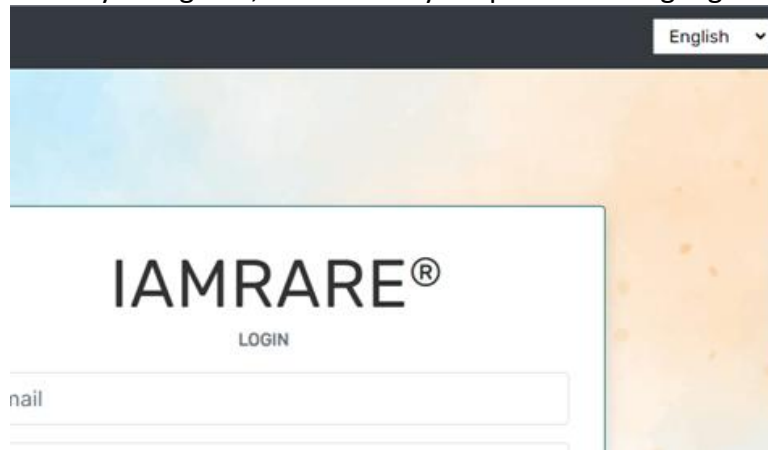


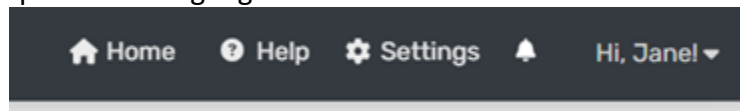
Participant User Guide

Language Selection

- To change your platform language selection on the login/register page, select the dropdown that says “English”, and choose your preferred language.



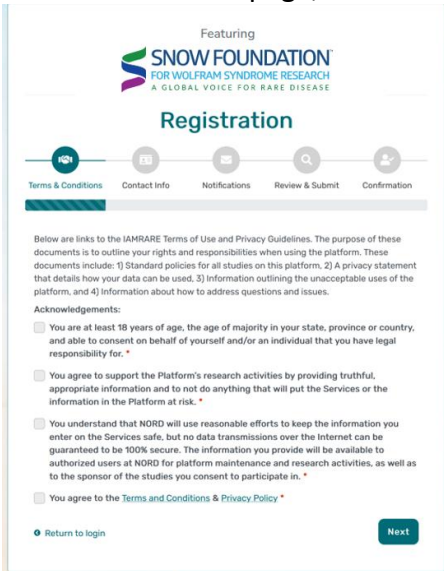
- To change your platform language selection after you’ve logged in, click “Settings”, and choose your preferred language.



- This study is available in English, French, Spanish, German, Italian, and Portuguese.

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
SNOW FOUNDATION™
FOR WOLFRAM SYNDROME RESEARCH
A GLOBAL VOICE FOR RARE DISEASE

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

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”.

Featuring

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Registration

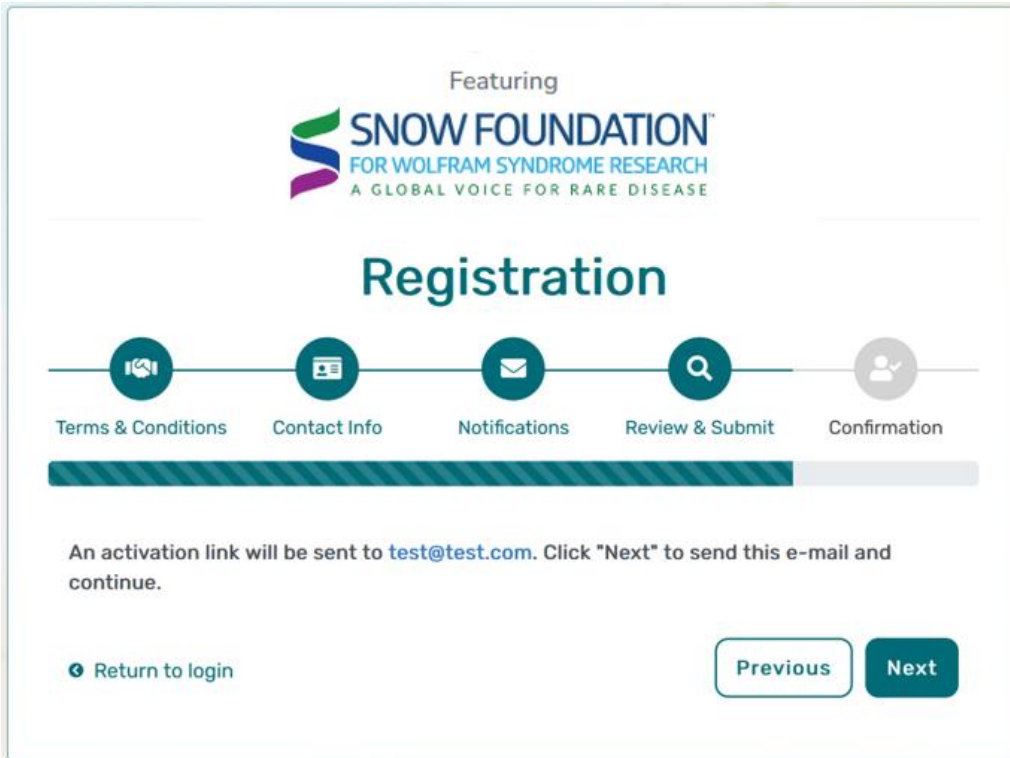
Terms & Conditions Contact Info Notifications Review & Submit Confirmation

