



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



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



GLOBAL
SCHAAF-YANG SYNDROME
REGISTRY

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



GLOBAL
SCHAAF-YANG SYNDROME
REGISTRY

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

GLOBAL
SCHAAF-YANG SYNDROME
REGISTRY

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 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](#)

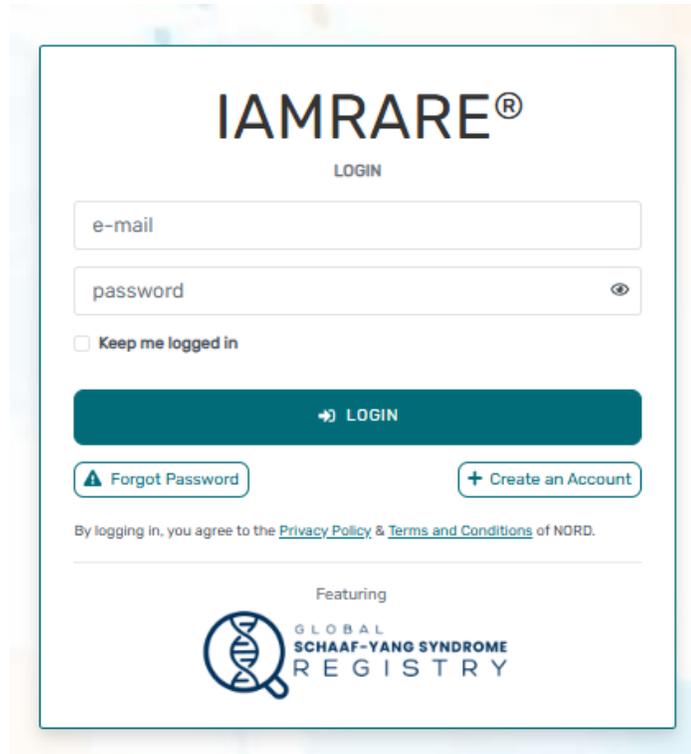
- Step 6: Your validation is now complete. Select “Go to Login Page”.

E-mail Validation

Registration is complete! You can now log in.

[GO TO LOGIN PAGE](#)

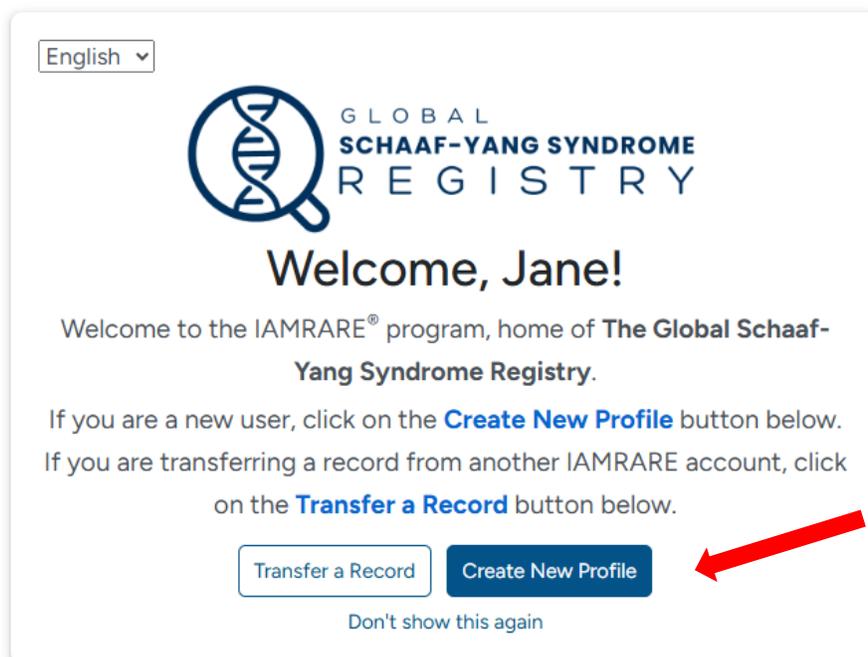
- Step 7: Log in using your new e-mail and password.



