


TSW Patient 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



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”.

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REGISTRY

Registration

Terms & Conditions Contact Info Notifications Review & Submit Confirmation

Country of Residence *

First Name * Last Name *

E-mail *

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

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

Yes No

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

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

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- 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

Password

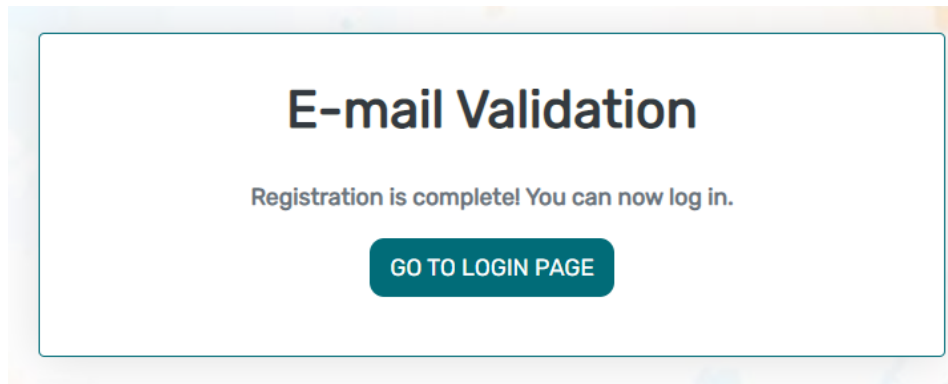
A password must be at least 8 characters long: ✗
- contain 1 uppercase letter ✗
- contain 1 lowercase letter ✗
- contain 1 digit ✗
- not contain text from top 1000 commonly used passwords ✗

