



Stiff Person Syndrome Global 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".

Featuring

SPS GLOBAL REGISTRY

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

SPS GLOBAL REGISTRY

Registration

Terms & Conditions Contact Info Notifications Review & Submit Confirmation

Country of Residence *

First Name * Last Name *

First Name Last Name

E-mail *

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



SPS GLOBAL REGISTRY

Registration

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

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

Yes No

A teal arrow points to the "Next" button.

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

Featuring



SPS GLOBAL REGISTRY

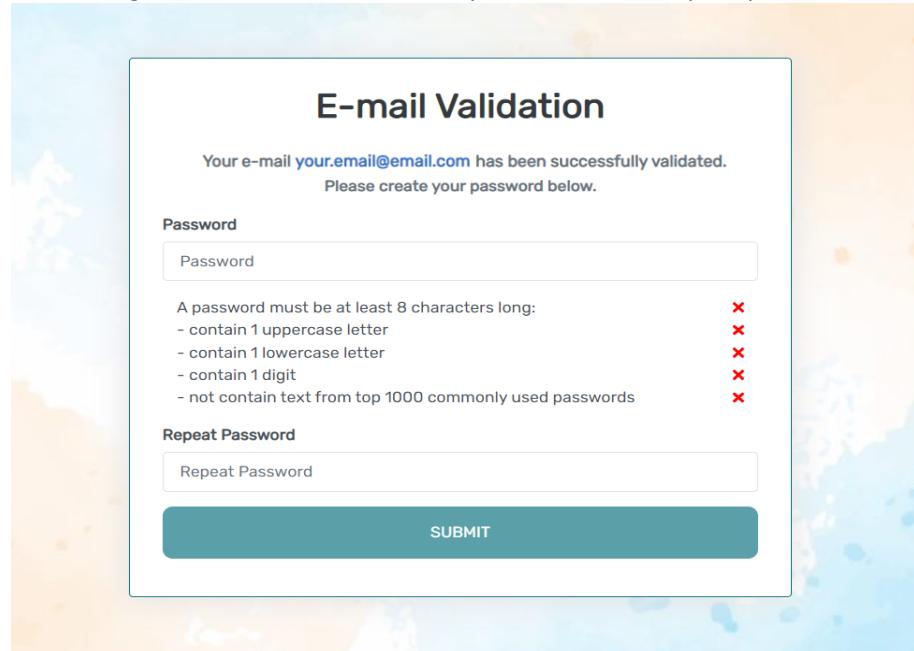
Registration

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

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

A teal 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.

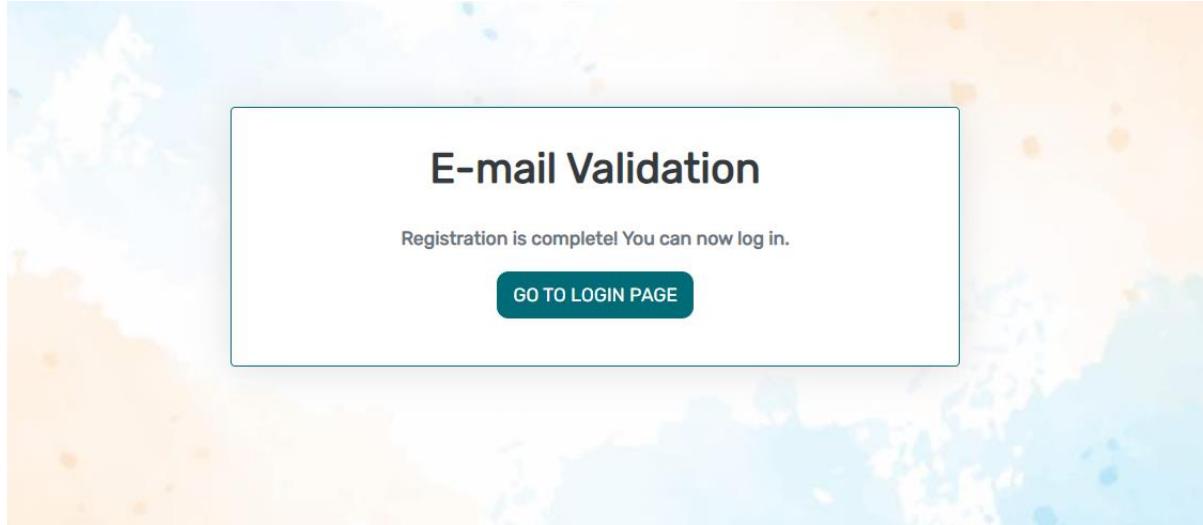
Password

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".