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.



Featuring

 **SNOW FOUNDATION™**
FOR WOLFRAM SYNDROME RESEARCH
A GLOBAL VOICE FOR RARE DISEASE

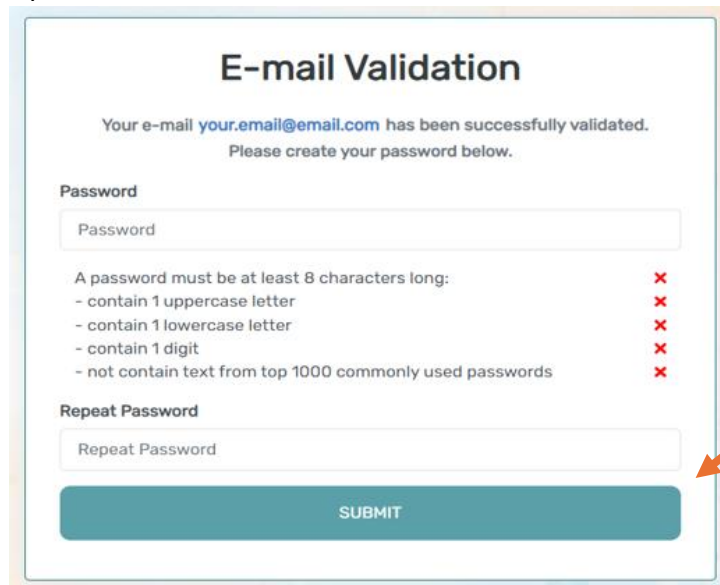
Registration

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

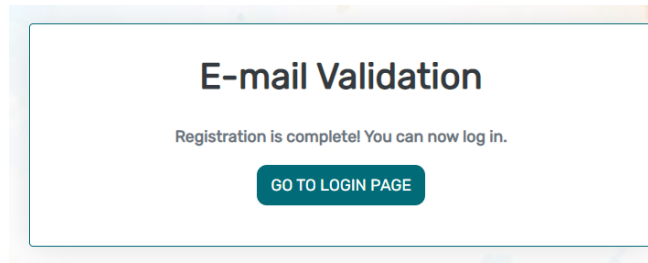
A password must be at least 8 characters long: ✗
- contain 1 uppercase letter ✗
- contain 1 lowercase letter ✗
- contain 1 digit ✗
- not contain text from top 1000 commonly used passwords ✗

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®

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](#)

Featuring



Add a Participant

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

English ▾



Welcome, Jane!

Welcome to the IAMRARE[®] program, home of **Wolfram Syndrome Global Patient 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.

×

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 ? * ⓘ

Profile Image
 OR
 No image selected

Consent to the Study

- Step 1: Click on “Yes, complete consent for this study.”

English ▼

Thank you for registering your first participant!

Would you like to consent to participate in Wolfram Syndrome Global Patient Registry?

Not right now

Yes, complete consent for this participant.



- Step 2: Read through the consent overview and answer any questions.

Consent to **Wolfram Syndrome Global Patient Registry** ×

John Smith

Consent Overview

Those eligible to participate in our study include:
Participant: An individual diagnosed with Wolfram 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 Wolfram syndrome, defined as a spouse, parent, sibling, offspring, close relative, close friend, guardian and/or significant other of the individual who had Wolfram 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 Wolfram syndrome. I participated in their medical care.