Repeat Password

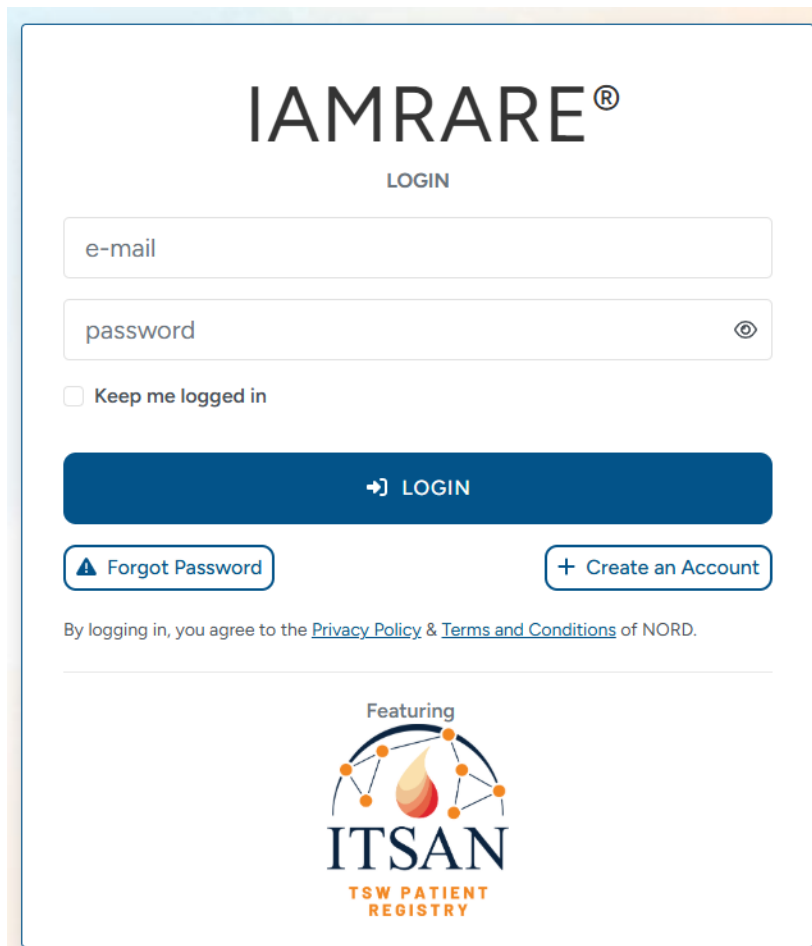
Repeat Password

SUBMIT

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

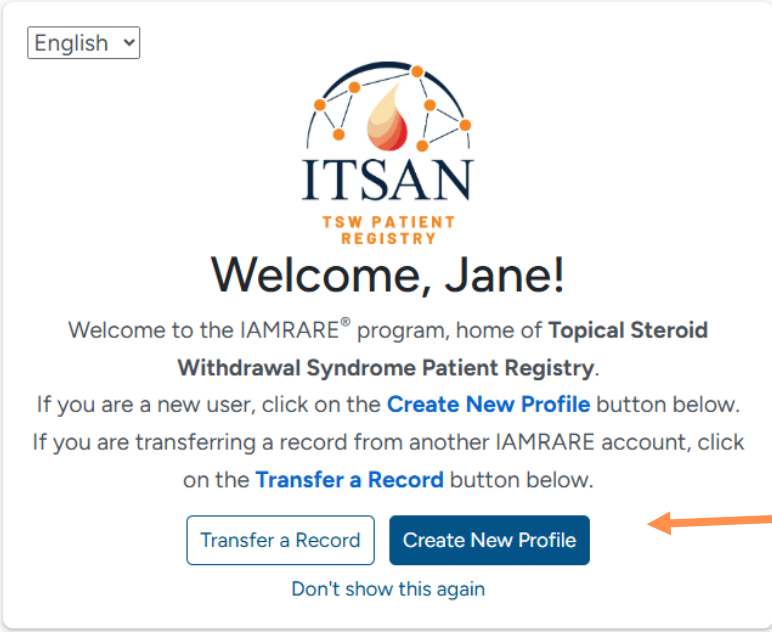


- Step 7: Log in using your new e-mail and password.




Add a Participant

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



English ▾



Welcome, Jane!

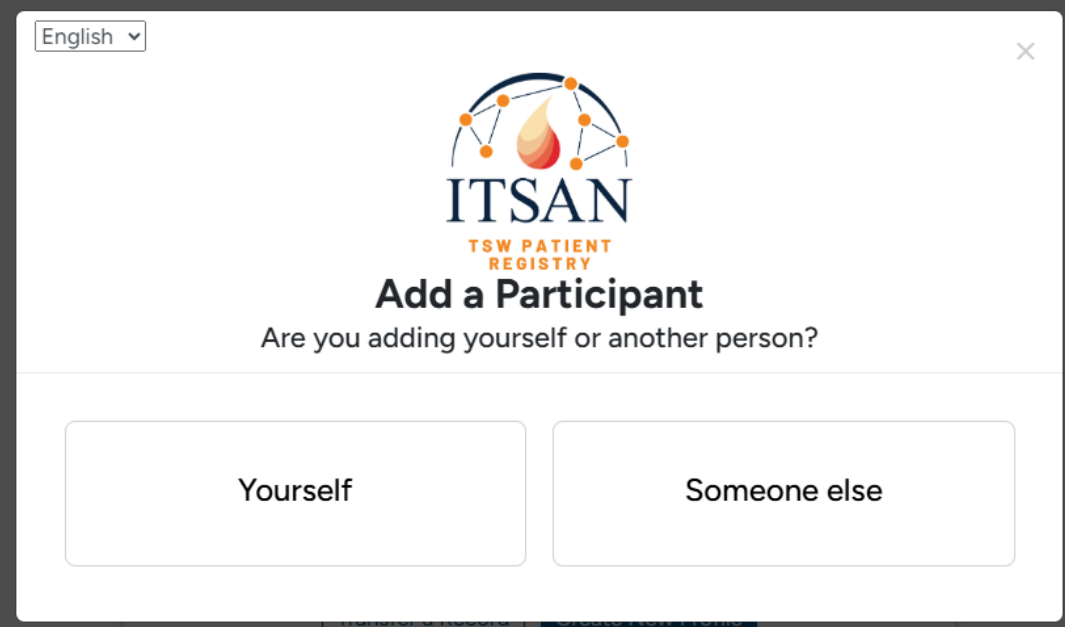
Welcome to the IAMRARE[®] program, home of **Topical Steroid Withdrawal Syndrome Patient Registry**.

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.



English ▾



Add a Participant

Are you adding yourself or another person?

[Yourself](#) [Someone else](#)

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

Add Participant [X]

Who Is Being Added as a Participant? [?] 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 * [?]** [mm/dd/yyyy] [📅]

Sex Recorded on Birth Certificate * [?] [Sex Recorded on Birth Certificate] [v]

Country of Residence * [?] [Choose country] [v] **State/Province/Region of Residence * [?]** [Type 'NA' if none]

Country of Birth * [Choose country of birth] [v] **City/Municipality of Birth *** [City/Municipality of Birth]

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 Topical Steroid Withdrawal Syndrome Patient 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 Topical Steroid Withdrawal Syndrome Patient Registry

Jane Smith

Consent Overview

Those eligible to participate in our study include:

Participant: An individual diagnosed with Topical Steroid Withdrawal Syndrome (TSW) 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 Topical Steroid Withdrawal Syndrome (TSW) 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.

