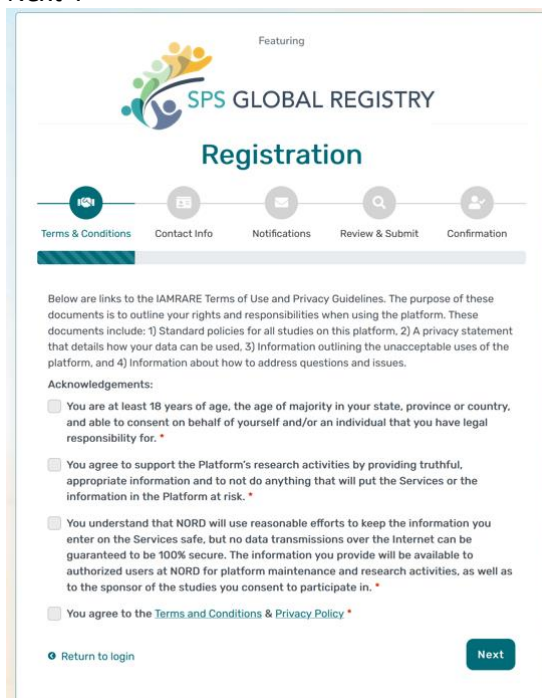




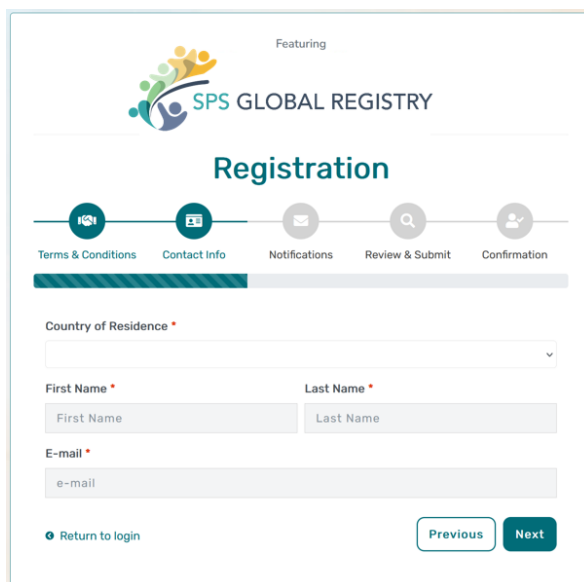
Stiff Person Syndrome Global Registry Participant User Guide

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”.


This screenshot shows the first step of the registration process. At the top, the SPS GLOBAL REGISTRY logo is displayed. Below it, the word "Registration" is centered. A progress bar with five icons (Terms & Conditions, Contact Info, Notifications, Review & Submit, Confirmation) is shown, with the first icon highlighted. The main content area contains a paragraph of text about the IAMRARE Terms of Use and Privacy Guidelines, followed by a section titled "Acknowledgements:" with four checkboxes. The first checkbox is selected. At the bottom left is a "Return to login" link, and at the bottom right is a "Next" button. A teal arrow points to the "Next" button.

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

This screenshot shows the second step of the registration process. At the top, the SPS GLOBAL REGISTRY logo is displayed. Below it, the word "Registration" is centered. A progress bar with five icons (Terms & Conditions, Contact Info, Notifications, Review & Submit, Confirmation) is shown, with the second icon highlighted. The main content area contains a form with the following fields: "Country of Residence" (a dropdown menu), "First Name" (a text input field), "Last Name" (a text input field), and "E-mail" (a text input field). At the bottom left is a "Return to login" link, and at the bottom right are "Previous" and "Next" buttons. A teal arrow points to the "Next" button.

- 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

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](#)

