



## Stiff Person Syndrome Spectrum Disorders 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

SPSPD 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](#) and [Privacy Policy](#) and have read the [Consumer Health Data Privacy Notice](#). \*

[Return to login](#) **Next**

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

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SPSPD GLOBAL 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

## 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

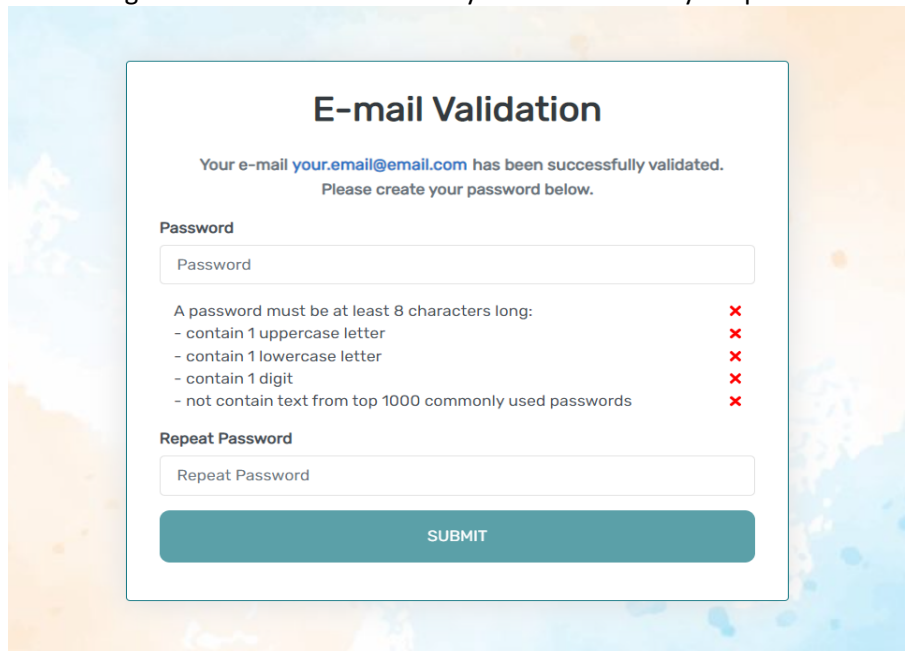
## Registration

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](mailto:your.email@email.com) has been successfully validated.  
Please create your password below.

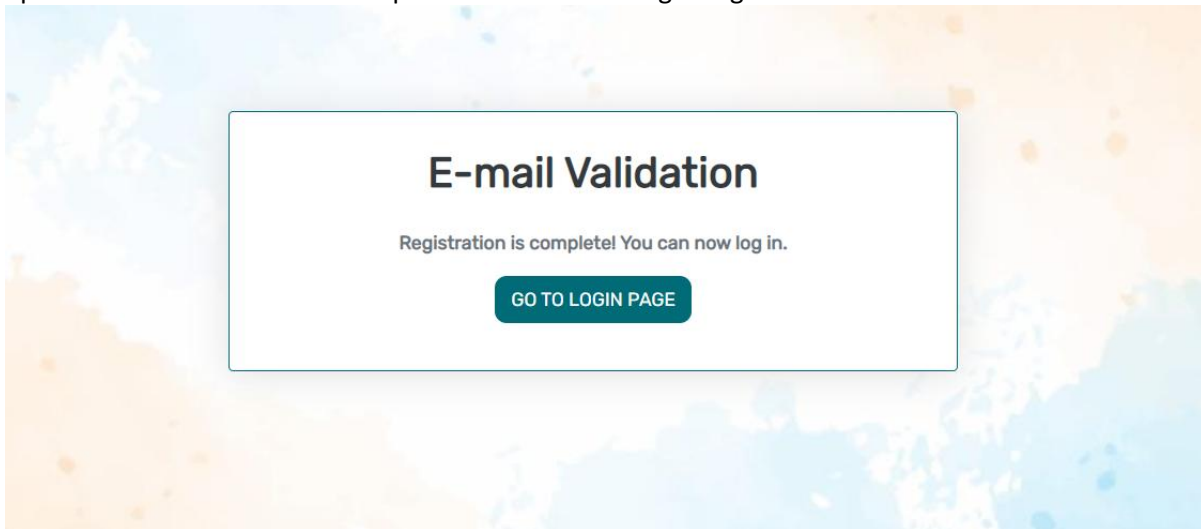
**Password**

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.