[Next](#)

Consent to Topical Steroid Withdrawal Syndrome Patient Registry

Jane Smith

Adult Consent

Consent to Participate in the Topical Steroid Withdrawal Syndrome Patient Registry (TSW Patient Registry) and to Allow Your Data to be Shared for Future Research

Title: Topical Steroid Withdrawal Syndrome Patient Registry (TSW Patient Registry)

Co-Principal Investigator: Kathryn Tullos

Co-Principal Investigator: Michelle Li

Address: ITSAN, P.O. Box 303, Dacula, GA, 30019

E-mail: Registry@itsan.org

ITSAN: International Topical Steroid Awareness Network (ITSAN)

Key Information

You are invited to take part in a research study for people with Topical Steroid Withdrawal Syndrome (TSW Syndrome). This form will help you decide if you want to participate. You can contact the study staff above if you have any other questions. Their e-mail address is listed above.

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Consent to Topical Steroid Withdrawal Syndrome Patient Registry

Jane Smith

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.

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 Topical Steroid Withdrawal Syndrome Patient 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 Topical Steroid Withdrawal Syndrome Patient 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 Topical Steroid Withdrawal Syndrome Patient 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 Topical Steroid Withdrawal Syndrome Patient Registry

Jane Smith

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 Topical Steroid Withdrawal Syndrome Patient Registry

Select Opt-Ins for this study

- Interest in hearing about other studies from [International Topical Steroid Awareness Network \(ITSAN\)](#)
- 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 [International Topical Steroid Awareness Network \(ITSAN\)](#)
- Interest in signing up for a [International Topical Steroid Awareness Network \(ITSAN\)](#) newsletter

- Step 5: Once you've reviewed your consent, click "Close". You will then have access to start taking surveys.

Taking Surveys

- Step 1: Click “Take Survey” for an available survey.

The screenshot shows a user interface for a survey. At the top, there is a dark blue header with a back arrow and the text "Back to the study list". Below this is a white card containing a user profile for "Jane Smith" with a dropdown arrow and a date "5-May-2000". The main content area is titled "Topical Steroid Withdrawal Syndrome Patient Registry" and shows "Surveys" with a yellow notification bubble indicating "1 pending". On the right, there are filters: "All (1)" (highlighted in blue), "Complete (0)", and "Pending (1)". A progress indicator shows "0% Getting Started" with the text "Not Started" below it. A blue button labeled "Take Survey" with a pencil icon is positioned on the right, and an orange arrow points to it from the right side of the screen.

View Responses and Reports

- Step 1: Once you have submitted a survey, you are able to view your responses to that. Click “View Responses” to see your completed survey.

The screenshot shows the same user interface as the previous one, but with updated survey data. The header and user profile remain the same. The survey title is "Topical Steroid Withdrawal Syndrome Patient Registry". The "Surveys" section now shows a yellow notification bubble for "8 pending". The filters on the right are "All (10)" (highlighted in blue), "Complete (2)", and "Pending (8)". There are two survey entries listed, each with a green checkmark icon. The first entry is "Getting Started" with the text "Completed on 28-Jul-2025" and a blue button labeled "View Responses" with a circled "1" next to it. An orange arrow points from the text "Completed on 28-Jul-2025" to the "View Responses" button. The second entry is "Demographics" with the text "Last Completed on 28-Jul-2025" and a blue button labeled "View Responses" with a circled "1" next to it. Below the "Demographics" entry is a blue button labeled "Retake Survey" with a pencil icon.

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). At the top left is a 'Back to participant list' link. Below it is a user profile card with Jane Smith's name and a search icon. To the right is a 'Search Studies' button with a magnifying glass icon and a link to 'Learn about searching for studies'. The main content area has an 'Enrolled Studies' header with a book icon and instructions: '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.' To the right is a 'Shortcuts' section with two buttons: 'Request Transfer' and 'Consent/Opt-Ins', with an orange arrow pointing to the latter.

- 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). At the top left is a 'Back to the study list' link. Below it is a user profile card. The main content is a table with the following columns: Study Name, Consent Status, Consented On, and Actions. The table contains one row for 'Topical Steroid Withdrawal Syndrome Patient Registry' with a 'Consented' status and a date of '28-Jul-2025'. The Actions column contains three buttons: 'View Consent', 'Revoke', and 'Opt-Ins', with orange arrows pointing to the 'Revoke' and 'Opt-Ins' buttons.