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

Terms & Conditions Contact Info Notifications Review & Submit Confirmation

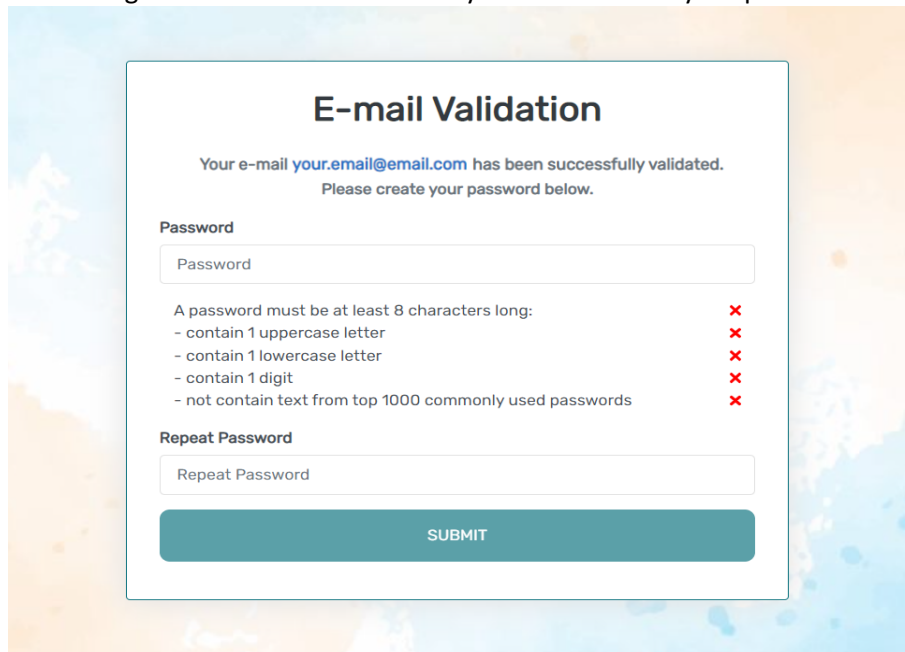
An activation link will be sent to test@test.com. Click "Next" to send this e-mail and continue.

[Return to login](#)

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

A 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.

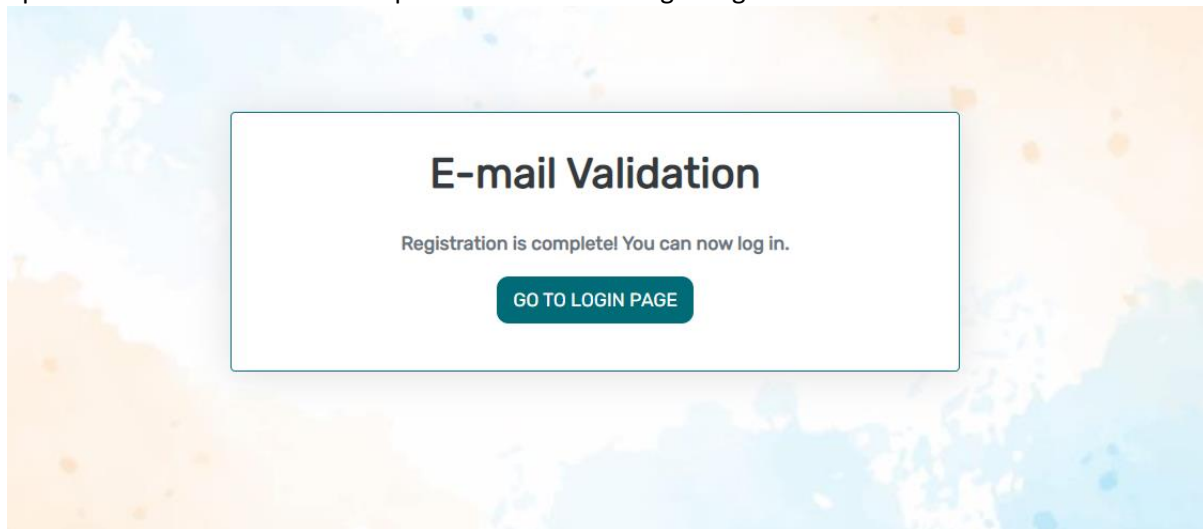
Password

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”.

