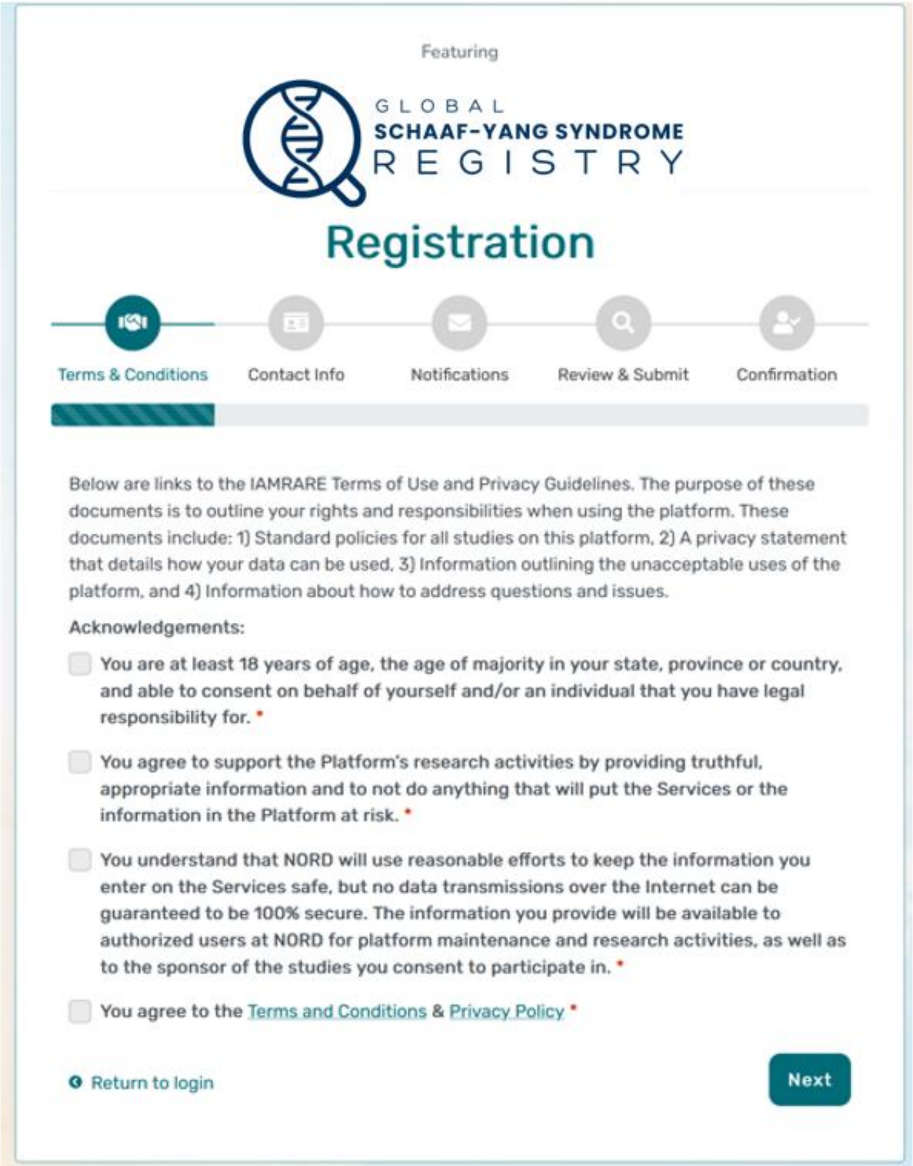
GLOBAL
SCHAAF-YANG SYNDROME
REGISTRY

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”.



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:

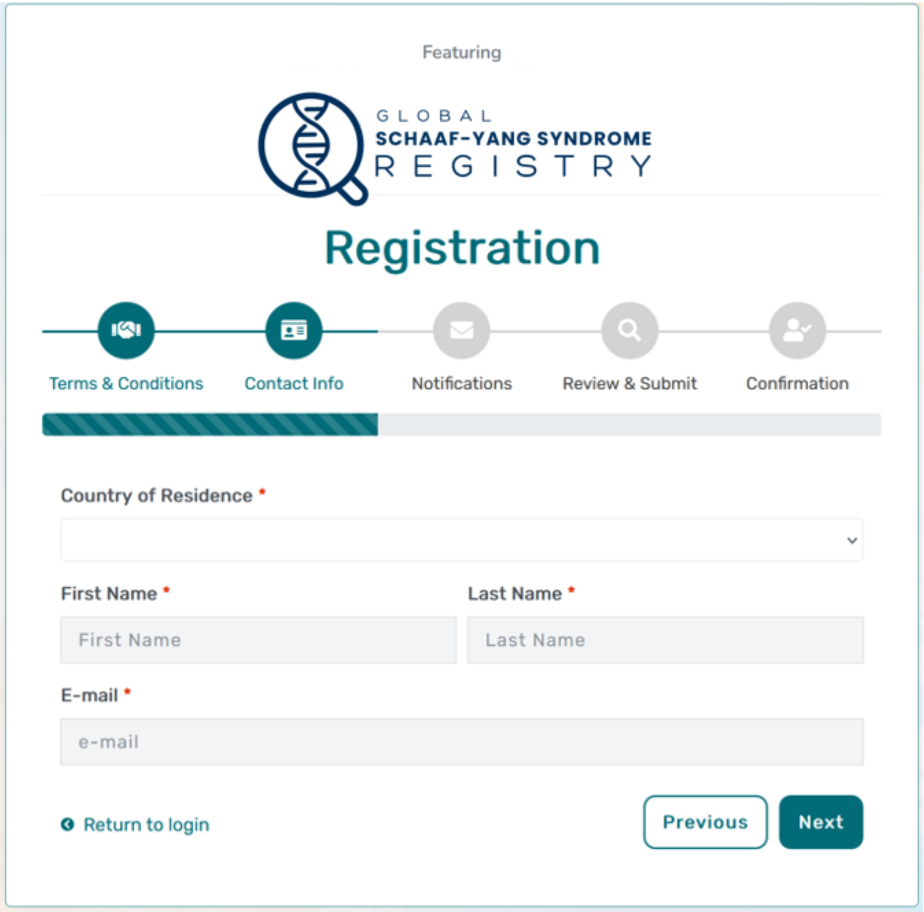
☐ You are at least 18 years of age, the age of majority in your state, province or country, and able to consent on behalf of yourself and/or an individual that you have legal responsibility for. *