[Next](#)

- Step 3: Scroll down and read through the consent form thoroughly. Once you finish reading, click the “Next” button.

Consent to **Wolfram Syndrome Global Patient Registry** ×

John Smith

- Lodge a complaint with an appropriate supervisory authority.

Please note that the rights to erase personal data or restrict or withdraw permission for the processing of personal information are subject to limitations provided for by Article 17 of the General Data Protection Regulation, namely, that such rights may be limited as necessary to protect the public interest in the area of public health or for archiving purposes in the public and scientific interest.

Getting Answers to Your Questions about the Wolfram Syndrome Global Patient Registry

We have used some technical terms in this form and talked about issues in research and data sharing with which you may not have been familiar. Take as long as you need or want to consider what was presented here and whether you want to share the Study Participant's personal and medical information with the registry. If you have any questions or want anything explained further, please contact the Wolfram Syndrome Global Patient Registry staff at: please contact the Wolfram Syndrome Global Patient Registry staff at: pat@thesnowfoundation.org. It is our responsibility to answer your questions.

An Institutional Review Board (IRB) has reviewed this registry to ensure that it meets ethical and regulatory standards for protecting your rights. An IRB is an independent group that reviews research proposals to make sure they properly protect participants. For questions about those protections and your rights as a Study Participant in this registry, or to discuss other study related concerns or complaints with someone who is not part of this registry team, please contact North Star Review Board at 877-673-8439 (toll free) or info@northstarreviewboard.org. You may want to contact the IRB if:

- You have questions, concerns, or complaints that are not being answered by the research team;
- You are not getting answers from the research team;
- You cannot reach the research team; or
- You want to talk to someone else about the research.
- You have questions about your rights and those of the Study Participant in this registry.

IMPORTANT: Please do not sign the form on the next page unless you have had all your questions answered.

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

- Step 4: Once you click “Next” and 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 Wolfram Syndrome Global Patient Registry

John Smith



Authorization

The following statements are intended to ensure 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 you and the Study Participant have no further questions about the registry and your 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 Wolfram Syndrome Global Patient Registry on behalf of the Study Participant. After signing, a copy of the consent form will be emailed to you. If you cannot comfortably answer "Yes" to these statements or you have further questions, 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 Wolfram Syndrome Global Patient 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 Wolfram Syndrome Global Patient Registry for the purposes described above under Study Aims.

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

Previous

Next

- Step 5: Click Continue to Opt-ins.

Consent to Wolfram Syndrome Global Patient Registry

John 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 6: Select your Opt-ins and click Save and Review.

Opt-Ins for Wolfram Syndrome Global Patient Registry



Select Opt-Ins for this study

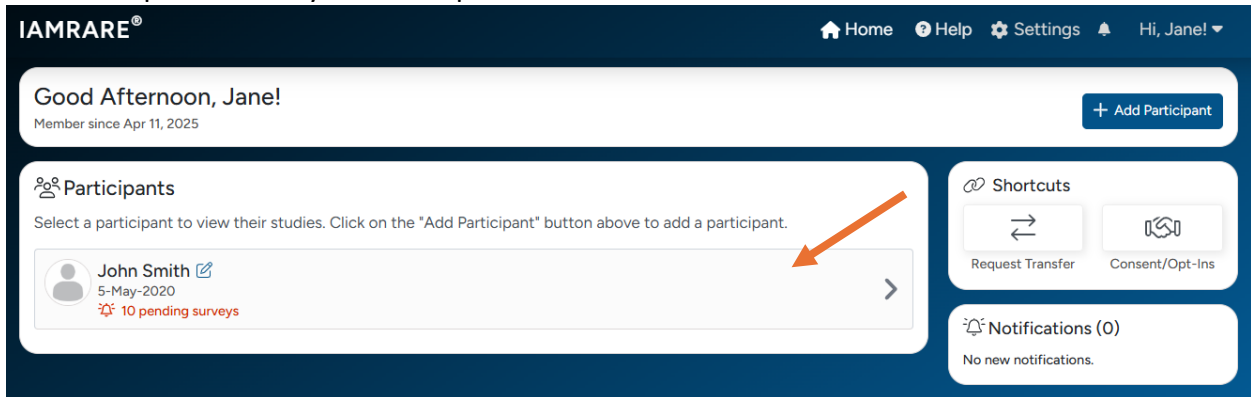
- ☐ Interest in hearing about other studies from [The Snow Foundation for Wolfram Syndrome Research](#)
- ☐ Interest in hearing about relevant clinical trials
- ☐ Interest in donating specimens or DNA (biobanking) for future research

Save and Review

- Step 7: Download a copy of your consent or click Close.
- Step 8: You will now have access to start taking surveys.