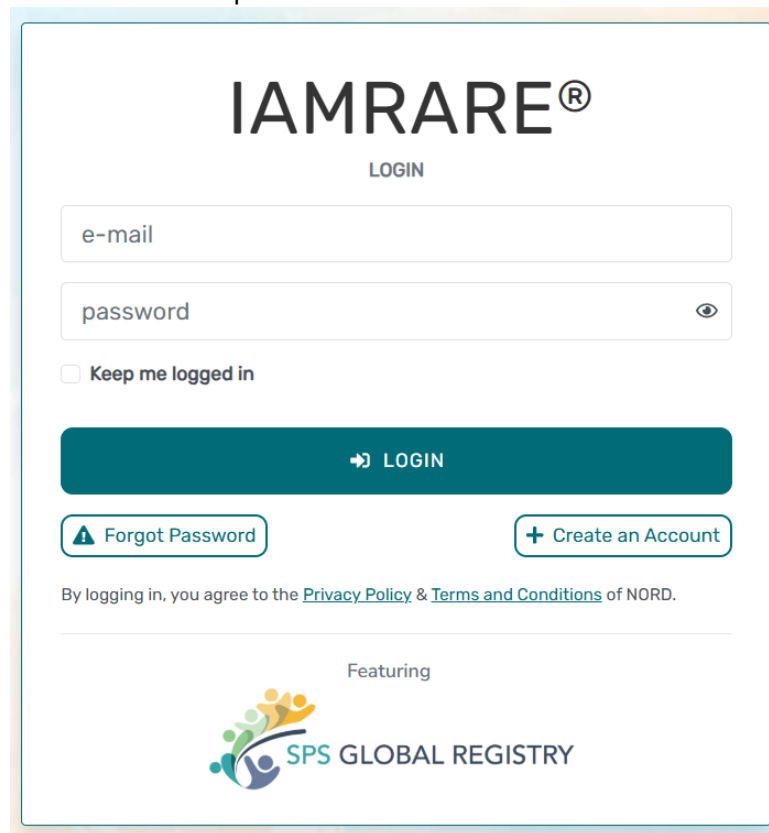


E-mail Validation

Registration is complete! You can now log in.

GO TO LOGIN PAGE

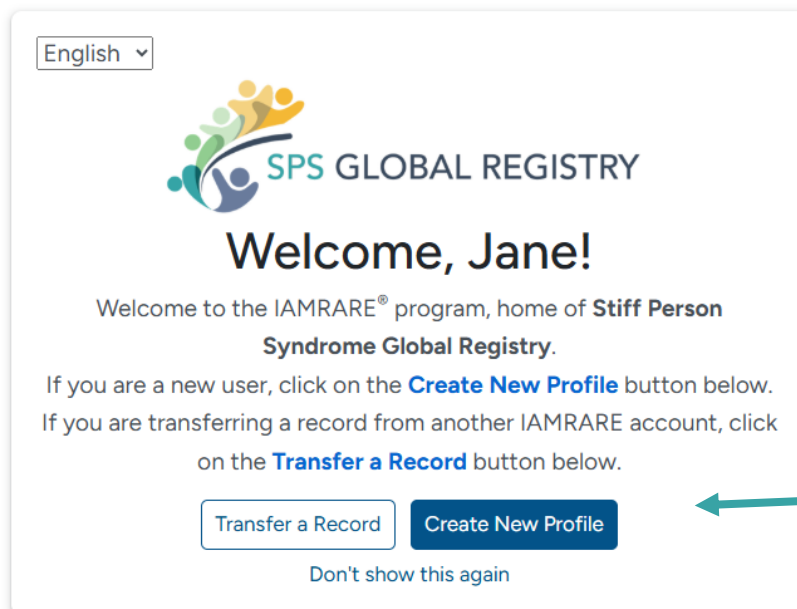
- Step 7: Log in using your new e-mail and password.



The image shows the IAMRARE LOGIN page. At the top is the IAMRARE® logo. Below it is the word "LOGIN". There are two input fields: "e-mail" and "password" (with an eye icon for toggling visibility). Below the password field is a checkbox labeled "Keep me logged in". A large teal button with a right arrow icon and the text "LOGIN" is centered. Below this are two smaller buttons: "Forgot Password" (with a warning icon) and "Create an Account" (with a plus icon). A line of text states: "By logging in, you agree to the [Privacy Policy](#) & [Terms and Conditions](#) of NORD." At the bottom, it says "Featuring" above the SPS GLOBAL REGISTRY logo.