☐ 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. *

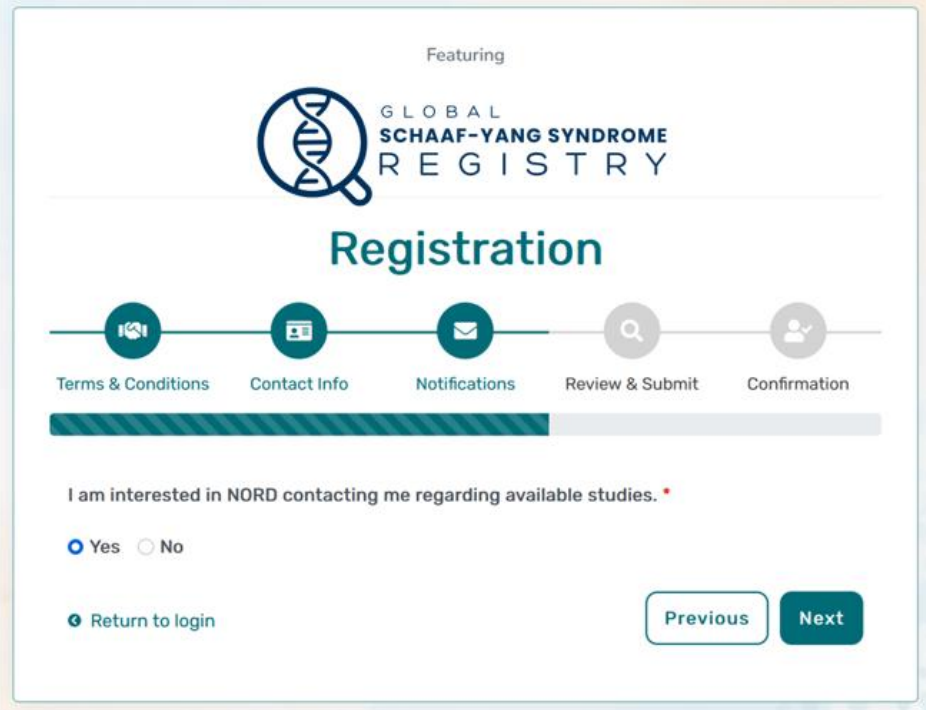
☐ You understand that NORD will use reasonable efforts to keep the information you enter on the Services safe, but no data transmissions over the Internet can be guaranteed to be 100% secure. The information you provide will be available to authorized users at NORD for platform maintenance and research activities, as well as to the sponsor of the studies you consent to participate in. *

☐ You agree to the Terms and Conditions & Privacy Policy *

- Step 2: Enter your personal information in the spaces provided. When you are finished with this page, click "Next".



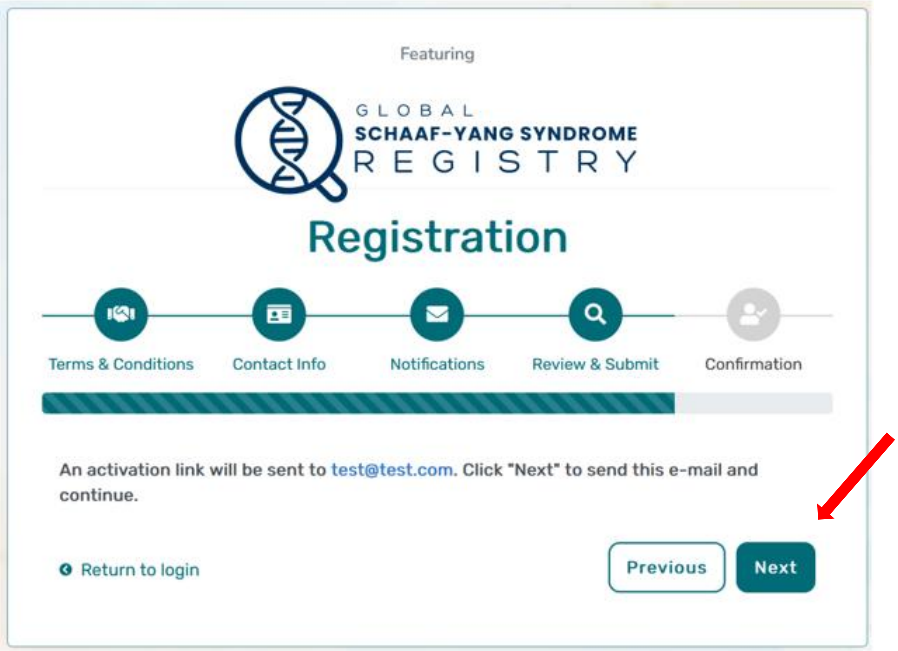
- Step 3: Select whether you are interested in being contacted by NORD regarding available studies. When you are finished with this page, click "Next".



I am interested in NORD contacting me regarding available studies. *

● Yes ○ No

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



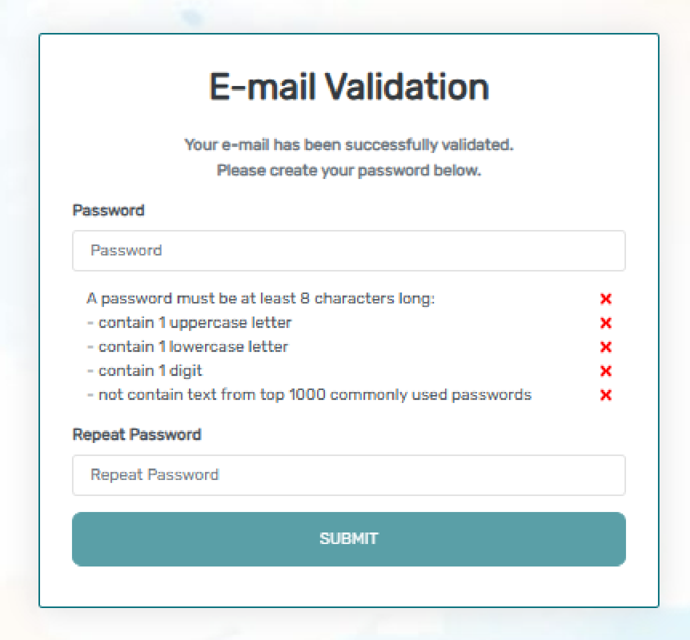
Featuring

GLOBAL SCHAAF-YANG SYNDROME REGISTRY

Registration

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

- 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

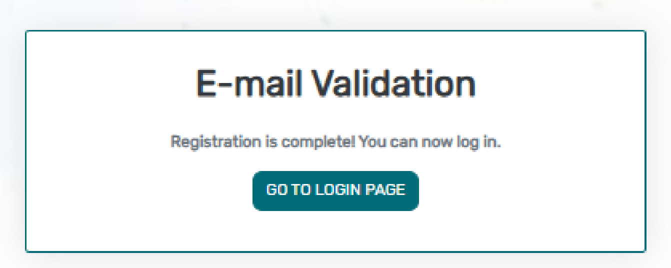
Your e-mail has been successfully validated.
Please create your password below.