Taking Surveys

- Step 1: Click on your Participant.



IAMRARE® Home Help Settings Hi, Jane!

Good Afternoon, Jane!
Member since Apr 11, 2025 [+ Add Participant](#)

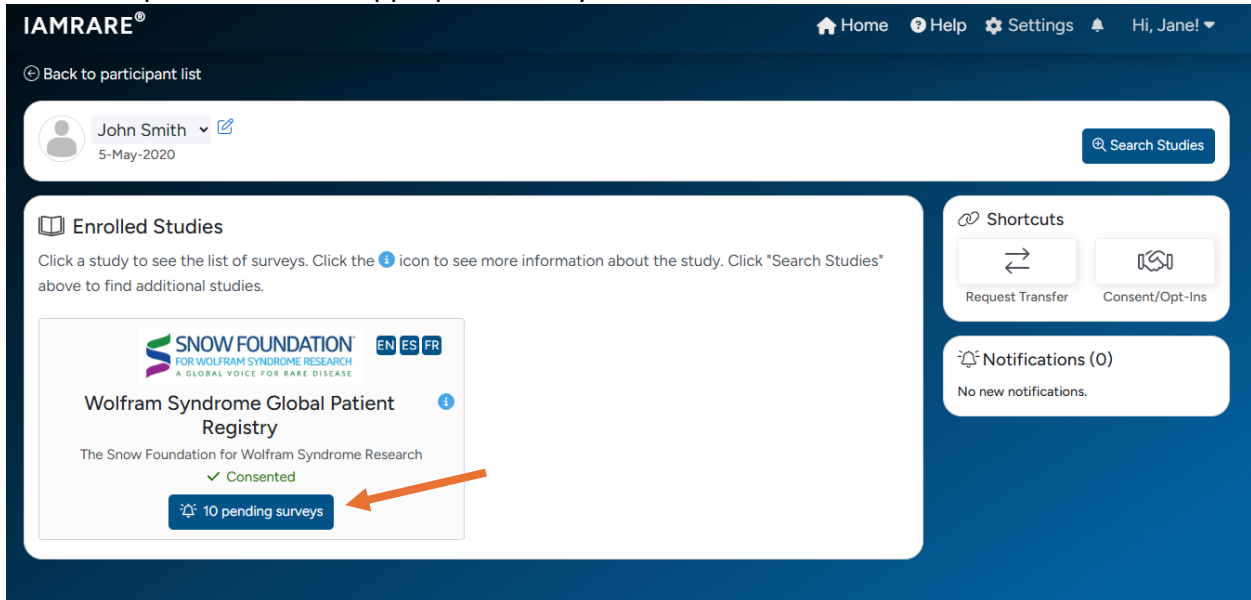
Participants
Select a participant to view their studies. Click on the "Add Participant" button above to add a participant.

John Smith 5-May-2020
10 pending surveys

Shortcuts
Request Transfer Consent/Opt-Ins

Notifications (0)
No new notifications.

- Step 2: Click on the appropriate study.



IAMRARE® Home Help Settings Hi, Jane!

[Back to participant list](#)

John Smith 5-May-2020 [Search Studies](#)