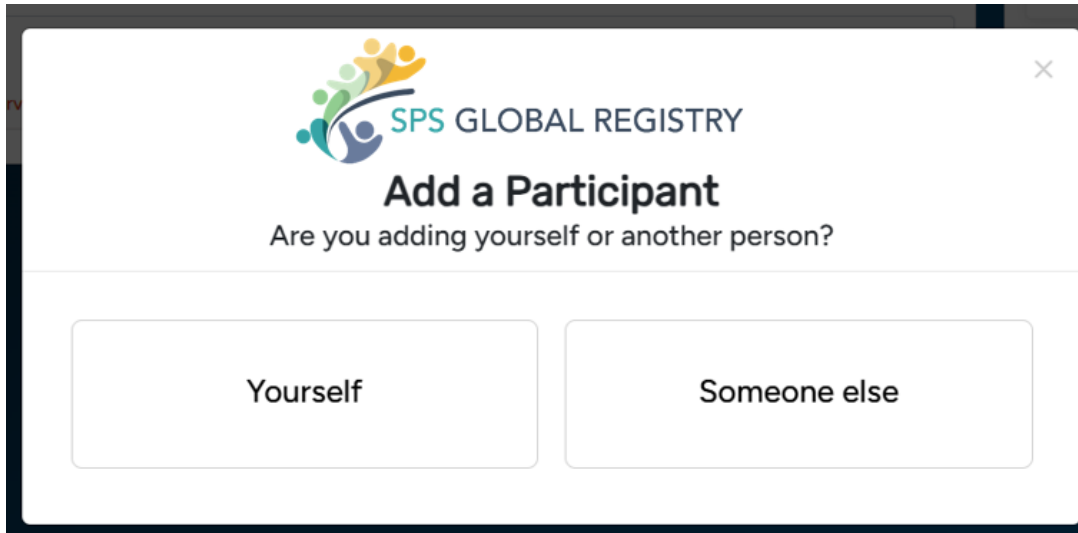
Add a Participant

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



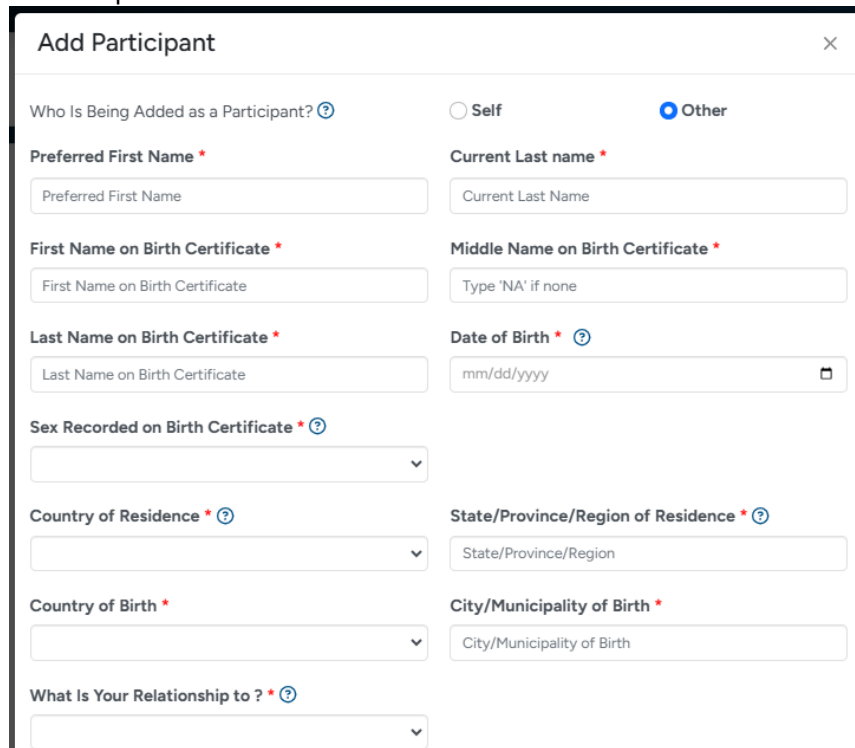
The image shows a welcome screen for a user named Jane. At the top left is a language dropdown menu set to "English". Below it is the SPS GLOBAL REGISTRY logo. The main heading is "Welcome, Jane!". Below this is a welcome message: "Welcome to the IAMRARE® program, home of **Stiff Person Syndrome Global Registry**." Two lines of instructions follow: "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 are two buttons: "Transfer a Record" and "Create New Profile". A teal arrow points to the "Create New Profile" button. Below the buttons is a link: "Don't show this again".

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



The image shows a web form titled "SPS GLOBAL REGISTRY" with a logo of stylized people in various colors. Below the logo, the heading "Add a Participant" is displayed, followed by the question "Are you adding yourself or another person?". There are two large, light gray buttons: "Yourself" on the left and "Someone else" on the right. A close button (X) is in the top right corner.