# IAMRARE®

LOGIN

  
   
 Keep me logged in


[→ LOGIN](#)

[⚠ Forgot Password](#) [+ Create an Account](#)

By logging in, you agree to the [Privacy Policy & Terms and Conditions](#) of NORD and have read the [Consumer Health Data Privacy Notice](#).

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Featuring



### Add a Participant

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

English ▾



## Welcome, Tester!

Welcome to the IAMRARE® program, home of **Stiff Person Syndrome Spectrum Disorders Global 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.

The screenshot shows a web form titled "Add a Participant" with the SPSD Global Registry logo. At the top left, there is a language dropdown menu set to "English". Below the logo, the text asks "Are you adding yourself or another person?". Two large buttons are presented: "Yourself" and "Someone else".

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

The screenshot shows the "Add Participant" form with the "Other" radio button selected. The form contains the following fields:

- Who Is Being Added as a Participant? (radio buttons for Self and 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 \* (calendar icon)
- Sex Recorded on Birth Certificate \* (dropdown menu)
- Country of Residence \* (dropdown menu)
- State/Province/Region of Residence \* (dropdown menu)
- Country of Birth \* (dropdown menu)
- City/Municipality of Birth \*
- What Is Your Relationship to ? \* (dropdown menu)

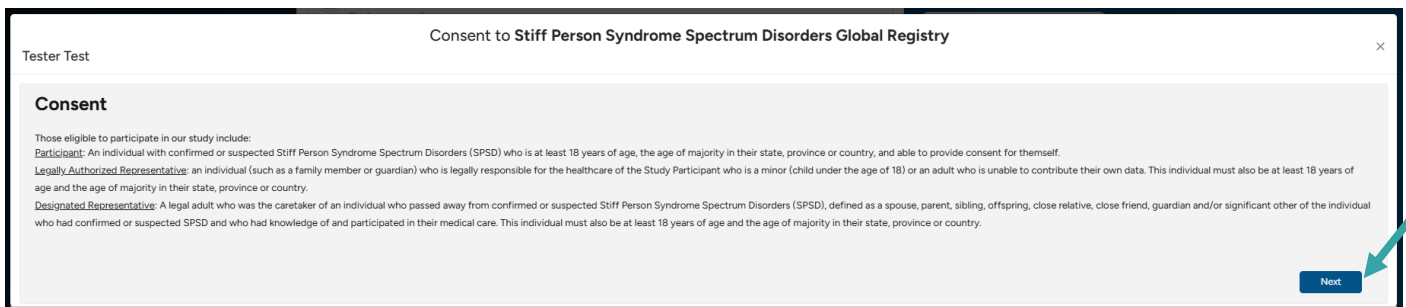
## Consent to the Study

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



The screenshot shows a white dialog box with a dark border and a close button (X) in the top right corner. At the top left is the SPSPD Global Registry logo, which consists of stylized human figures in green, blue, and orange. To the right of the logo is the text "SPSPD GLOBAL REGISTRY". Below the logo and text, the main text reads: "Thank you for registering your first participant! Would you like to consent to participate in **Stiff Person Syndrome Spectrum Disorders Global Registry?**". At the bottom of the dialog box, there are two buttons: a light blue button labeled "Not right now" and a dark blue button labeled "Yes, complete consent for this participant.". A teal arrow points from the right side of the dialog box towards the "Yes, complete consent for this participant." button.

- 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.”



The screenshot shows a web page titled "Consent to Stiff Person Syndrome Spectrum Disorders Global Registry" with a close button (X) in the top right corner. The page is labeled "Tester Test" in the top left. The main content is under the heading "Consent". Below the heading, there is a paragraph of text: "Those eligible to participate in our study include: **Participant:** An individual with confirmed or suspected Stiff Person Syndrome Spectrum Disorders (SPSD) 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 confirmed or suspected Stiff Person Syndrome Spectrum Disorders (SPSD), defined as a spouse, parent, sibling, offspring, close relative, close friend, guardian and/or significant other of the individual who had confirmed or suspected SPSPD and who had knowledge of 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." At the bottom right of the page, there is a dark blue button labeled "Next". A teal arrow points from the right side of the page towards the "Next" button.