The image shows the IAMRARE LOGIN page. At the top, it says "IAMRARE®" and "LOGIN". Below that are two input fields: "e-mail" and "password". There is a checkbox for "Keep me logged in". A large teal button with a right arrow and "LOGIN" is in the center. Below the button are two smaller buttons: "Forgot Password" with a warning icon and "Create an Account" with a plus icon. At the bottom, it says "By logging in, you agree to the [Privacy Policy](#) & [Terms and Conditions](#) of NORD." Below that is a section titled "Featuring" with the logo for "GLOBAL SCHAAF-YANG SYNDROME REGISTRY".

Add a Participant

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



The image shows a welcome message for a user named Jane. At the top left, there is a language dropdown menu set to "English". Below that is the logo for "GLOBAL SCHAAF-YANG SYNDROME REGISTRY". The main heading is "Welcome, Jane!". Below the heading, it says "Welcome to the IAMRARE® program, home of **The Global SchAAF-Yang Syndrome Registry.**" There are two paragraphs of text: "If you are a new user, click on the **Create New Profile** button below." and "If you are transferring a record from another IAMRARE account, click on the **Transfer a Record** button below." At the bottom, there are two buttons: "Transfer a Record" and "Create New Profile". A red arrow points to the "Create New Profile" button. Below the buttons, it says "Don't show this again".

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

GLOBAL SCHAAF-YANG SYNDROME REGISTRY

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 *

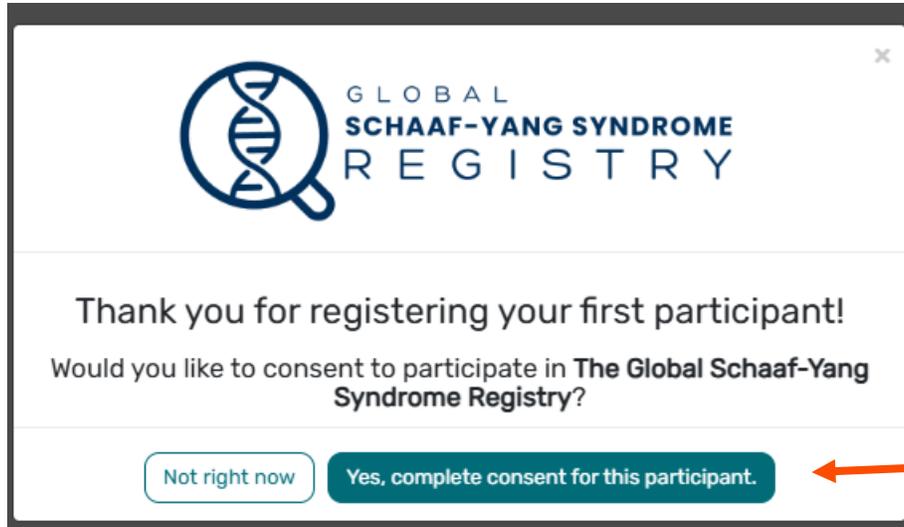
Country of Birth *

City/Municipality of Birth *

What Is Your Relationship to ? *

Consent to the Study

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

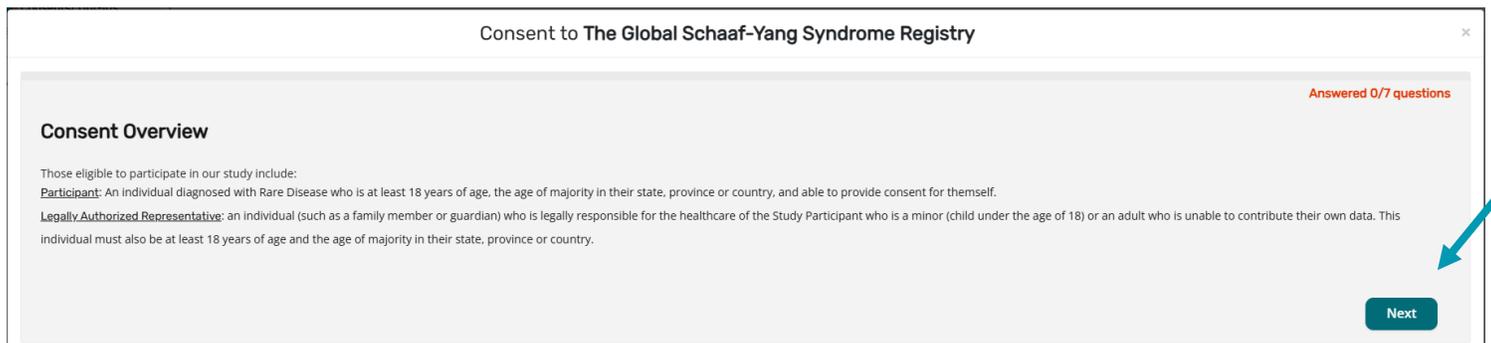


GLOBAL
SCHAAF-YANG SYNDROME
REGISTRY

Thank you for registering your first participant!
Would you like to consent to participate in The Global Schaaf-Yang Syndrome Registry?