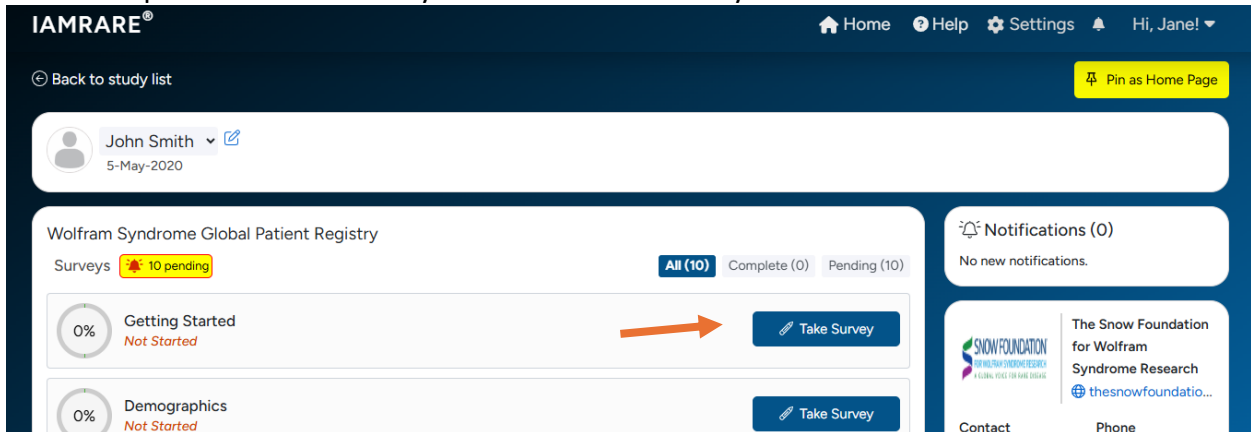
Enrolled Studies
Click a study to see the list of surveys. Click the **i** icon to see more information about the study. Click "Search Studies" above to find additional studies.

Wolfram Syndrome Global Patient Registry
The Snow Foundation for Wolfram Syndrome Research
Consented
10 pending surveys

Shortcuts
Request Transfer Consent/Opt-Ins

Notifications (0)
No new notifications.

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



IAMRARE® Home Help Settings Hi, Jane! [Pin as Home Page](#)

[Back to study list](#)

John Smith 5-May-2020

Wolfram Syndrome Global Patient Registry

Surveys **10 pending** All (10) Complete (0) Pending (10)

Getting Started 0% Not Started [Take Survey](#)

Demographics 0% Not Started [Take Survey](#)

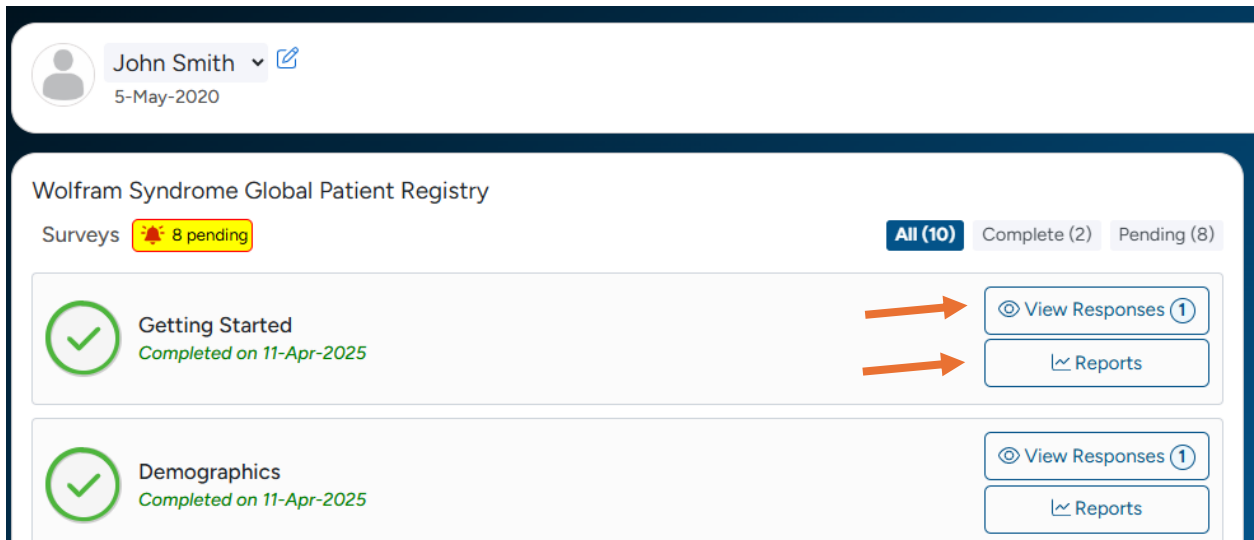
Notifications (0)
No new notifications.

The Snow Foundation for Wolfram Syndrome Research
thesnowfoundatio...
Contact Phone

- You can click the “Pin as Home Page” button if you want to be brought directly to this page the next time you log in.

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.