Tester Test

## Consent to Stiff Person Syndrome Spectrum Disorders Global Registry

**Adult Consent**

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

**Title:** Stiff Person Syndrome Spectrum Disorders Global Registry (SPSD 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](mailto: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 Spectrum Disorders Global Registry ("SPSD Global Registry" or referred to as "the Registry"). 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 SPSD Global Registry is a research study that collects data on patients diagnosed with confirmed and suspected (probable or possible) Stiff Person Syndrome Spectrum Disorders (SPSD), to achieve the objectives outlined in the next section below. The study has been developed in close partnership with The SPSRF Registry Steering Committee comprised of patients, caregivers, clinicians, researchers, and data experts. The SPSRF Medical Advisory Board and Patient Advisory Committee also played a critical role in the design of the study. Your participation is key to the Registry's success, which relies on patients sharing their knowledge and experience with SPSD to help advance research.

For the purpose of enrolling in this registry, a legal adult is defined as a person who is at least 18 years of age, the age of majority in their state, province, or country, and able to consent for themselves.

A "Study Participant" is the person of legal age with confirmed or suspected SPSD who is able to enter information about himself.

"You" refers to the person reading this form and providing the information.  
 "We" refers to the organization, Sponsor (The SPSRF), who is doing the research.

Take as long as you need to consider this information and decide if you want to share your personal and medical information with the Registry. If you have any questions or want anything explained further, email our registry team at [spsglobalregistry@stiffperson.org](mailto:spsglobalregistry@stiffperson.org) or call (301) 244-9314. Thank you!

Please note the Registry cannot provide medical advice or answer specific medical questions. For resources that support people with SPSD, please visit The SPSRF website at <https://www.stiffperson.org>. For medical assistance, contact your doctor's office. If you are having a medical emergency, call 911. If you are having suicidal thoughts or mental health risks, call 988 Suicide & Crisis Helpline.

Tester Test

## Consent to Stiff Person Syndrome Spectrum Disorders Global Registry

**Authorization**

The following statements are intended to:

- Make sure that you have had the time and opportunity to consider whether you 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 your participation;
- That you wish to provide personal data to the Registry for the purposes of the study;
- That you allow for your data to be used for future research; 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 SPSD Global Registry. 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 my personal and medical data to be shared for the purpose of research. All my questions about the SPSD Global Registry have been answered to my satisfaction, and I understand the purpose of the Registry and the risks of participation.

I wish to provide my research data to the SPSD Global Registry for the purposes described above under Purpose and Objectives of the SPSD Global Registry.

I wish to provide my research data to the SPSD Global Registry for future research within recognized ethical standards for scientific research, as described under How We Will Use Your Data.

I acknowledge that I am at least 18 years of age, the age of majority in my state, province or country, and able to provide consent for myself.

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

Tester Test

## Consent to Stiff Person Syndrome Spectrum Disorders Global Registry

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 Stiff Person Syndrome Spectrum Disorders Global Registry**

Select Opt-Ins for this study

- 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
- Interest in learning about upcoming events such as webinars and conferences
- Interest in support services offered 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, Tester! ▾

Good Afternoon, Tester!  
Member since Apr 30, 2026 [+ Add Participant](#)

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

- Tester Test [✎](#)  
1-Jan-2000  
🔔 1 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, Tester! ▾

⌕ Back to the participant list

Tester Test ▾ 1-Jan-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.

SPSID GLOBAL REGISTRY English ⓘ

#### Stiff Person Syndrome Spectrum Disorders Global Registry

The Stiff Person Syndrome Research Foundation

✓ Consented

🔍 1 pending surveys

Shortcuts

Request Transfer Consent/Opt-Ins

Notifications (0)

No new notifications.

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

Tester Test ▾ 1-Jan-2000

### Stiff Person Syndrome Spectrum Disorders Global Registry

Surveys 🚨 1 pending All (1) Complete (0) Pending (1)

#### Phase 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.

### View Consent and Opt-Ins

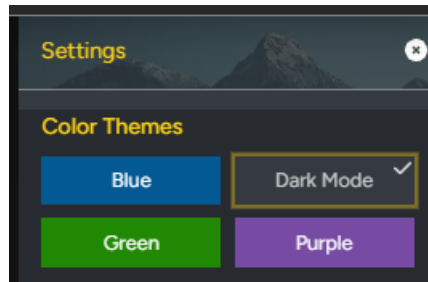
- Step 1: Once you have consented to the study, you are able to view your consent at any time. Navigate to the Enrolled Studies page. Then, click “Consents/Opt-Ins” to see your consent and opt-ins. You may revoke your consent at any time by clicking “Revoke”. You may also edit your Opt-Ins by clicking “Opt-Ins”.