Not right now 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.”



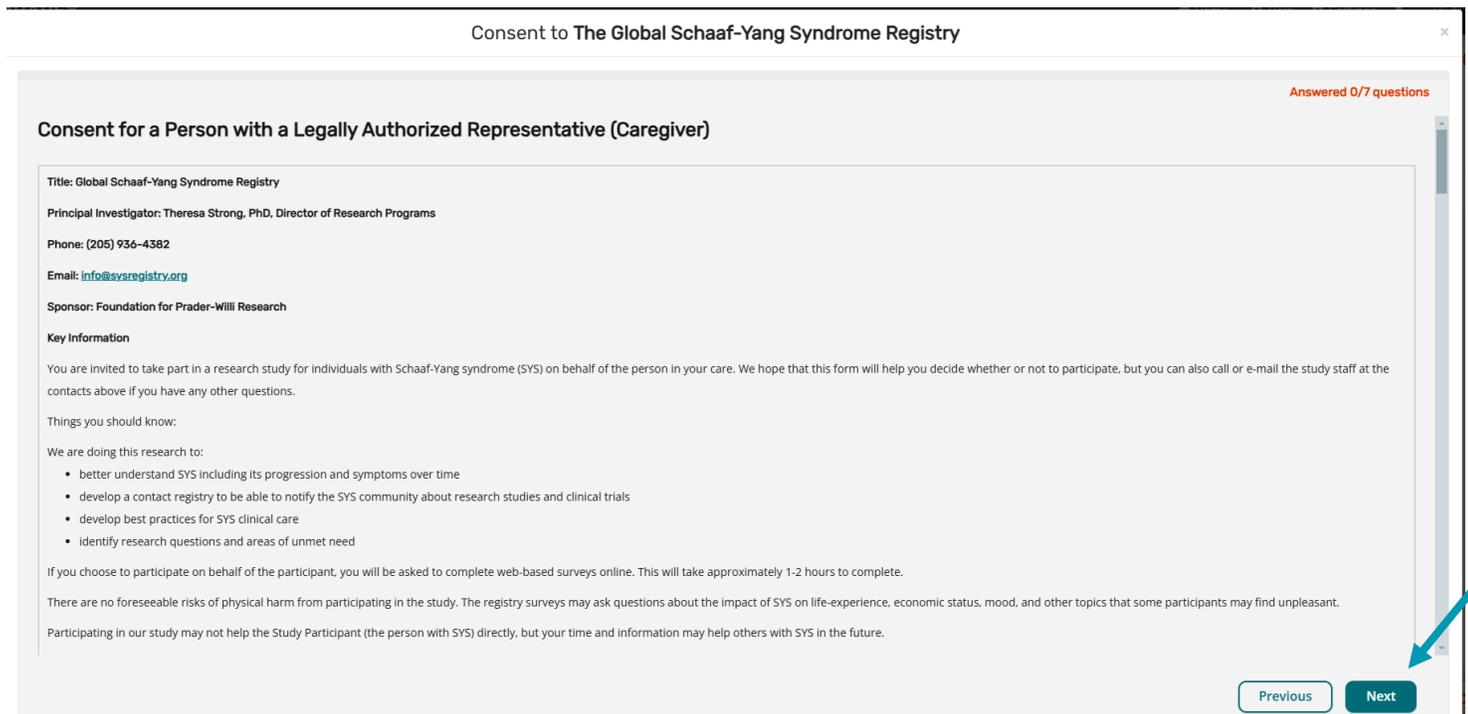
Consent to The Global Schaaf-Yang Syndrome Registry

Consent Overview

Those eligible to participate in our study include:
Participant: An individual diagnosed with Rare Disease 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.