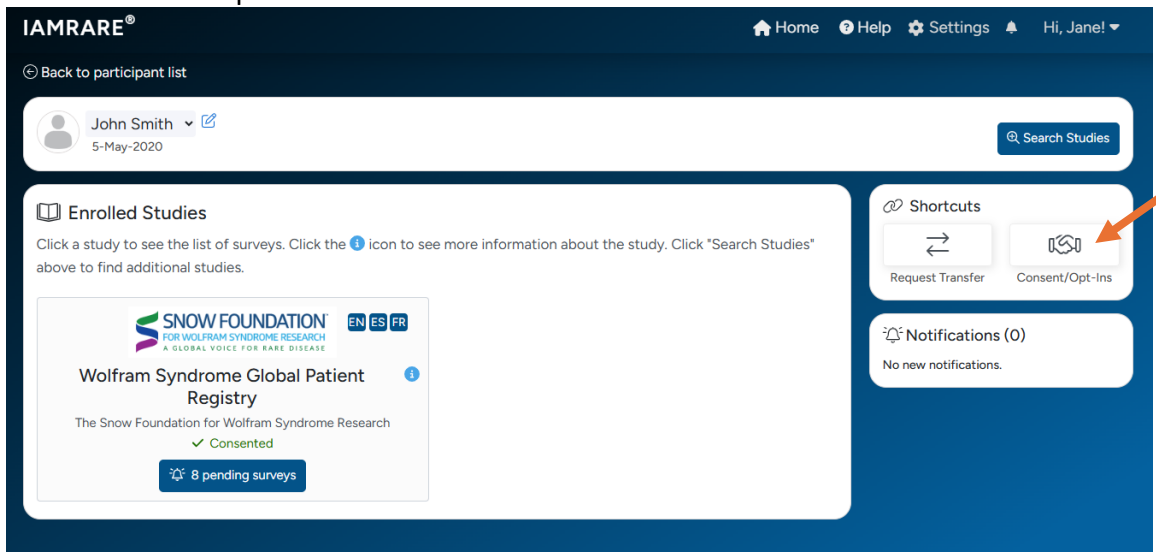
The screenshot shows the user profile for John Smith, logged in on 5-May-2020. The main heading is "Wolfram Syndrome Global Patient Registry". Below this, there's a "Surveys" section with a yellow badge indicating "8 pending". To the right, there are filters for "All (10)", "Complete (2)", and "Pending (8)".

Two survey cards are visible:

- Getting Started**: Completed on 11-Apr-2025. It has two buttons: "View Responses 1" and "Reports". Two orange arrows point from the survey title to these buttons.
- Demographics**: Completed on 11-Apr-2025. It also has two buttons: "View Responses 1" and "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.



The screenshot shows the IAMRARE interface. At the top, there's a navigation bar with "Home", "Help", "Settings", and a user greeting "Hi, Jane!". Below this is a "Back to participant list" link.

The user profile for John Smith (5-May-2020) is shown. A "Search Studies" button is in the top right.

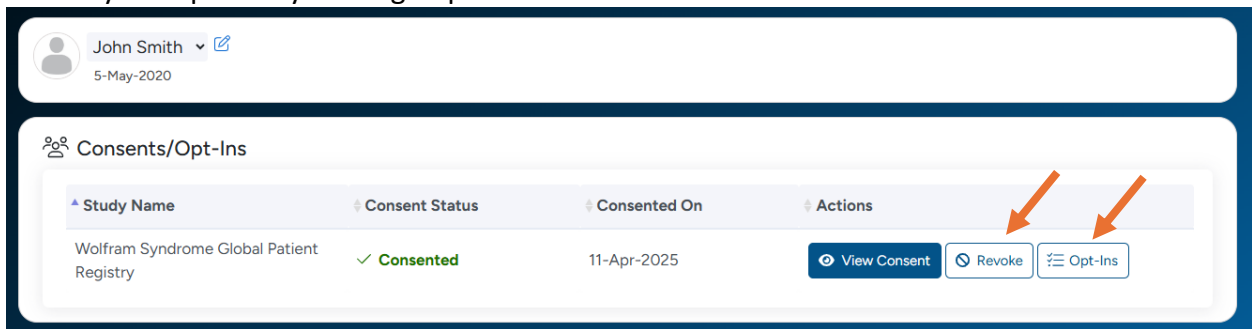
The main section is titled "Enrolled Studies" with instructions: "Click a study to see the list of surveys. Click the ⓘ icon to see more information about the study. Click 'Search Studies' above to find additional studies."

A study card for "Wolfram Syndrome Global Patient Registry" is displayed, showing it is "Consented" and has "8 pending surveys".