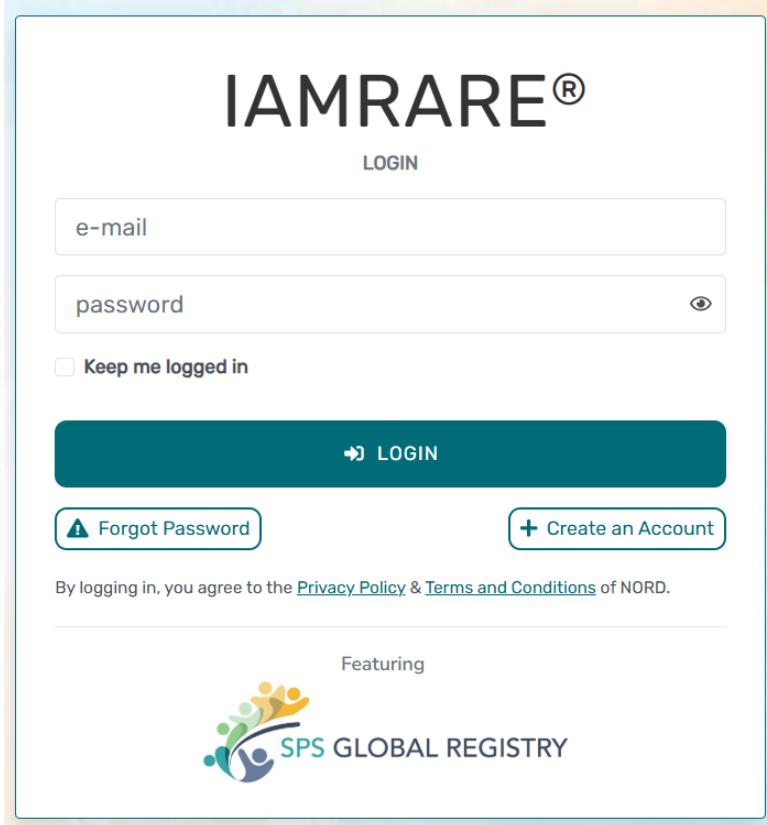


E-mail Validation

Registration is complete! You can now log in.

GO TO LOGIN PAGE

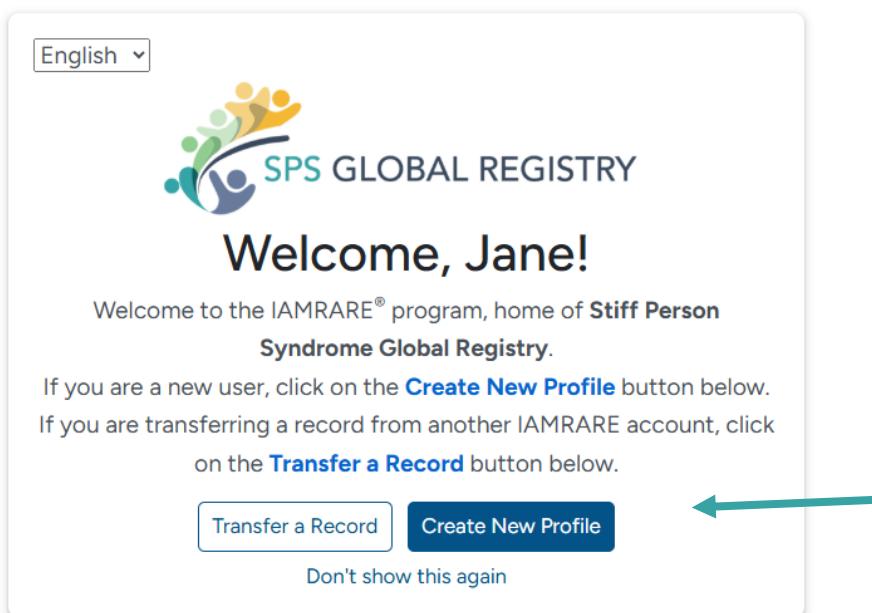
- Step 7: Log in using your new e-mail and password.