Study Name	Consent Status	Consented On	Actions
Stiff Person Syndrome Spectrum Disorders Global Registry	✓ Consented	30-Apr-2026	View Consent, Revoke, Opt-Ins

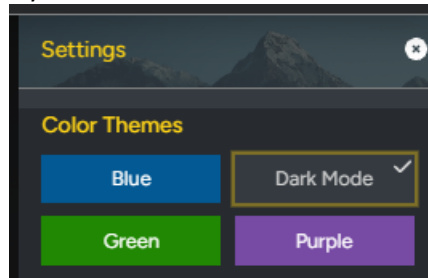
### Dark Mode Settings

- 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.

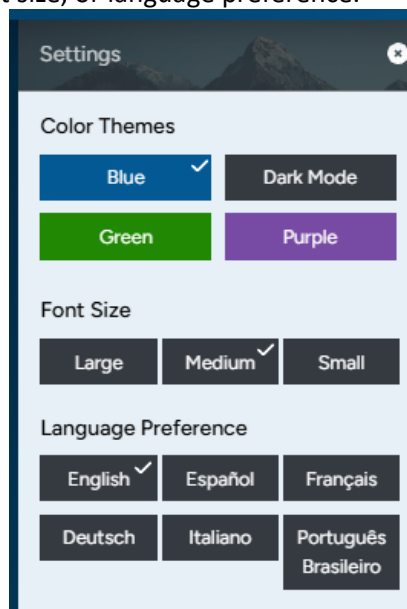


## Display Settings

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



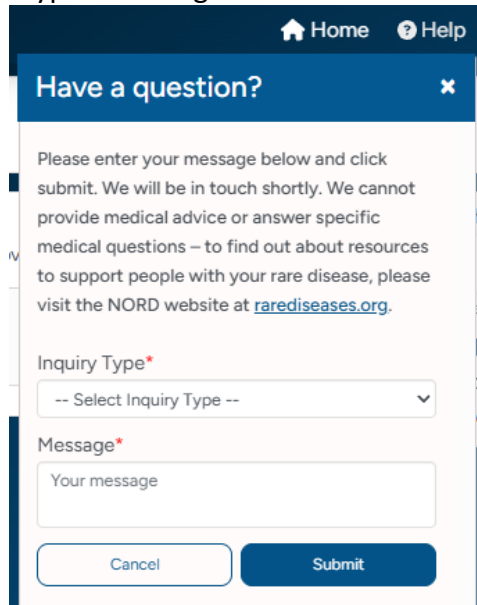
- Step 2: Select a color theme, a font size, or language preference.



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

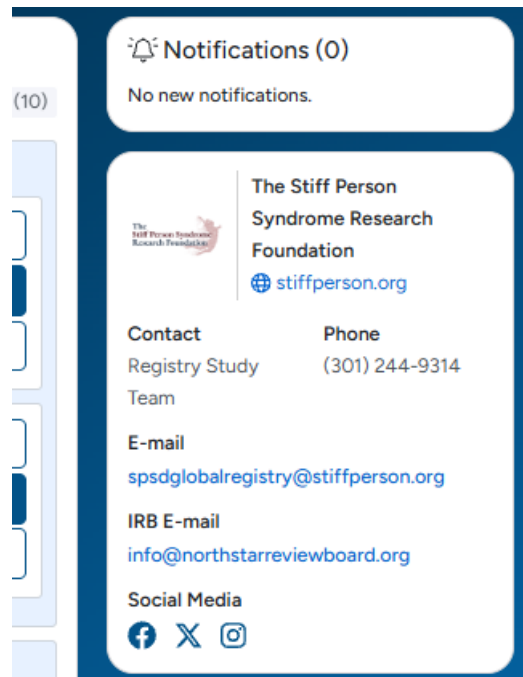
## Need Assistance?

- 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 application interface with a dark blue header containing 'Home' and 'Help' icons. Below the header is a white modal window titled 'Have a question?' with a close button (X). The modal contains the following 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 text is a dropdown menu labeled 'Inquiry Type\*' with the placeholder text '-- Select Inquiry Type --'. Underneath is a text input field labeled 'Message\*' with the placeholder text 'Your message'. At the bottom of the modal 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.



The screenshot shows a contact information card for 'The Stiff Person Syndrome Research Foundation'. The card has a dark blue header with a notification icon and the text 'Notifications (0)' and 'No new notifications.' Below this is the foundation's logo and name, followed by the website 'stiffperson.org'. The contact information is organized into sections: 'Contact' (Registry Study Team), 'Phone' ((301) 244-9314), 'E-mail' (spsdglobalregistry@stiffperson.org), and 'IRB E-mail' (info@northstarreviewboard.org). At the bottom, there is a 'Social Media' section with icons for Facebook, X, and Instagram.