On the right side, there's a "Shortcuts" section with two buttons: "Request Transfer" and "Consent/Opt-Ins". An orange arrow points to the "Consent/Opt-Ins" button.

Below the shortcuts is a "Notifications (0)" section stating "No new notifications."

- Step 2: You may revoke your consent at any time by clicking “Revoke”. You may also edit your Opt-Ins by clicking “Opt-Ins”.



John Smith 5-May-2020

Consents/Opt-Ins

Study Name	Consent Status	Consented On	Actions
Wolfram Syndrome Global Patient Registry	✓ Consented	11-Apr-2025	View Consent Revoke Opt-Ins

Dark Mode Settings

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



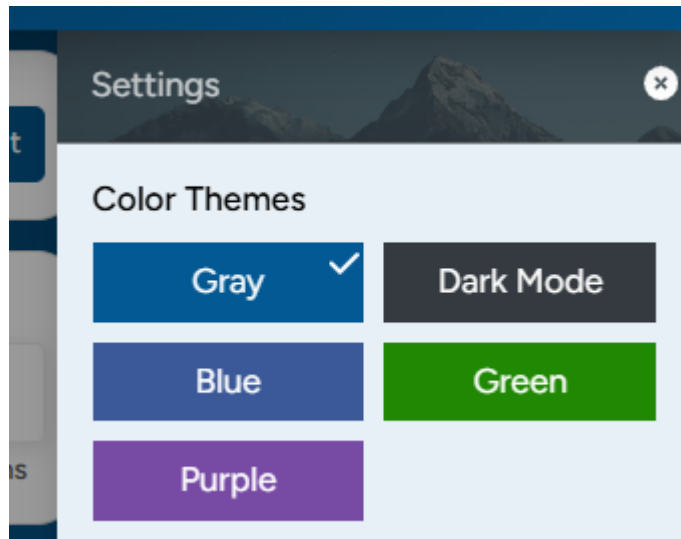
IAMRARE® Home Help Settings Hi, Jane! ▼

Good Afternoon, Jane!
Member since Apr 11, 2025

+ Add Participant

Participants Shortcuts

- Step 2: Select Dark Mode.