The image shows the IAMRARE® login page. At the top is the IAMRARE® logo. Below it is a 'LOGIN' button. The page contains fields for 'e-mail' and 'password', with a visibility icon next to the password field. There is a 'Keep me logged in' checkbox. A large teal 'LOGIN' button with a right-pointing arrow is centered. Below the button are two links: 'Forgot Password' with a warning icon and 'Create an Account' with a plus icon. A note at the bottom states: 'By logging in, you agree to the [Privacy Policy](#) & [Terms and Conditions](#) of NORD.' Below the login area, the text 'Featuring' is followed by the 'SPS GLOBAL REGISTRY' logo, which features stylized human figures in blue, green, and yellow.

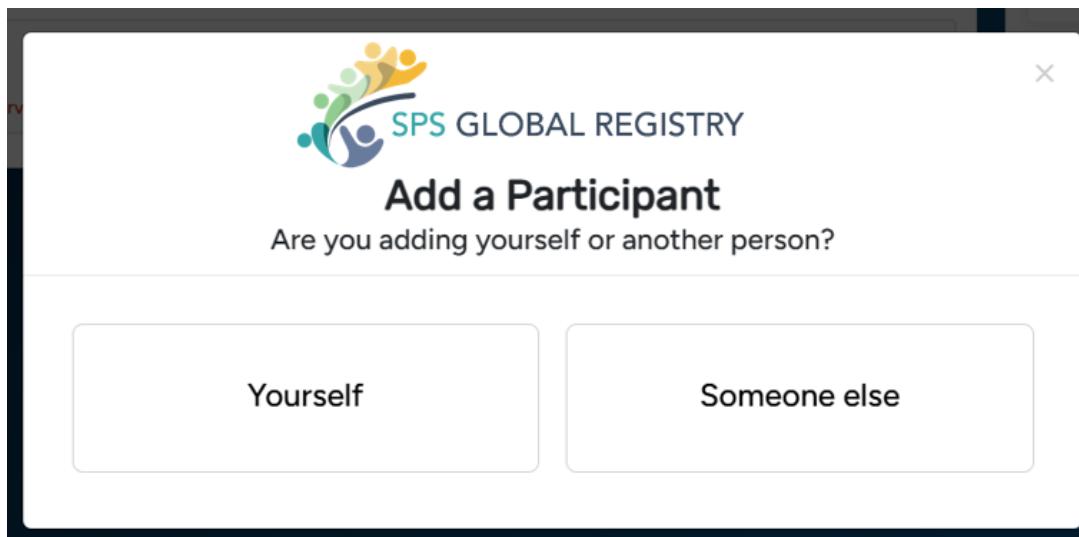
Add a Participant

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



The image shows the 'Welcome to IAMRARE®' page. At the top left is a language dropdown set to 'English'. The top center features the 'SPS GLOBAL REGISTRY' logo with stylized human figures. Below the logo, the text 'Welcome, Jane!' is displayed in a large, bold font. A message follows: 'Welcome to the IAMRARE® program, home of **Stiff Person Syndrome Global Registry**.'. Below this, instructions are given: '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.' At the bottom are two buttons: 'Transfer a Record' and 'Create New Profile'. A teal arrow points to the 'Create New Profile' button. A link 'Don't show this again' is at the bottom.

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



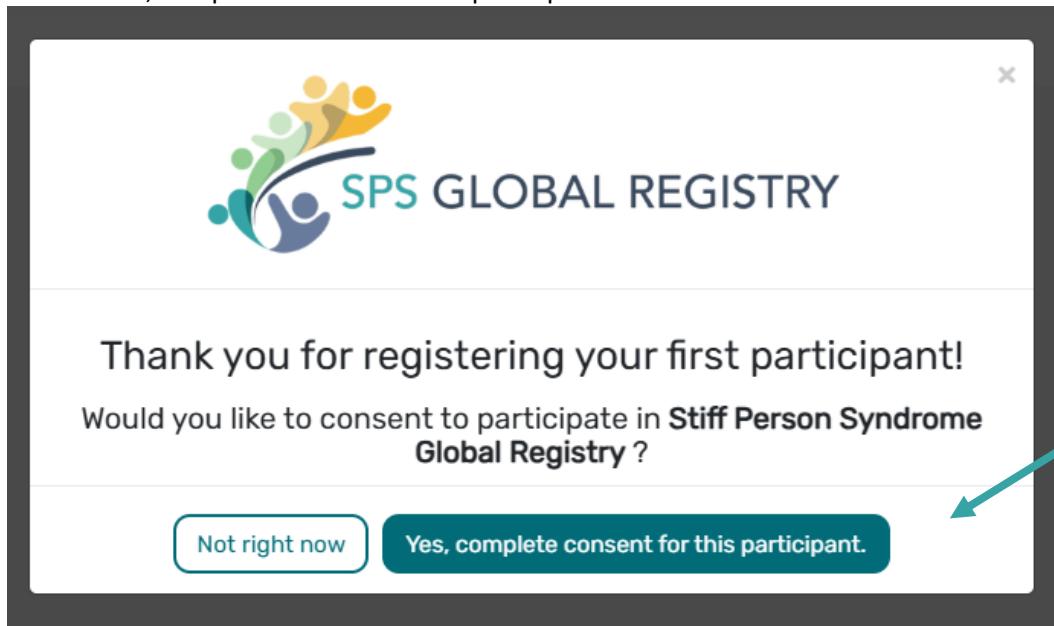
- Step 3: Fill out the Participant's information.

