: Select Dark Mode.



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

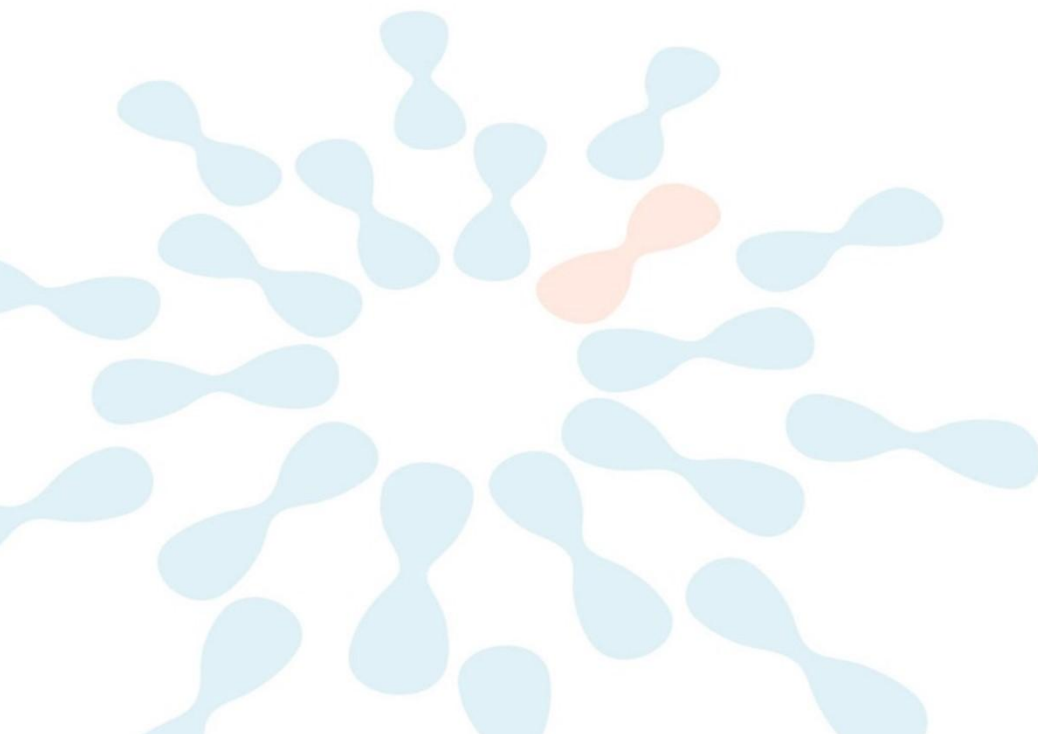
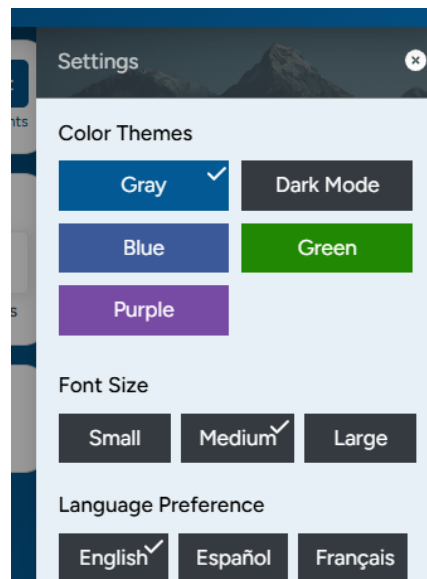


Display Settings

- 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.



For Researchers

Drive Research

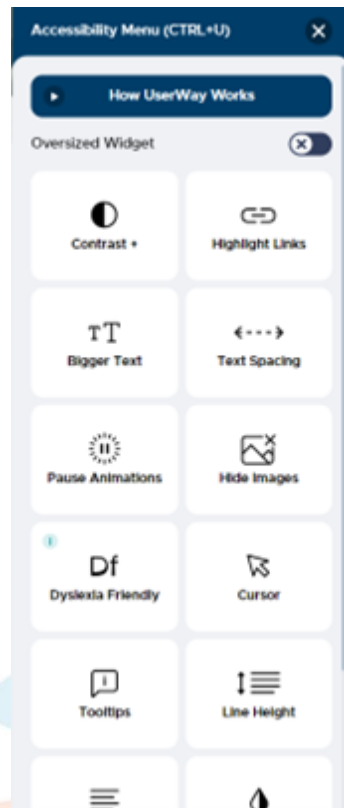
This is a unique rare disease patient registry. Are you interested in using our data to further your rare disease research?



For Patients

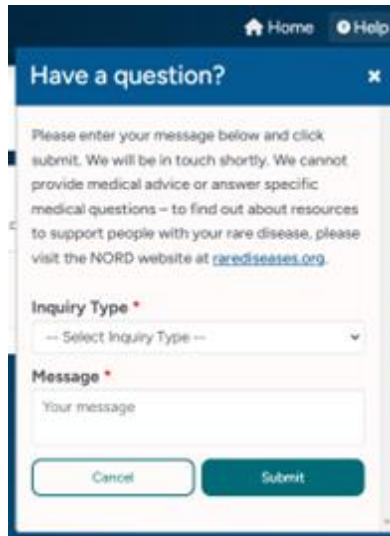
Get Involved

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



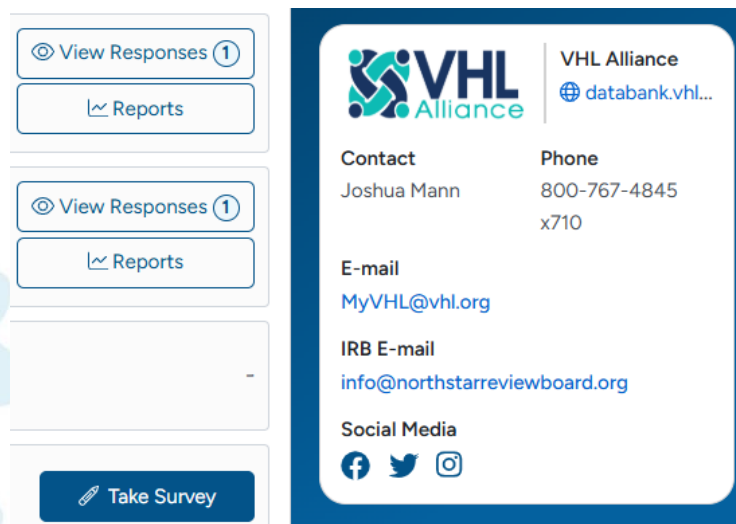
Need Assistance?

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



The screenshot shows a mobile app interface with a dark blue header containing 'Home' and 'Help' icons. Below the header is a white modal titled 'Have a question?' with a close button. The modal contains a text area for a message, a dropdown menu for 'Inquiry Type' (currently showing '-- Select Inquiry Type --'), and a 'Submit' button. A disclaimer text is visible above the input fields: '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.'

- 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 panel for the VHL Alliance. It includes the VHL Alliance logo, the website 'databank.vhl...', and contact details for Joshua Mann. The contact information is organized into sections: Contact (Joshua Mann), Phone (800-767-4845 x710), E-mail (MyVHL@vhl.org), IRB E-mail (info@northstarreviewboard.org), and Social Media (Facebook, Twitter, Instagram). A 'Take Survey' button is also visible at the bottom left of the panel.