Settings

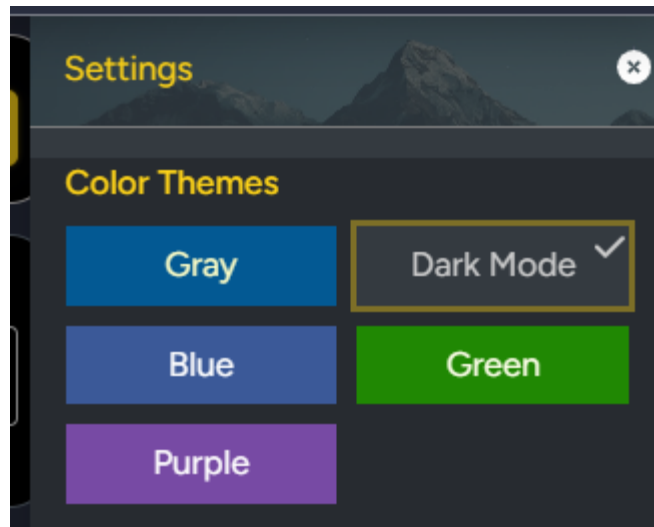
Color Themes

Gray ✓ Dark Mode

Blue Green

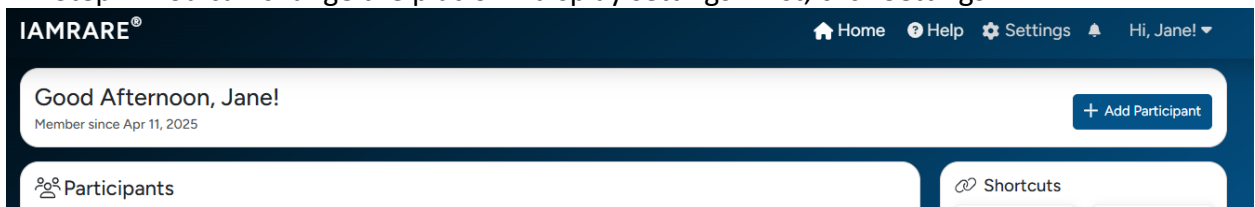
Purple

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

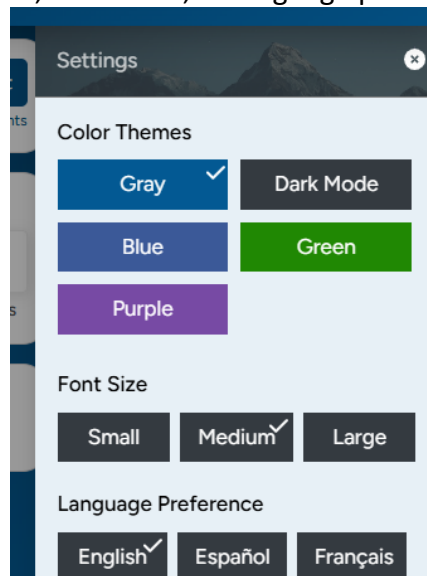


Display Settings

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



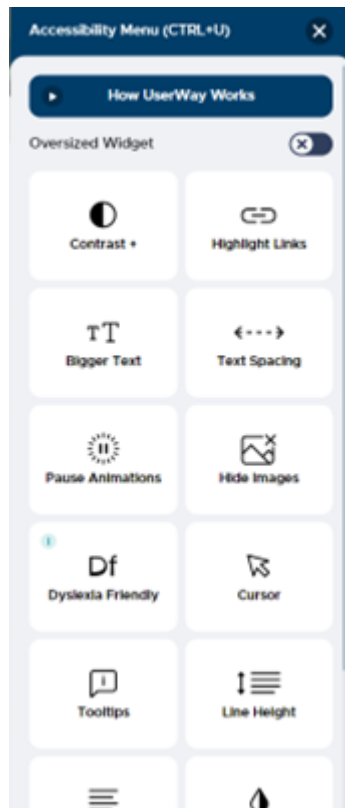
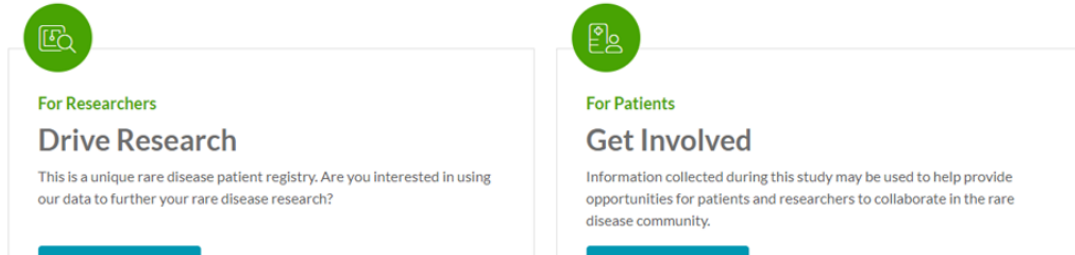
- Step 2: Select a color theme, a font size, or language preference.



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

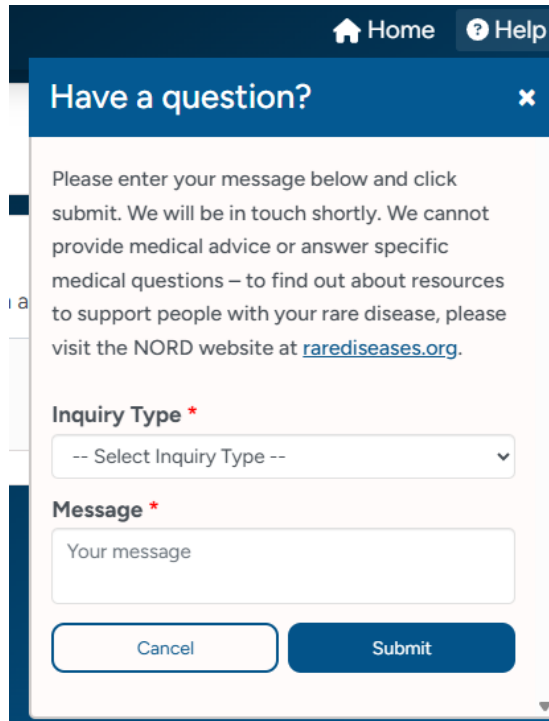
Microsite Visibility

- Step 1: You can change how you view the microsite [<https://wsglobalregistry.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.



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 web interface with a dark blue header containing 'Home' and 'Help' links. A modal window titled 'Have a question?' is open. Inside the modal, there is a paragraph of text, a dropdown menu for 'Inquiry Type', a text input field for 'Message', and two buttons: 'Cancel' and 'Submit'.

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.

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.