 A screenshot of the 'Add Participant' form. The title 'Add Participant' is at the top left. On the right side, there is a close button (X). The form is divided into several sections with labels and input fields:

- Who Is Being Added as a Participant?** (with a question mark icon): Self Other
- Preferred First Name ***: Preferred First Name
- Current Last name ***: Current Last Name
- First Name on Birth Certificate ***: First Name on Birth Certificate
- Middle Name on Birth Certificate ***: Type 'NA' if none
- Last Name on Birth Certificate ***: Last Name on Birth Certificate
- Date of Birth *** (with a question mark icon): mm/dd/yyyy
- Sex Recorded on Birth Certificate *** (with a question mark icon):
- Country of Residence *** (with a question mark icon):
- State/Province/Region of Residence *** (with a question mark icon): State/Province/Region
- Country of Birth ***:
- City/Municipality of Birth ***: City/Municipality of Birth
- What Is Your Relationship to ? *** (with a question mark icon):

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 Stiff Person Syndrome Global Registry

Answered 1/7 questions

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

Consent to Participate in the Stiff Person Syndrome Global Registry and to Allow Data to be Shared for Future Research

Title: Stiff Person Syndrome Global Registry (SPS Global Registry)

Principal Investigator: Tara Zier, Founder and CEO of The SPSRF

Co-Principal Investigators: Amanda Piquet, MD, FAAN and Scott Newsome, DO, MScS, FAAN, FANA

Phone: (301) 244-9314

E-mail: spsglobalregistry@stiffperson.org

Sponsor: The Stiff Person Syndrome Research Foundation (The SPSRF)

Key Information

Welcome! The Stiff Person Syndrome Research Foundation (SPSRF) is inviting you to take part in the Stiff Person Syndrome Global Registry ("SPS Global Registry" or referred to as "the Registry") on behalf of the individual in your care diagnosed with Stiff Person Syndrome (SPS) who is not able to provide their own consent. Your participation in the Registry is completely voluntary, and this consent form is meant to help you decide whether or not you'd like to participate.

The SPS Global Registry is a research study that collects data on patients diagnosed with Stiff Person Syndrome (SPS) to achieve the objectives outlined in the next section below. The study has

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

Consent to Stiff Person Syndrome Global Registry

Answered 1/7 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 SPS Global 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.

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

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

Consent to Stiff Person Syndrome Global 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.

[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 Stiff Person Syndrome Global Registry

Select Opt-Ins for this study

Interest in hearing about other studies from [The Stiff Person Syndrome Research Foundation](#)

Interest in hearing about relevant clinical trials

Interest in donating specimens or DNA (biobanking) for future research

Interest in genetic testing

Interest in learning more about [The Stiff Person Syndrome Research Foundation](#)

Interest in signing up for a [The Stiff Person Syndrome Research Foundation](#) newsletter

If eligible, I have interest in receiving [The Stiff Person Syndrome Research Foundation](#) merchandise that would be sent via electronic or postal mail

Support from other Patient Advocacy Groups

Interest in learning about upcoming events such as webinars and conferences

Support from [The Stiff Person Syndrome Research Foundation](#)

Interest in learning ways to support [The Stiff Person Syndrome Research Foundation](#)