Answered 0/7 questions

Next



Consent to The Global Schaaf-Yang Syndrome Registry

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

Title: Global Schaaf-Yang Syndrome Registry
Principal Investigator: Theresa Strong, PhD, Director of Research Programs
Phone: (205) 936-4382
Email: info@sysregistry.org
Sponsor: Foundation for Prader-Willi Research

Key Information

You are invited to take part in a research study for individuals with Schaaf-Yang syndrome (SYS) 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:

- better understand SYS including its progression and symptoms over time
- develop a contact registry to be able to notify the SYS community about research studies and clinical trials
- develop best practices for SYS clinical care
- identify research questions and areas of unmet need

If you choose to participate on behalf of the participant, you will be asked to complete web-based surveys online. This will take approximately 1-2 hours to complete.

There are no foreseeable risks of physical harm from participating in the study. The registry surveys may ask questions about the impact of SYS on life-experience, economic status, mood, and other topics that some participants may find unpleasant.

Participating in our study may not help the Study Participant (the person with SYS) directly, but your time and information may help others with SYS in the future.

Answered 0/7 questions

Previous Next

Consent to **The Global Schaaf-Yang Syndrome Registry**

Answered 2/7 questions

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 Global SYS 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 Global SYS 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 Global SYS Registry for the purposes described above under Study Aims.

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

Consent to **The Global Schaaf-Yang Syndrome Registry**

Answered 7/7 questions

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.

- 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 The Global Schaaf-Yang Syndrome Registry

Select Opt-Ins for this study

- Interest in hearing about other studies from [SYS by Foundation for Prader Willi Research](#)
- Interest in hearing about relevant clinical trials
- Interest in donating specimens or DNA (biobanking) for future research
- Interest in genetic testing

- 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.

IAMRARE® Home Help Settings Hi, Jane!

Good Afternoon, Jane!
Member since Mar 31, 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
🔔 1 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.

GLOBAL SCHAAF-YANG SYNDROME REGISTRY English
The Global Schaaf-Yang Syndrome Registry
SYS by Foundation for Prader Willi Research
✓ Consented
🔔 1 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

The Global Schaaf-Yang Syndrome Registry
Surveys 🔔 1 pending All (1) Complete (0) Pending (1)

0% **Welcome Survey**
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 the user profile for Jane Smith (5-May-2000) and the title 'The Global Schaaf-Yang Syndrome Registry'. Under 'Surveys', there are 3 pending surveys. Two completed surveys are listed: 'Welcome Survey' (Completed on 31-Mar-2025) and 'Demographics and Contact Information' (Last Completed on 31-Mar-2025). For the 'Welcome Survey', red arrows point to the 'View Responses' and 'Reports' buttons. For the 'Demographics and Contact Information' survey, red arrows point to the 'View Responses' and 'Reports' buttons, and a blue arrow points to the 'Retake Survey' button.

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 (5-May-2000). A red arrow points to the 'Enrolled Studies' section. Below the section title, there is a search bar and a 'Search Studies' button. A 'Shortcuts' section contains two buttons: 'Request Transfer' and 'Consent/Opt-Ins', with a red arrow pointing to the 'Consent/Opt-Ins' button.

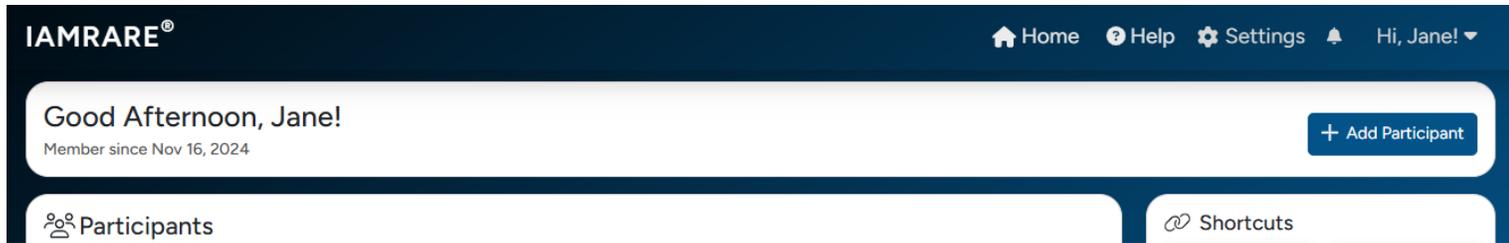
- Step 2: You may revoke your consent at any time by clicking “Revoke”. You may also edit your Opt-Ins by clicking “Opt-Ins”.