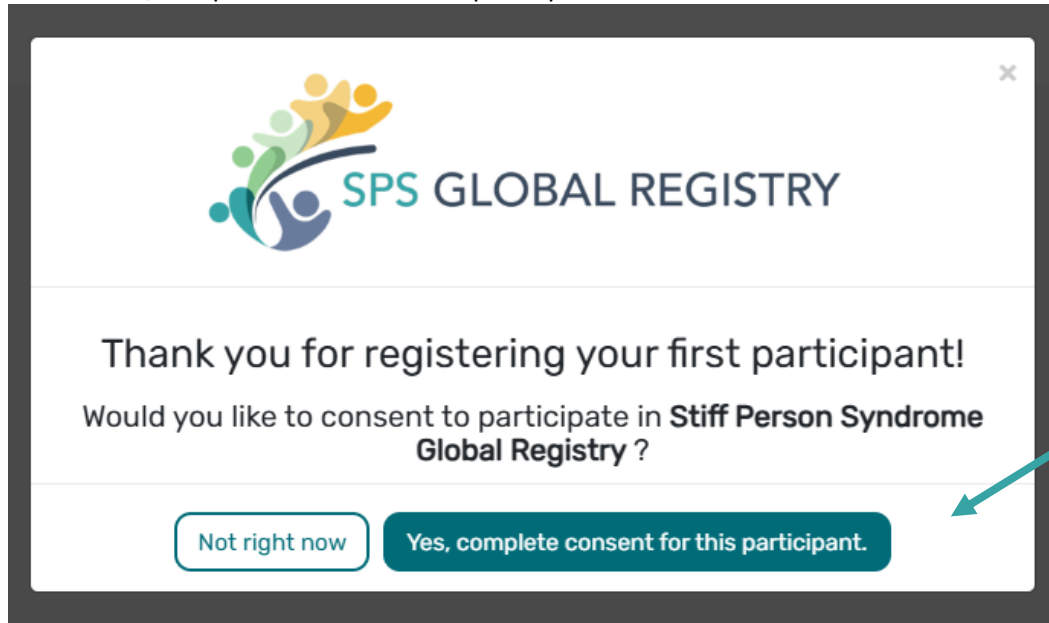
- Step 3: Fill out the Participant's information.



The image shows a detailed "Add Participant" form. At the top, it asks "Who Is Being Added as a Participant?" with two radio buttons: "Self" and "Other" (which is selected). The form is divided into two columns of input fields. The left column includes: "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 includes: "Current Last name", "Middle Name on Birth Certificate" (with a note "Type 'NA' if none"), "Date of Birth" (with a calendar icon), "State/Province/Region of Residence", and "City/Municipality of Birth". Red asterisks indicate required fields. Help icons (question marks) are present next to several labels.

Consent to the Study

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



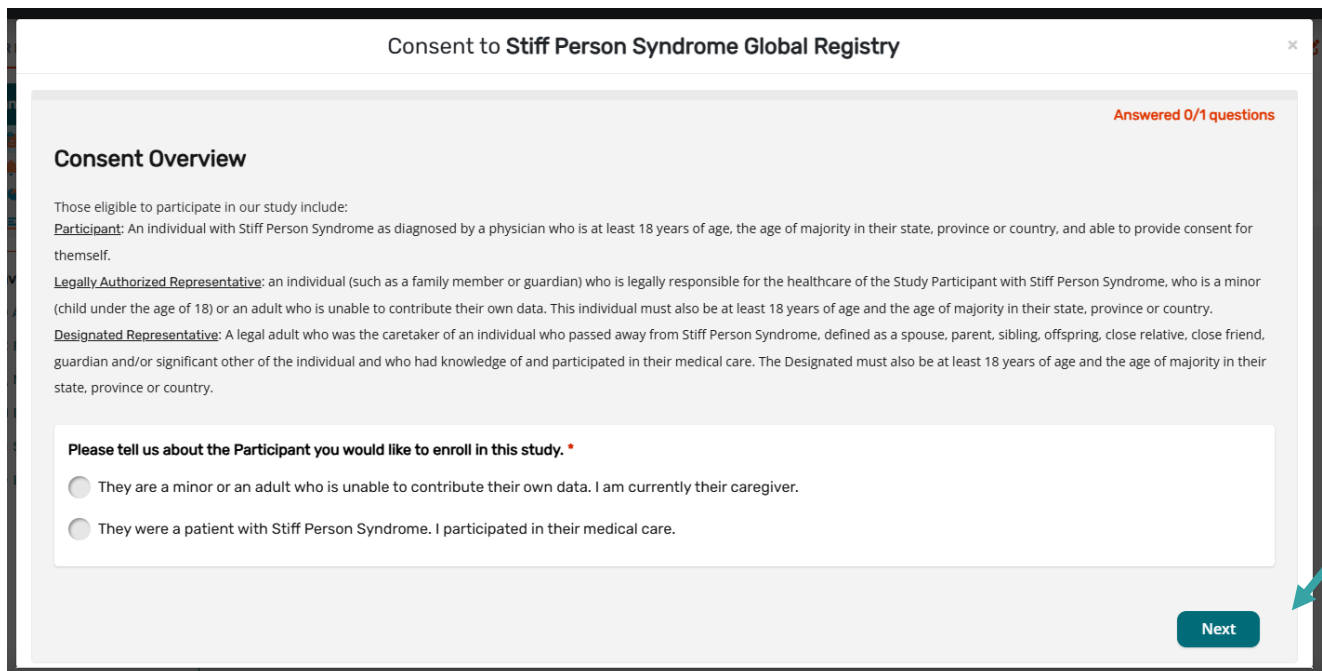
SPS GLOBAL REGISTRY

Thank you for registering your first participant!