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

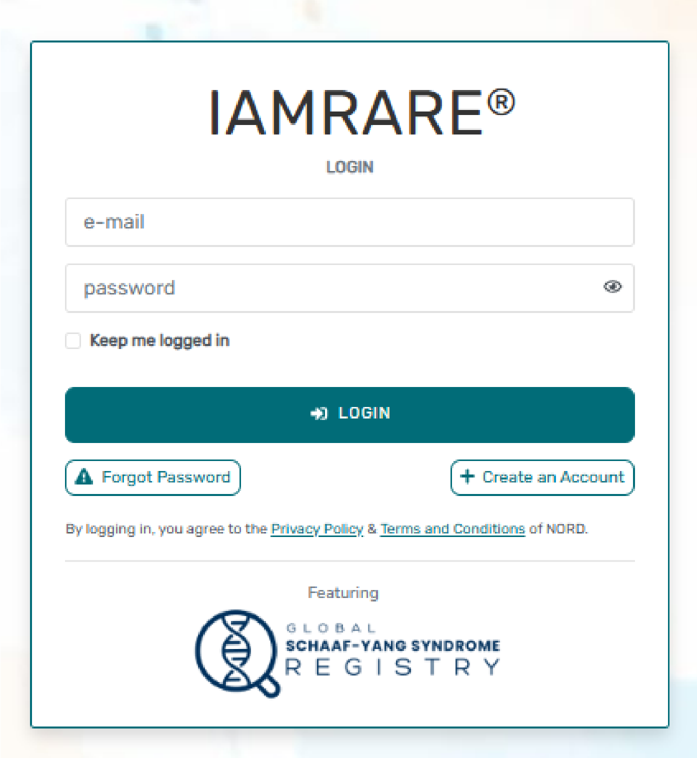
- Step 6: Your validation is now complete. Select “Go to Login Page”.



E-mail Validation

Registration is complete! You can now log in.

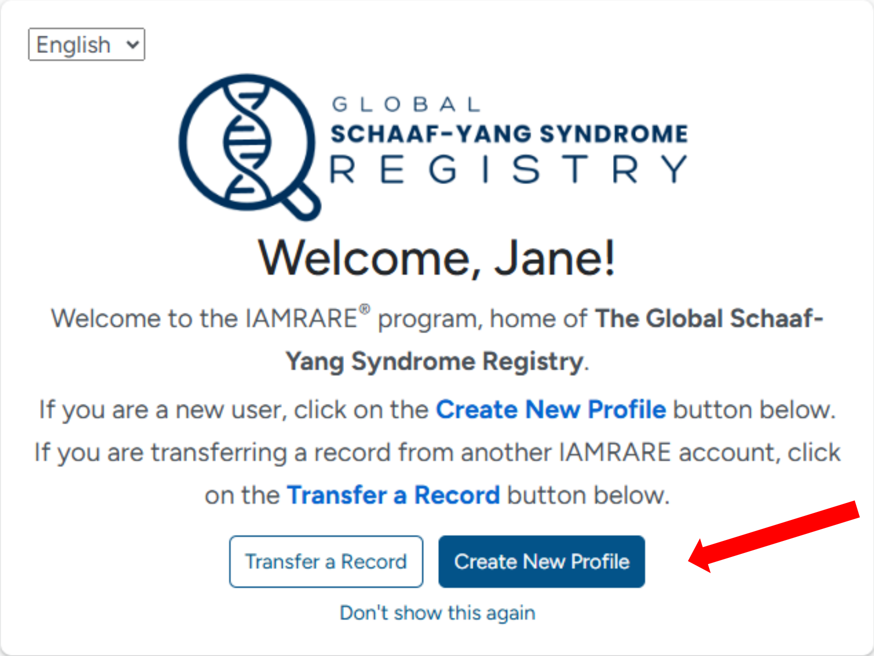
- Step 7: Log in using your new e-mail and password.



By logging in, you agree to the Privacy Policy & Terms and Conditions of NORD.

Add a Participant

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



Welcome, Jane!

Welcome to the IAMRARE® program, home of **The Global Schaaf-Yang Syndrome 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.

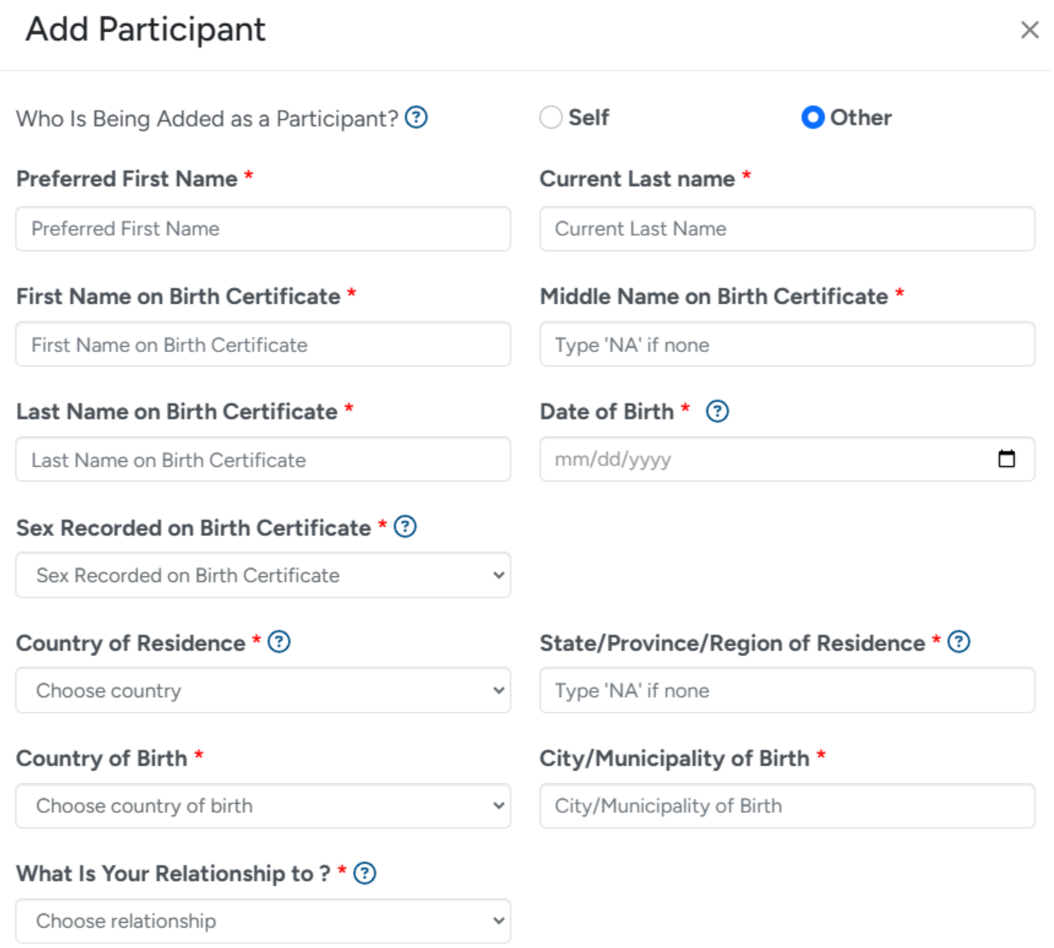
- Step 2: Select who you will be providing information about.