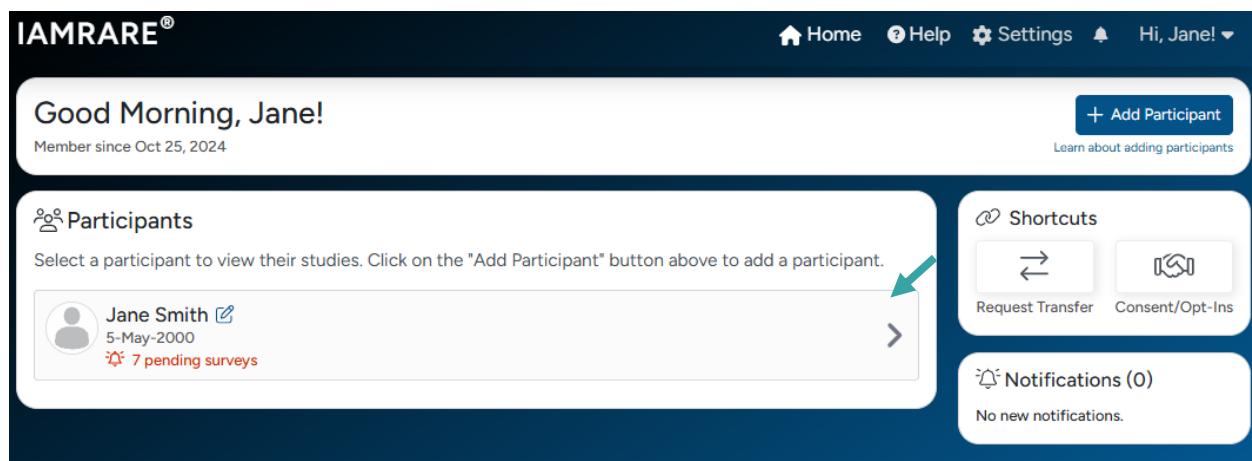
Save and Review



- 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®

Good Morning, Jane!

Member since Oct 25, 2024

Participants

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

Jane Smith  5-May-2000  7 pending surveys

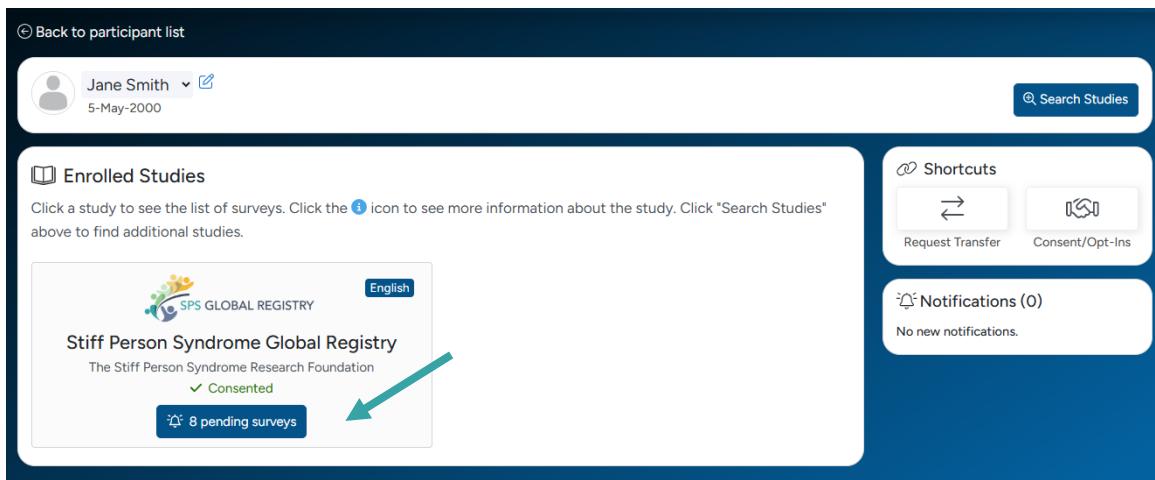
Shortcuts

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 *info* icon to see more information about the study. Click "Search Studies" above to find additional studies.