Would you like to consent to participate in **Stiff Person Syndrome Global 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 **Stiff Person Syndrome Global Registry**

Answered 0/1 questions

Consent Overview

Those eligible to participate in our study include:

Participant: An individual with Stiff Person Syndrome as diagnosed by a physician 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 with Stiff Person Syndrome, 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 Stiff Person Syndrome, defined as a spouse, parent, sibling, offspring, close relative, close friend, guardian and/or significant other of the individual and who had knowledge of and participated in their medical care. The Designated 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 Stiff Person Syndrome. I participated in their medical care.

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®

Home Help Settings Hi, Jane!

Good Morning, Jane!
Member since Oct 25, 2024

+ Add Participant
Learn about adding participants

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

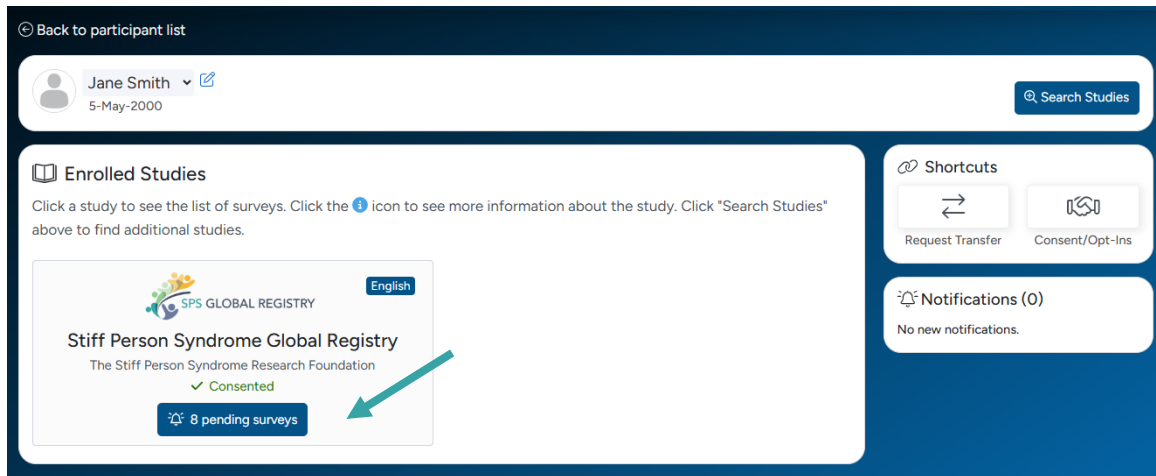
Jane Smith
5-May-2000
7 pending surveys

Shortcuts

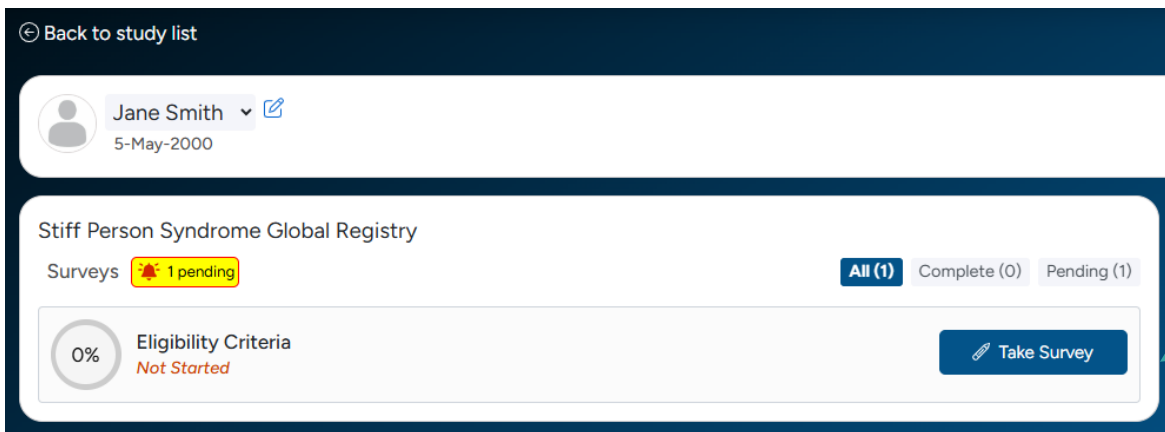
Request Transfer Consent/Opt-Ins

Notifications (0)
No new notifications.

- Step 2: Click on the appropriate study.