GLOBAL SCHAAF-YANG SYNDROME REGISTRY

Add a Participant

Are you adding yourself or another person?

- 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** *
Preferred First Name	Current Last Name
First Name on Birth Certificate *	**Middle Name on Birth Certificate** *
First Name on Birth Certificate	Type 'NA' if none
Last Name on Birth Certificate *	**Date of Birth** *
Last Name on Birth Certificate	mm/dd/yyyy
Sex Recorded on Birth Certificate *	
Sex Recorded on Birth Certificate	
Country of Residence *	**State/Province/Region of Residence** *
Choose country	Type 'NA' if none
Country of Birth *	**City/Municipality of Birth** *
Choose country of birth	City/Municipality of Birth
What Is Your Relationship to ? *	
Choose relationship	

Consent to the Study

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

Thank you for registering your first participant!

Would you like to consent to participate in **The Global Schaaf-Yang Syndrome Registry**?

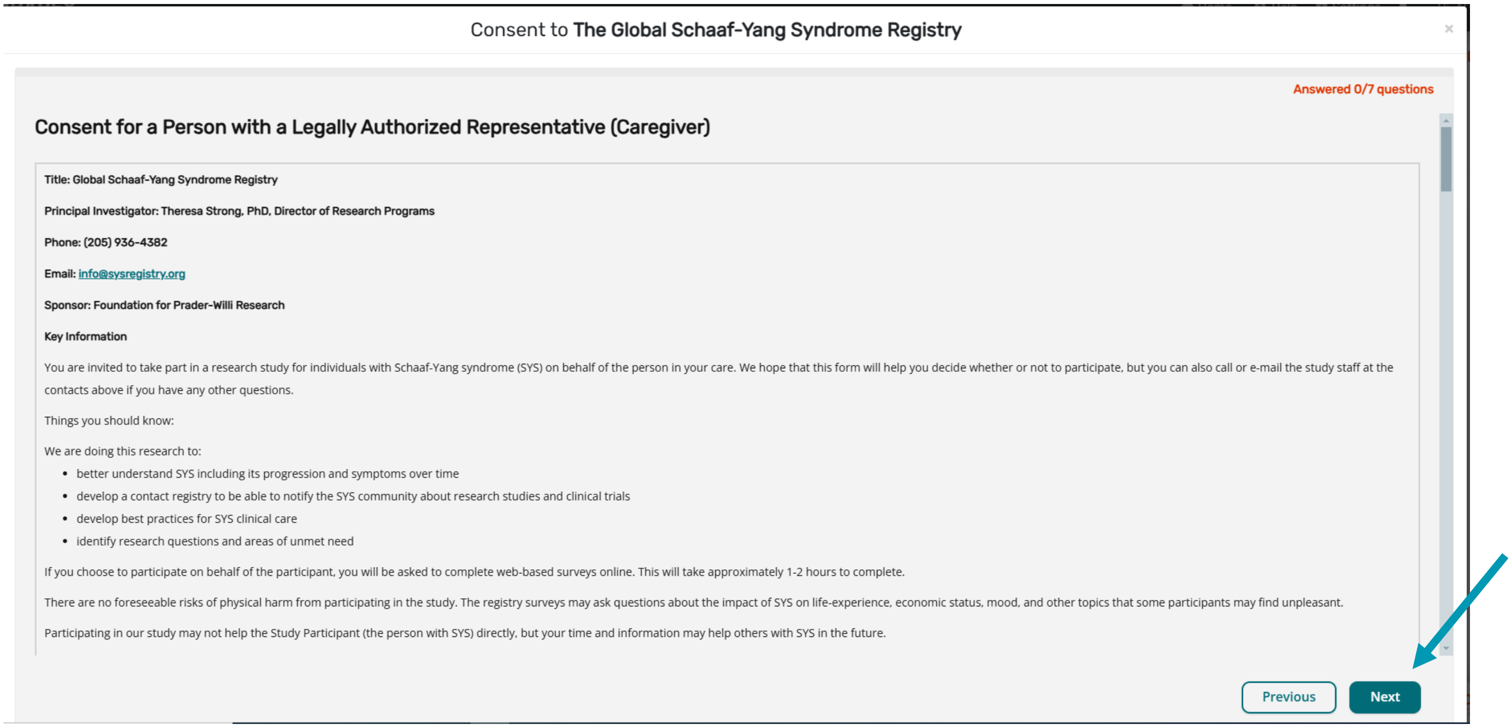
- Step 2: Scroll down and read through the consent form thoroughly. Once you finish each page, click the “Next” button. Once you reach the Authorization form, read through the statements thoroughly. If you are comfortable consenting to participate in the study, please read each statement and authorize your consent. After checking the boxes, click “Next.”


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

Answered 0/7 questions

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 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.


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

Answered 0/7 questions

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.

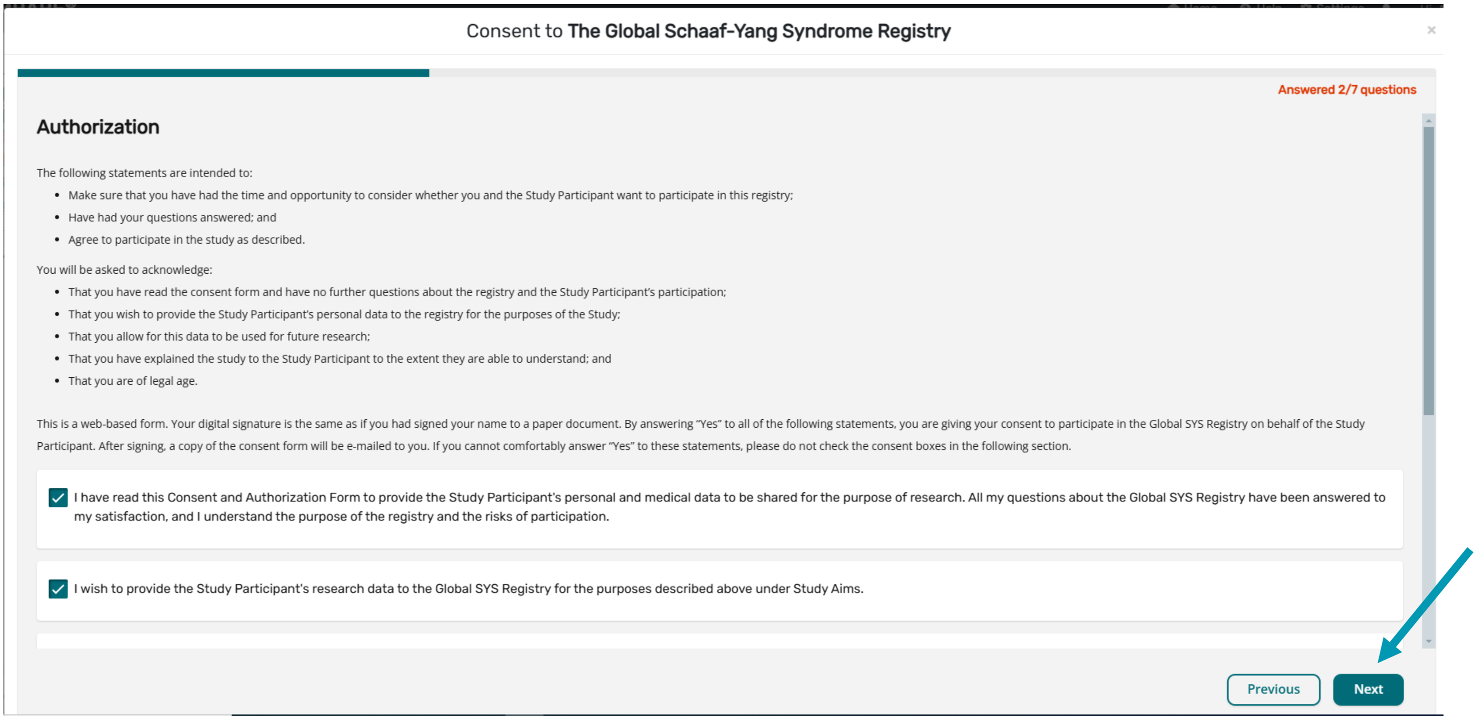
Things you should know:

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.



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:

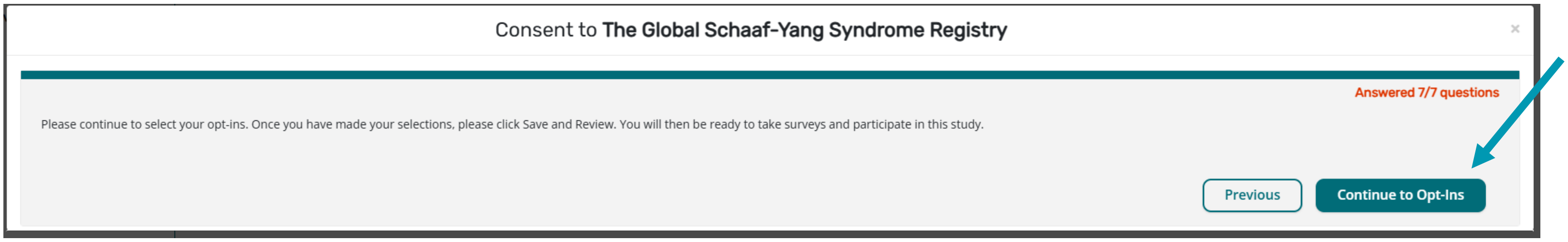
- That you have read the consent form and have no further questions about the registry and the Study Participant's participation;
- That you wish to provide the Study Participant's personal data to the registry for the purposes of the Study;
- That you allow for this data to be used for future research;
- 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.

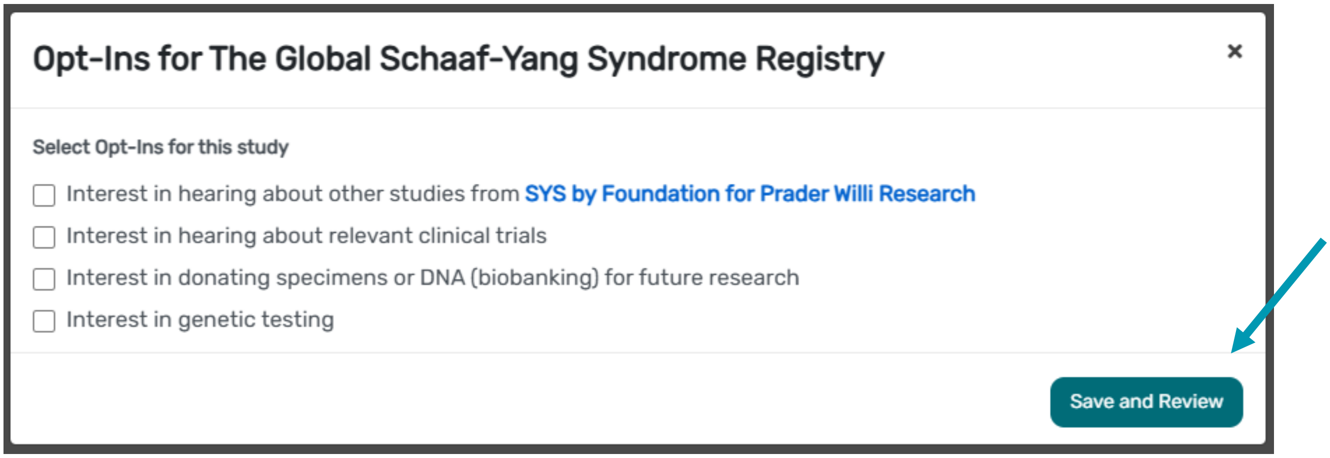
☑ I wish to provide the Study Participant's research data to the Global SYS Registry for the purposes described above under Study Aims.

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



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".

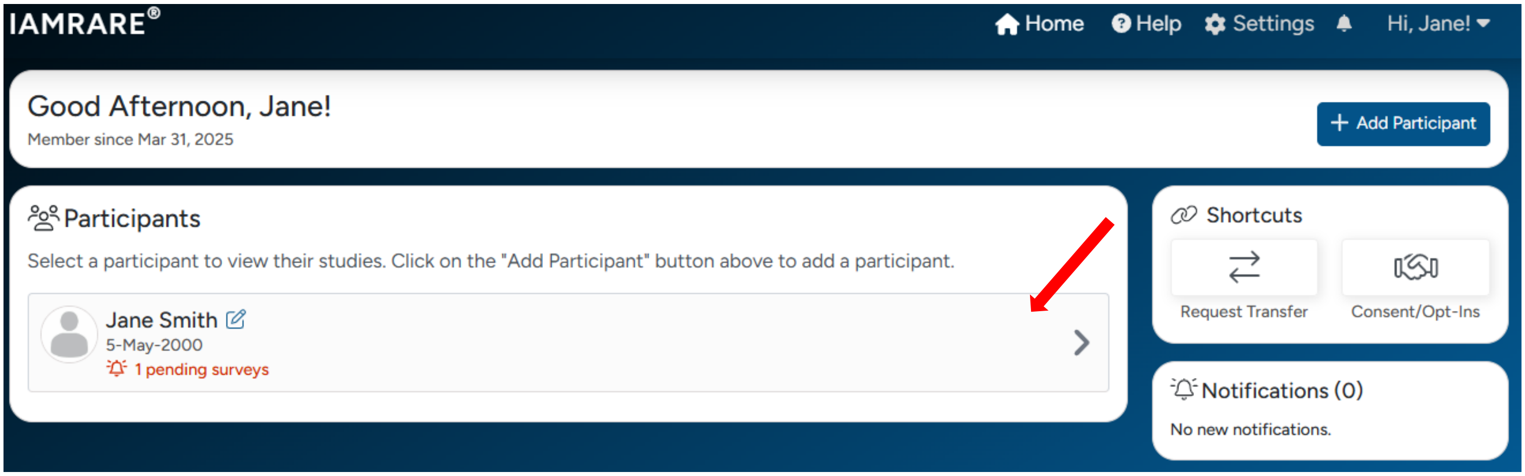


☐ Interest in hearing about other studies from SYS by Foundation for Prader Willi Research
☐ Interest in hearing about relevant clinical trials
☐ Interest in donating specimens or DNA (biobanking) for future research
☐ Interest in genetic testing

- 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.