SPS GLOBAL REGISTRY English

Stiff Person Syndrome Global Registry

The Stiff Person Syndrome Research Foundation ✓ Consented

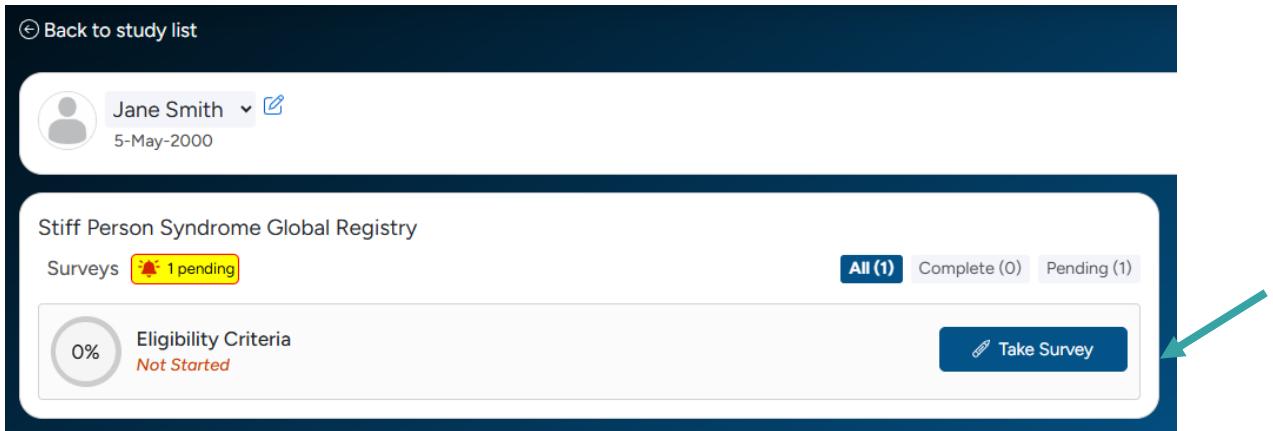
8 pending surveys

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

Stiff Person Syndrome Global Registry

Surveys 1 pending

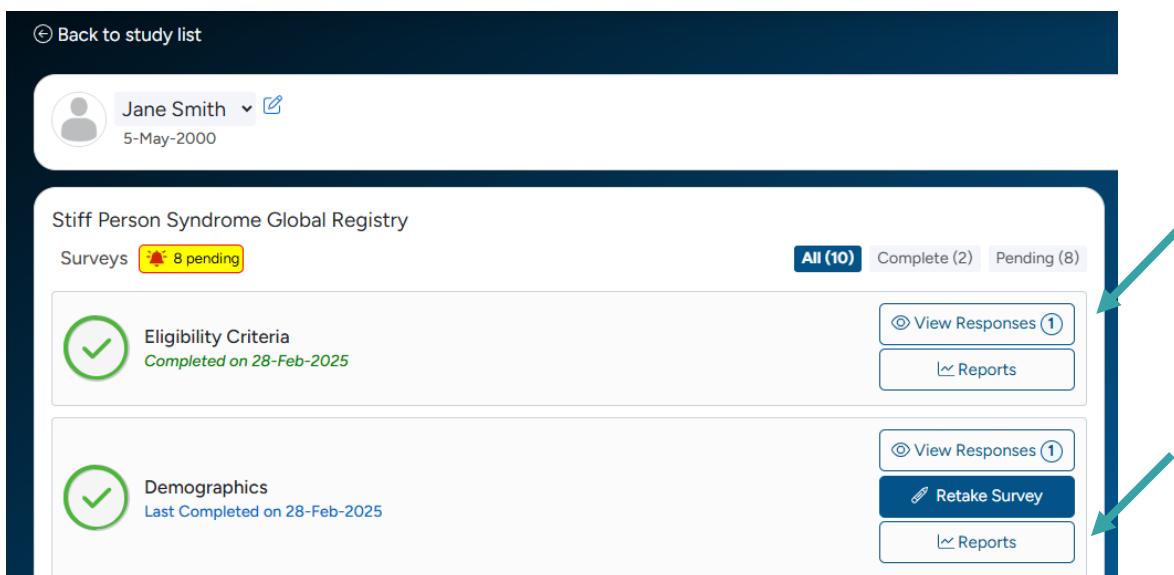
All (1) Complete (0) Pending (1)

0% Eligibility Criteria 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.