The screenshot shows the 'Consents/Opt-Ins' page for Jane Smith (5-May-2000). A table lists the study 'The Global Schaaf-Yang Syndrome Registry' with a 'Consented' status and a date of '31-Mar-2025'. In the 'Actions' column, there are three buttons: 'View Consent', 'Revoke', and 'Opt-Ins'. Red arrows point to the 'Revoke' and 'Opt-Ins' buttons.

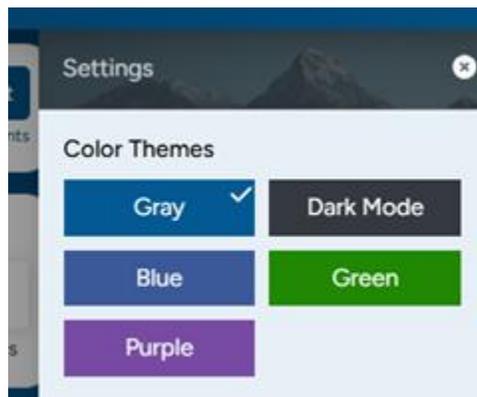
Study Name	Consent Status	Consented On	Actions
The Global Schaaf-Yang Syndrome Registry	Consented	31-Mar-2025	View Consent, Revoke, Opt-Ins

Dark Mode Settings

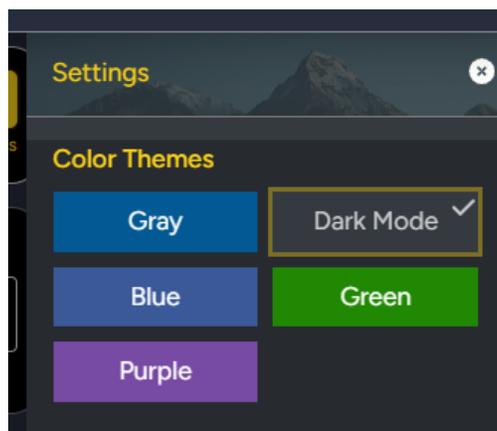
- Step 1: You can view the platform in Dark Mode. First, click Settings.



- Step 2: Select Dark Mode.



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

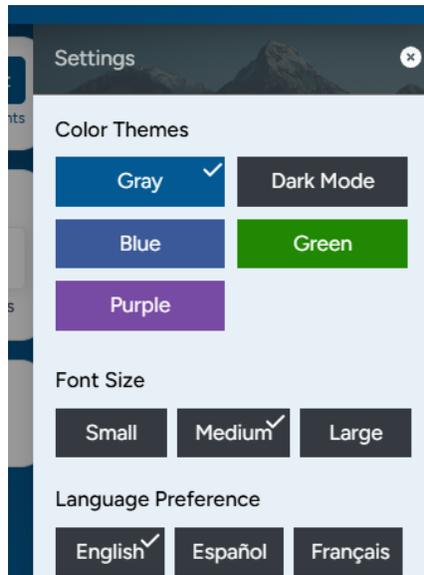


Display Settings

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



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

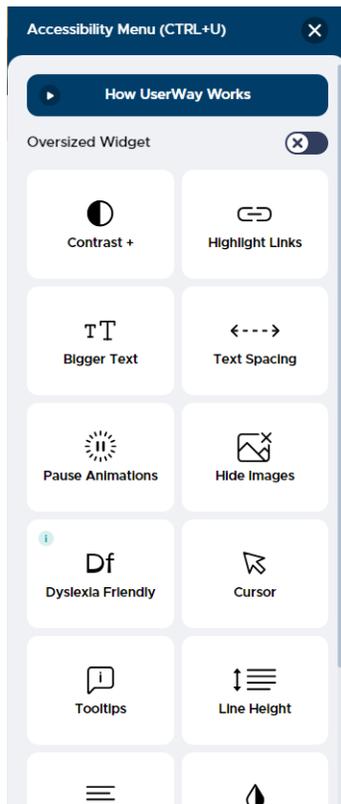


- Step 3: Exit the Settings menu, and your selection will be saved.