Good Afternoon, Jane!

Member since Mar 31, 2025

Participants

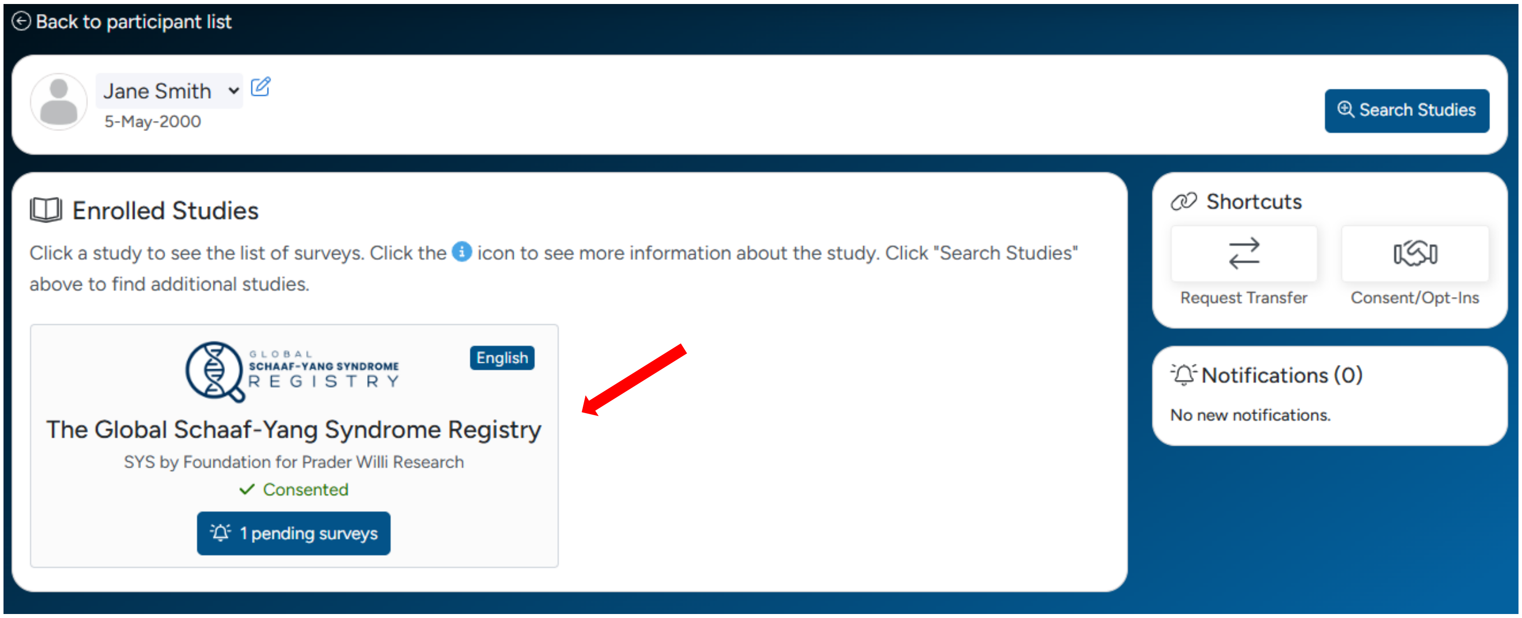
Select a participant to view their studies. Click on the "Add Participant" button above to add a participant.

Jane Smith
5-May-2000
1 pending surveys

Notifications (0)

No new notifications.

- Step 2: Click on the appropriate study.



Jane Smith
5-May-2000

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.

The Global Schaaf-Yang Syndrome Registry

SYS by Foundation for Prader Willi Research

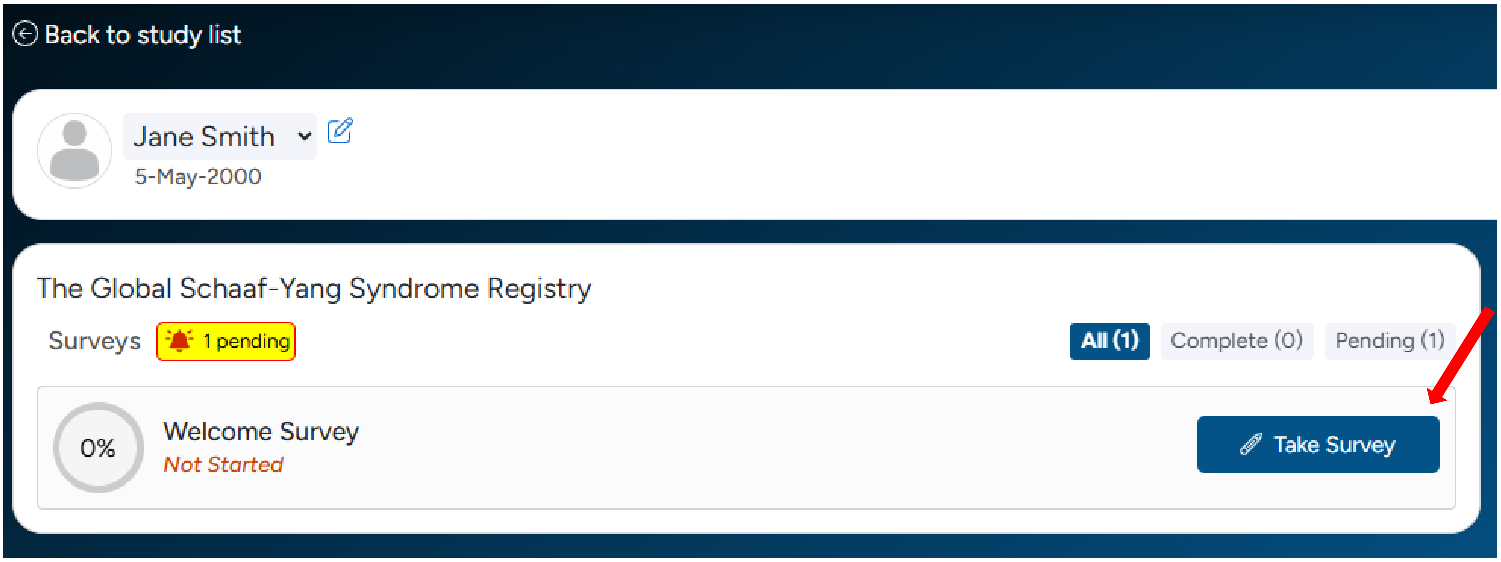
✓ Consented

1 pending surveys

Notifications (0)

No new notifications.