Back to study list

Jane Smith 5-May-2000

Stiff Person Syndrome Global Registry

Surveys 8 pending

All (10) Complete (2) Pending (8)

Eligibility Criteria Completed on 28-Feb-2025

View Responses (1)

Reports

Demographics Last Completed on 28-Feb-2025

View Responses (1)

Retake Survey

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. 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 'Enrolled Studies' section of the platform. At the top, there is a user profile for 'Jane Smith' with a dropdown arrow and a pencil icon. To the right is a 'Search Studies' button. Below this, a sub-section titled 'Enrolled Studies' is shown with a brief description: '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.' On the right side of this section, there is a 'Shortcuts' area with 'Request Transfer' and 'Consent/Opt-Ins' buttons. A green arrow points to the 'Consent/Opt-Ins' button.

The screenshot shows the 'Consents/Opt-Ins' page. At the top, there is a user profile for 'Jane Smith' with a dropdown arrow and a pencil icon. Below this, a table displays a single study entry: 'Stiff Person Syndrome Global Registry' with a 'Consented' status, 'Consented On' date '28-Feb-2025', and three buttons: 'View Consent', 'Revoke', and 'Opt-Ins'. A green arrow points to the 'Opt-Ins' button.

Dark Mode Settings

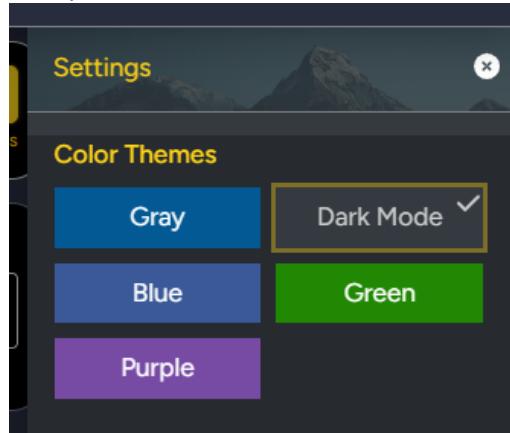
- Step 1: You can view the platform in Dark Mode. First, click Settings.

The screenshot shows the top navigation bar of the platform. It includes the 'IAMRARE®' logo, 'Home', 'Help', 'Settings', and a 'Hi, Jane!' dropdown. A green arrow points to the 'Settings' link.

- Step 2: Select Dark Mode.

The screenshot shows the 'Settings' page with a 'Color Themes' section. It lists five options: 'Gray' (selected), 'Dark Mode', 'Blue', 'Green', and 'Purple'. A green arrow points to the 'Dark Mode' button.

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

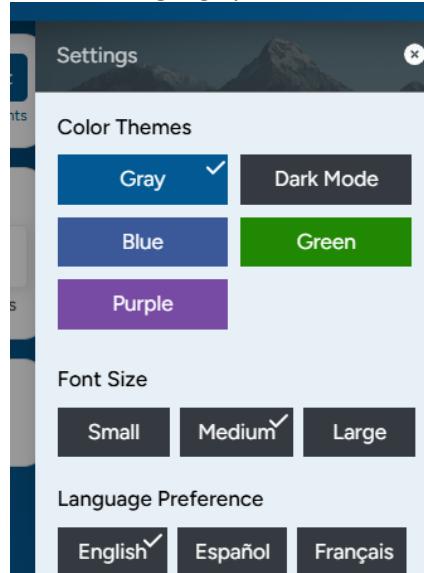


Display Settings

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



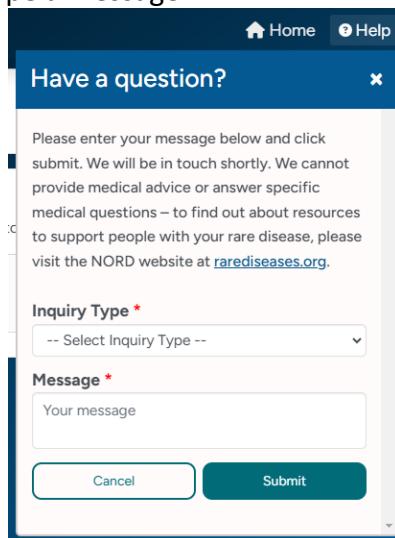
- Step 2: Select a color theme, a font size, or language preference.



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

Need Assistance?

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



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.



 The Stiff Person Syndrome Research Foundation

stiffperson.org

Contact	Phone
Registry Study	(301) 244-9314
Team	
E-mail	
spsglobalregistry@stiffperson.org	
IRB E-mail	
info@northstarreviewboard.org	
Social Media	
  	