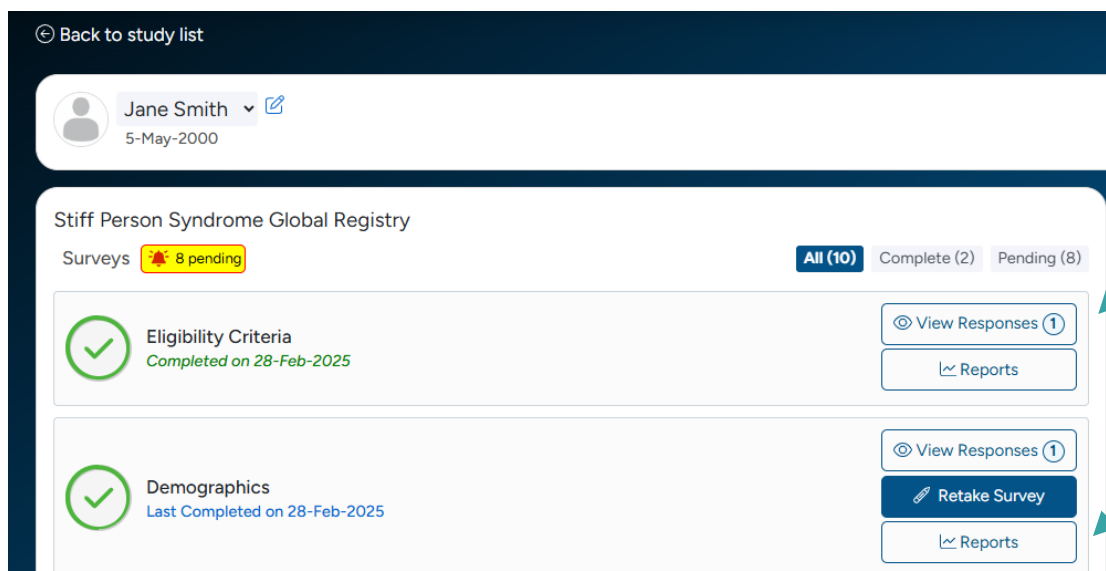


- Step 3: Click "Take Survey" for an available survey.



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.



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”.

Jane Smith 5-May-2000 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.

Shortcuts
Request Transfer Consent/Opt-Ins

Jane Smith 5-May-2000

Consents/Opt-Ins

Study Name	Consent Status	Consented On	Actions
Stiff Person Syndrome Global Registry	✓ Consented	28-Feb-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 Nov 16, 2024 + Add Participant

Participants Shortcuts

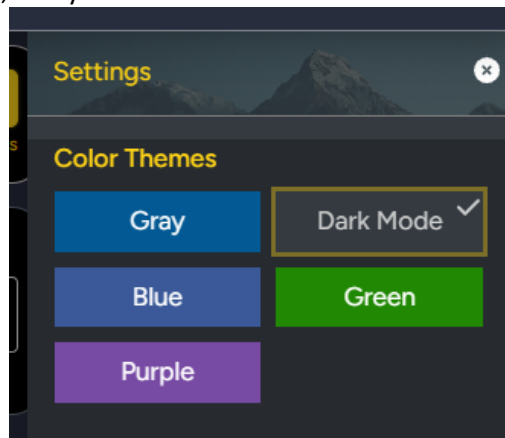
- Step 2: Select Dark Mode.

Settings

Color Themes

Gray ✓ Dark Mode Blue Green Purple

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

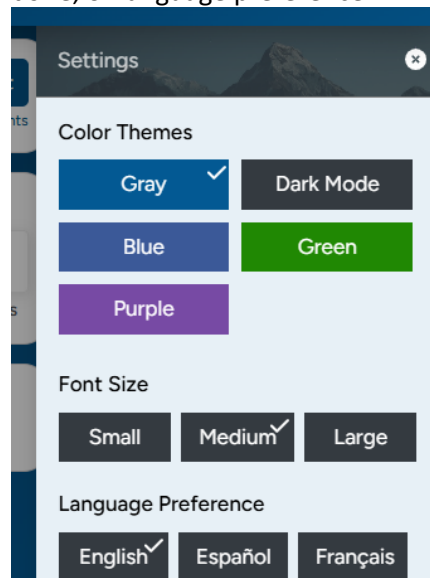


Display Settings

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



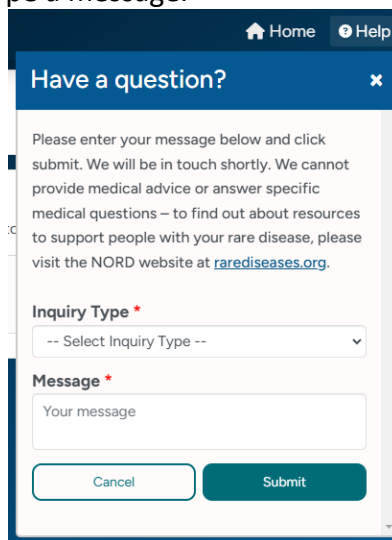
- Step 2: Select a color theme, a font size, or language preference.