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



Jane Smith
5-May-2000

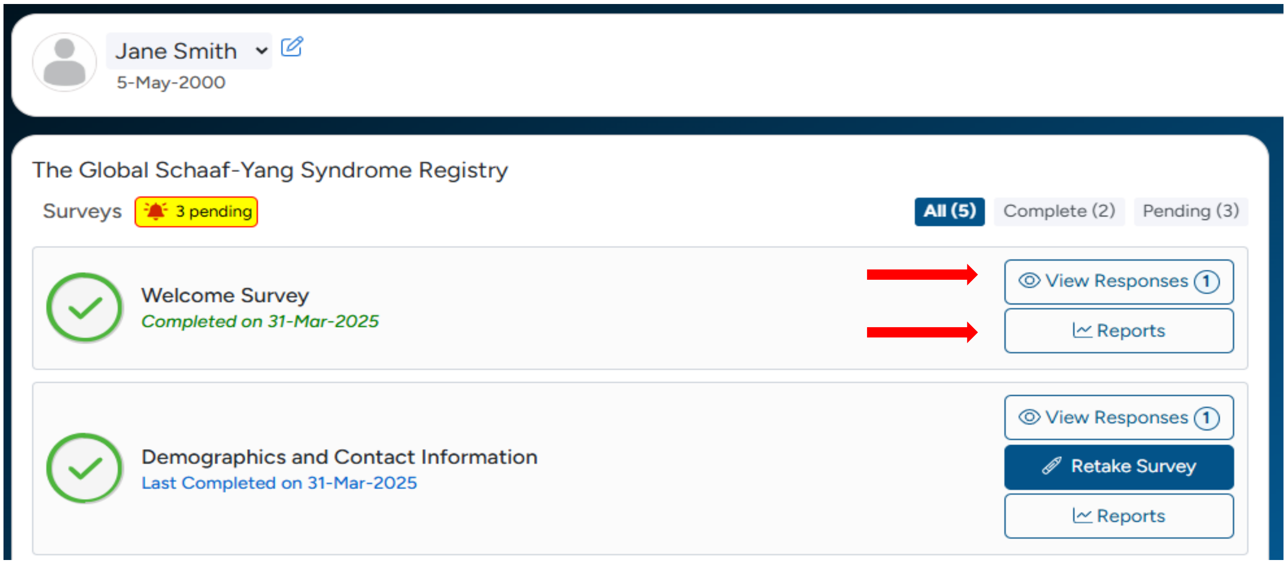
The Global Schaaf-Yang Syndrome Registry

Surveys 1 pending

0% Welcome Survey
Not Started

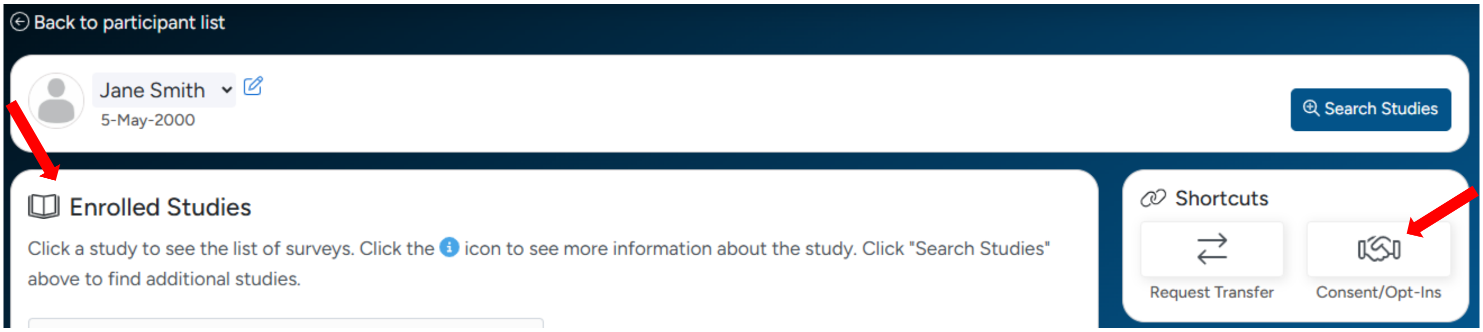
View Responses and Reports

- 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.



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.

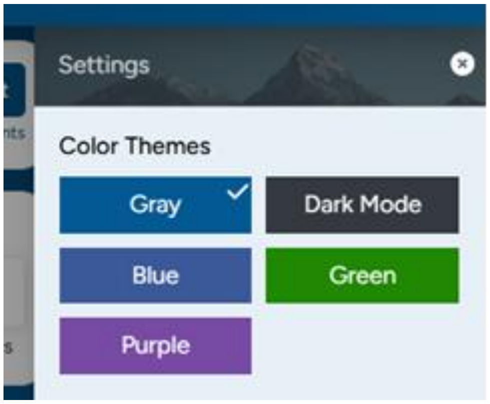
- Step 2: You may revoke your consent at any time by clicking “Revoke”. You may also edit your Opt-Ins by clicking “Opt-Ins”.

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

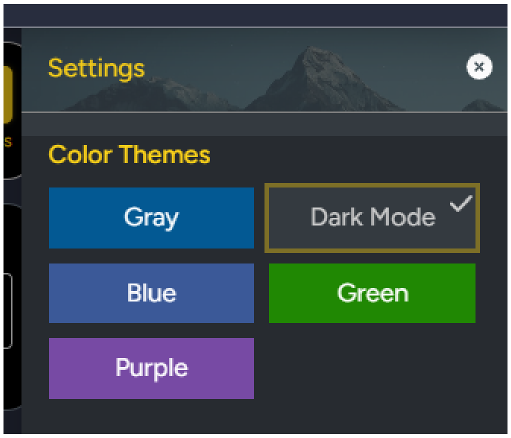
Dark Mode Settings

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

- Step 2: Select Dark Mode.



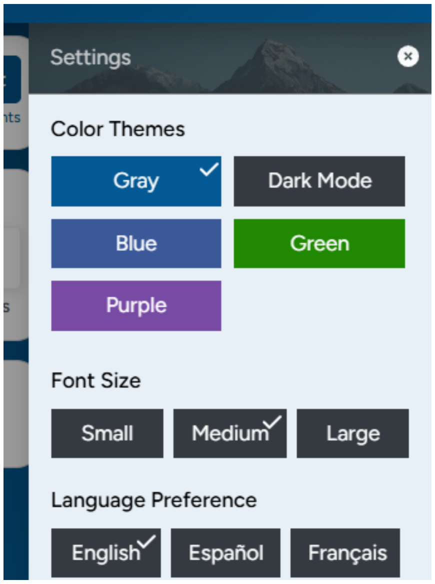
- Step 3: Exit the Settings menu, and your selection will be saved.