Study Name	Consent Status	Consented On	Actions
Topical Steroid Withdrawal Syndrome Patient Registry	✓ Consented	28-Jul-2025	View Consent Revoke Opt-Ins

Dark Mode Settings

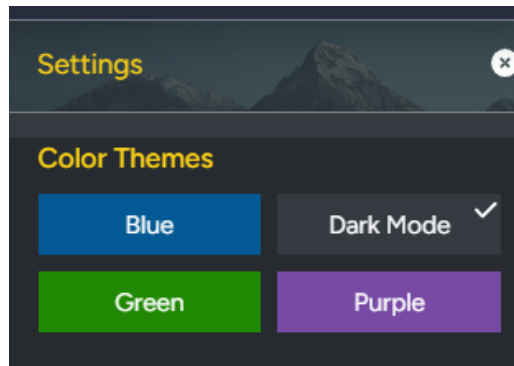
- Step 1: You can view the platform in Dark Mode. First, click Settings.

The screenshot shows the IAMRARE user interface. At the top is a navigation bar with 'Home', 'Help', 'Settings', and 'Hi, Jane!'. Below the navigation bar is a greeting: 'Good Afternoon, Jane!' with 'Member since Nov 16, 2024' and an 'Add Participant' button. The main content area has 'Participants' and 'Shortcuts' sections. An orange arrow points to the 'Settings' link in the navigation bar.

- Step 2: Select Dark Mode.

The screenshot shows the 'Settings' dialog box. Under the 'Color Themes' section, there are four buttons: 'Blue' (selected with a checkmark), 'Dark Mode', 'Green', and 'Purple'.

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

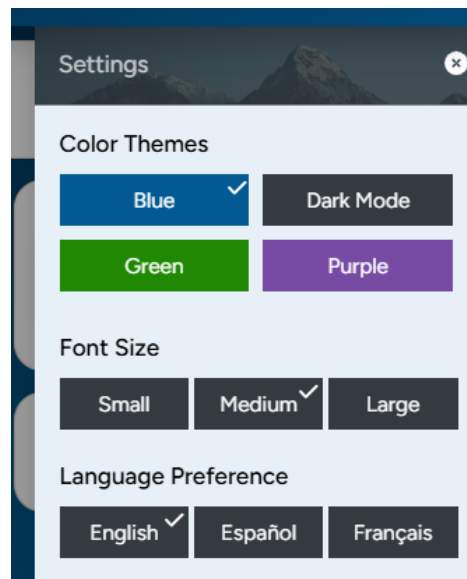


Display Settings

- 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.

Microsite Visibility


- Step 1: You can change how you view the microsite [insert URL] 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 Researchers

Drive Research

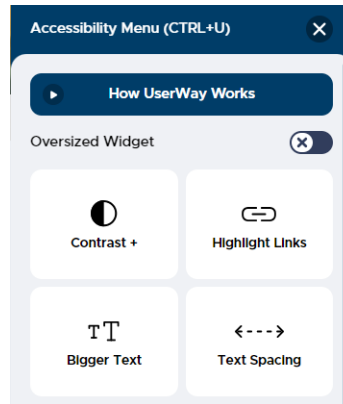
This is a unique rare disease patient registry. Are you interested in using our data to further your rare disease research?



For Patients

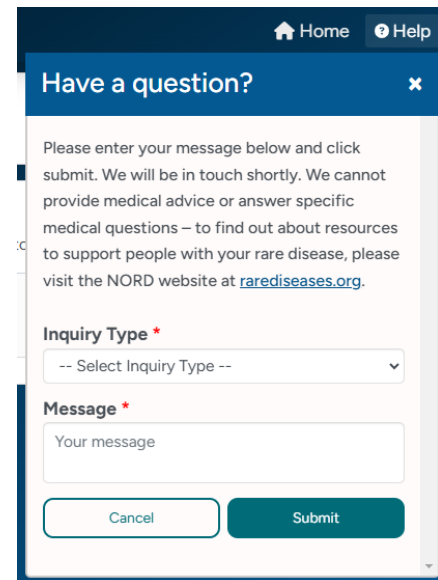
Get Involved

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




Need Assistance?

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



International Topical Steroid Awareness Network (ITSAN)

itsan.org

Contact
Michelle Li / Kathy Tullos

E-mail
Registry@itsan.org

IRB E-mail
info@northstarreviewboard.org

Social Media