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

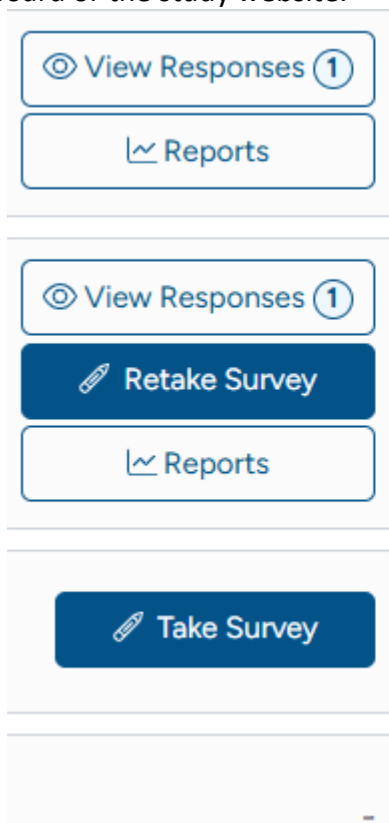
Need Assistance?

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

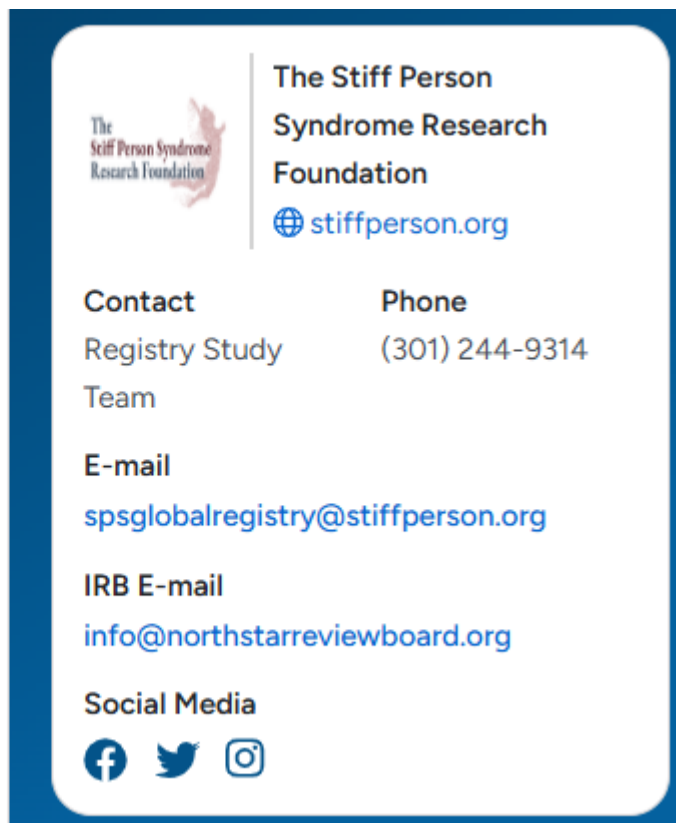


The screenshot shows a mobile app interface with a 'Home' button and a 'Help' button. A modal titled 'Have a question?' is open. It contains a text area for a message, a dropdown menu for 'Inquiry Type' with the placeholder '-- Select Inquiry Type --', and a 'Message' field with the placeholder 'Your message'. At the bottom are 'Cancel' and 'Submit' buttons. A disclaimer text is visible above the dropdown: '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 sidebar with several buttons. The first section contains 'View Responses' (with a notification badge '1') and 'Reports'. The second section contains 'View Responses' (with a notification badge '1'), 'Retake Survey' (with a pencil icon), and 'Reports'. The third section contains 'Take Survey' (with a pencil icon).



The screenshot shows a contact information card for 'The Stiff Person Syndrome Research Foundation'. It includes the logo, the website stiffperson.org, and contact details for the Registry Study Team. The contact information is organized into sections: Contact, Phone, E-mail, IRB E-mail, and Social Media.

Contact	Phone
Registry Study Team	(301) 244-9314

E-mail
spsglobalregistry@stiffperson.org

IRB E-mail
info@northstarreviewboard.org

Social Media
Facebook, Twitter, Instagram icons