Display Settings

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

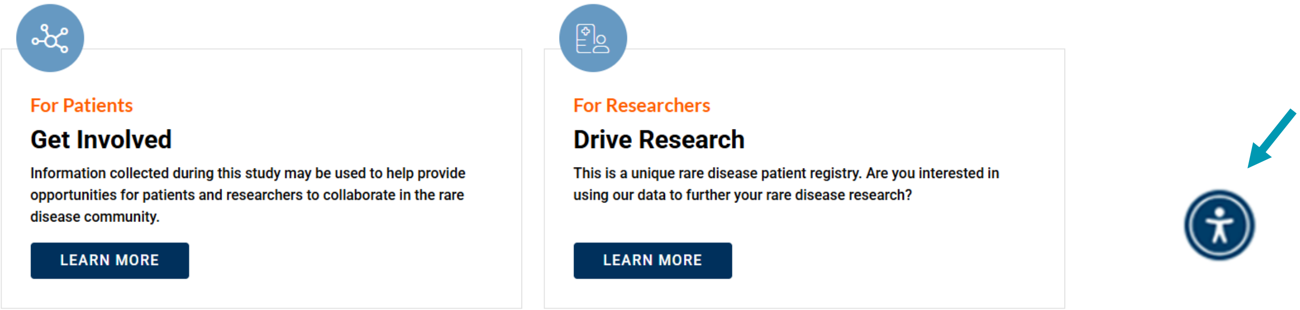
- Step 2: Select a color theme, a font size, or language preference.



- 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.



For Patients

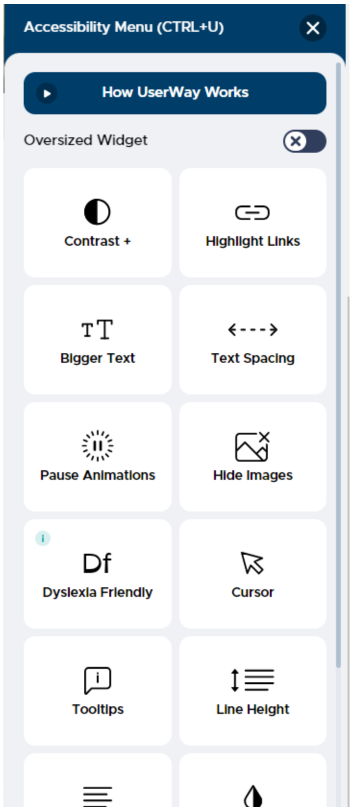
Get Involved

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

For Researchers

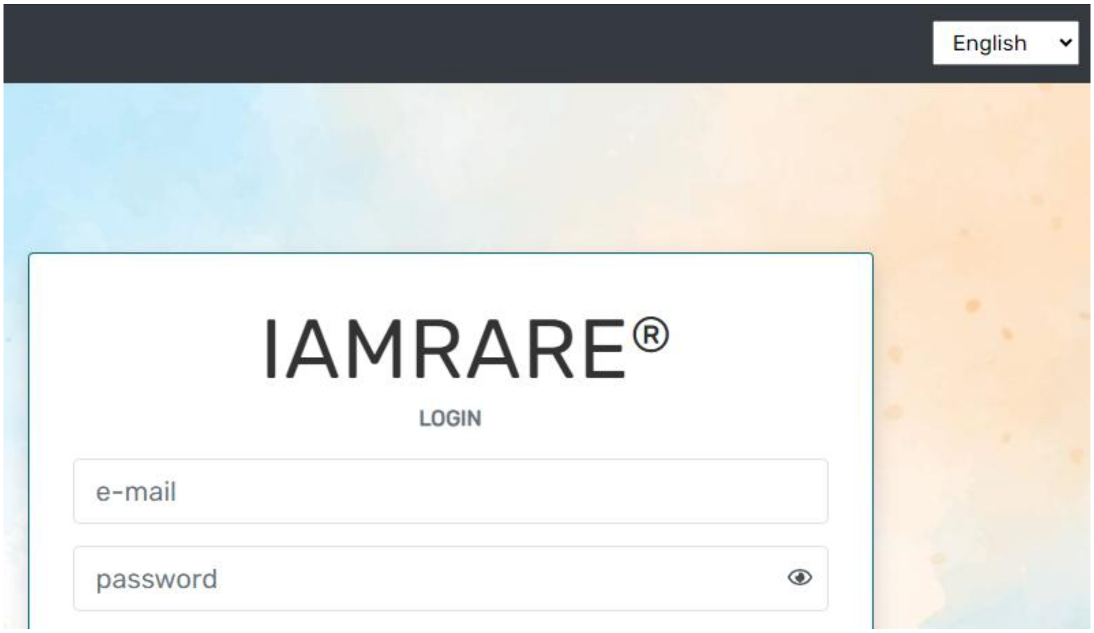
Drive Research

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



Language Selection

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

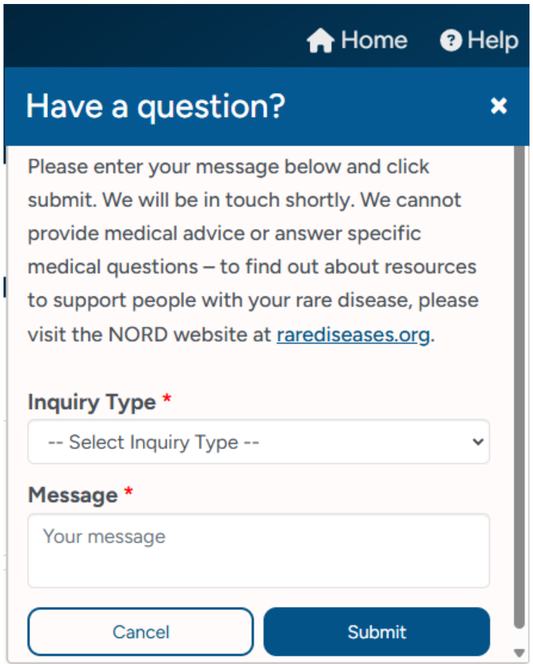


- To change your platform language selection after you've logged in, click "Settings", and choose your preferred language.

- 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.



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.

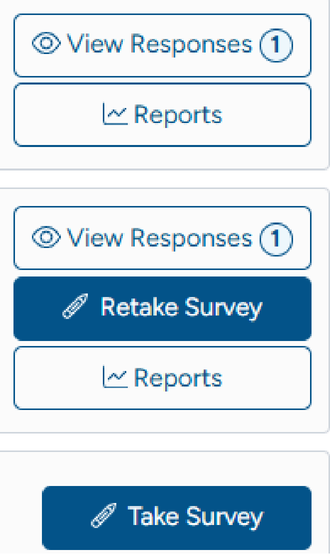
Inquiry Type *

-- Select Inquiry Type --

Message *

Your message

- 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.



SYS by Foundation for Prader Willi Research
fpwr.org

Contact
Jessica Bohonowych

Phone
888-322-5487

E-mail
info@sysregistry.org

IRB E-mail
info@northstarreviewboard.org