Microsite Visibility

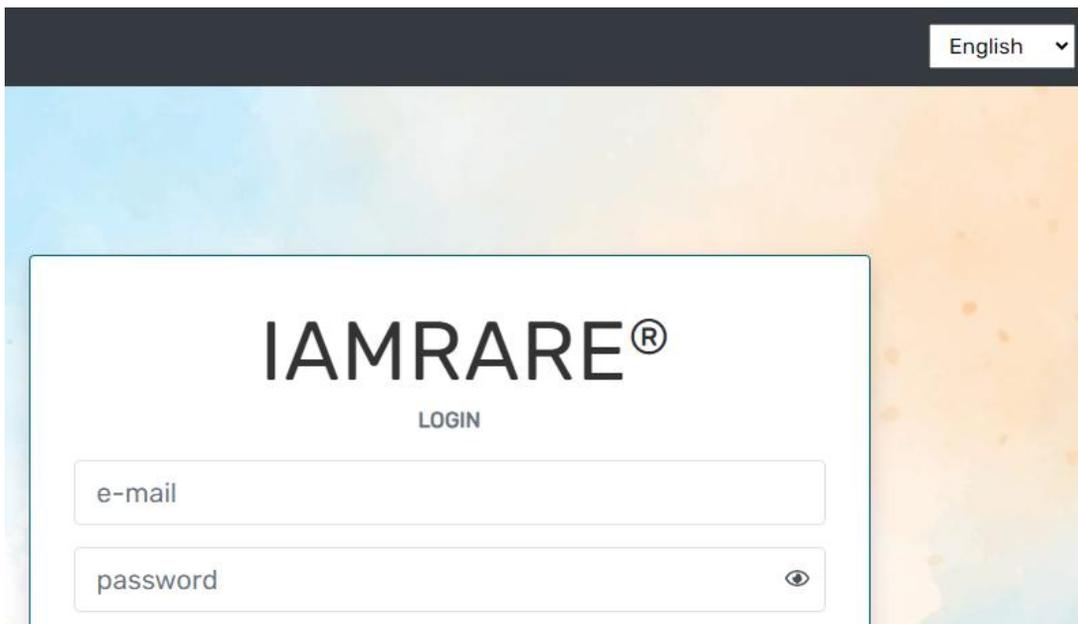
- Step 1: You can change how you view the microsite: www.sysregistry.org using an Accessibility menu. Click the icon of a person at the bottom of the screen. You are able to change the settings such as the contrast, text sizing, and text spacing.

The screenshot shows two main content areas on a white background. The left area is titled "For Patients" in orange, followed by "Get Involved" in bold black. Below this is a paragraph of text: "Information collected during this study may be used to help provide opportunities for patients and researchers to collaborate in the rare disease community." At the bottom of this area is a dark blue button with the text "LEARN MORE" in white. The right area is titled "For Researchers" in orange, followed by "Drive Research" in bold black. Below this is a paragraph of text: "This is a unique rare disease patient registry. Are you interested in using our data to further your rare disease research?" At the bottom of this area is a dark blue button with the text "LEARN MORE" in white. To the right of these two areas, there is a blue circular icon containing a white silhouette of a person. A blue arrow points from the top right towards this icon.

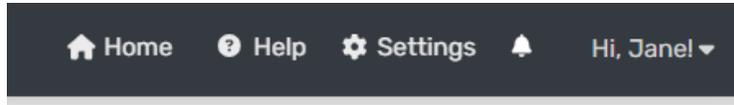


Language Selection

- 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 currently available in English and will be available in French and Spanish in the future.

Need Assistance?

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

 A white form with a blue header that says "Have a question?" and a close button (X). Below the header is a paragraph of text: "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\")." Below this is a dropdown menu labeled "Inquiry Type *" with the text "-- Select Inquiry Type --". Underneath is a text input field labeled "Message *" with the placeholder text "Your message". At the bottom are two buttons: "Cancel" and "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.

A vertical sidebar of buttons. From top to bottom: a button with a magnifying glass icon and "View Responses 1"; a button with a checkmark icon and "Reports"; a button with a magnifying glass icon and "View Responses 1"; a blue button with a pencil icon and "Retake Survey"; a button with a checkmark icon and "Reports"; and a blue button with a pencil icon and "Take Survey".

A contact information card with a blue border. On the left is the logo for the "GLOBAL SCHAAF-YANG SYNDROME REGISTRY" featuring a DNA helix. On the right, it says "SYS by Foundation for Prader Willi Research" and "fpwr.org". Below this, it lists "Contact" information: "Jessica Bohonowych" and "Phone 888-322-5487". It also lists "E-mail" as "info@sysregistry.org" and "IRB E-mail" as "info@northstarreviewboard.org".