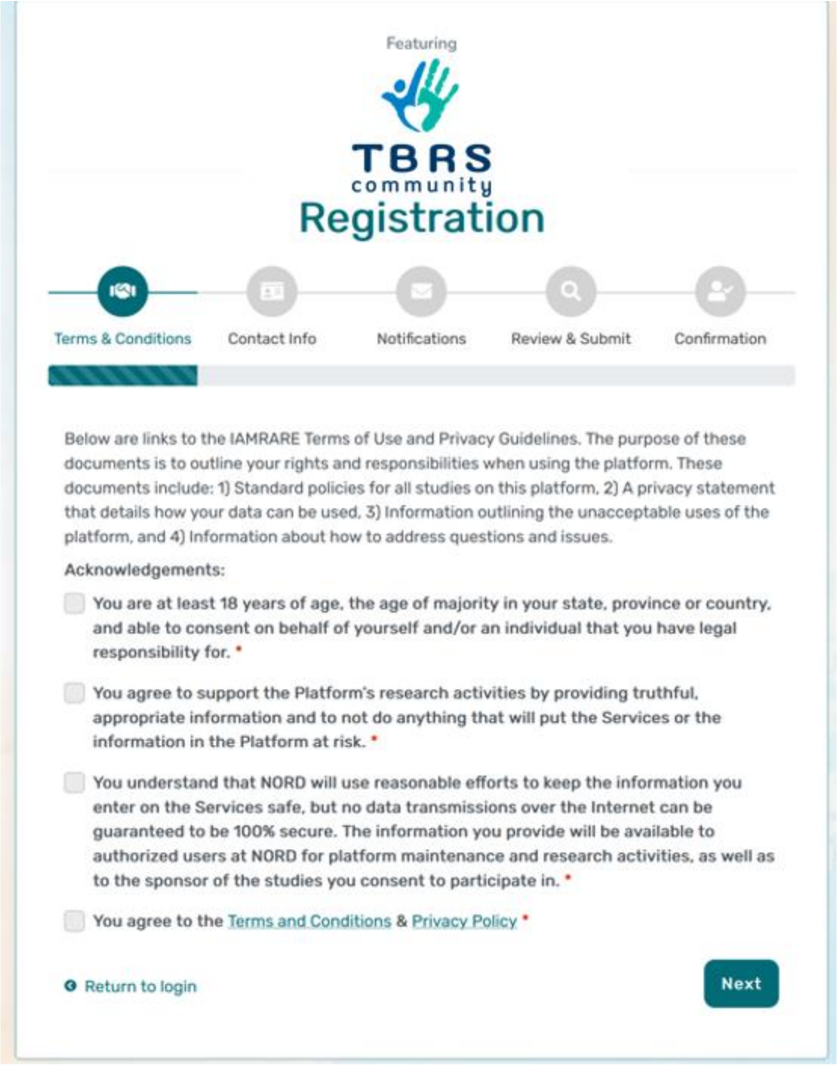
TBRS
community

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:

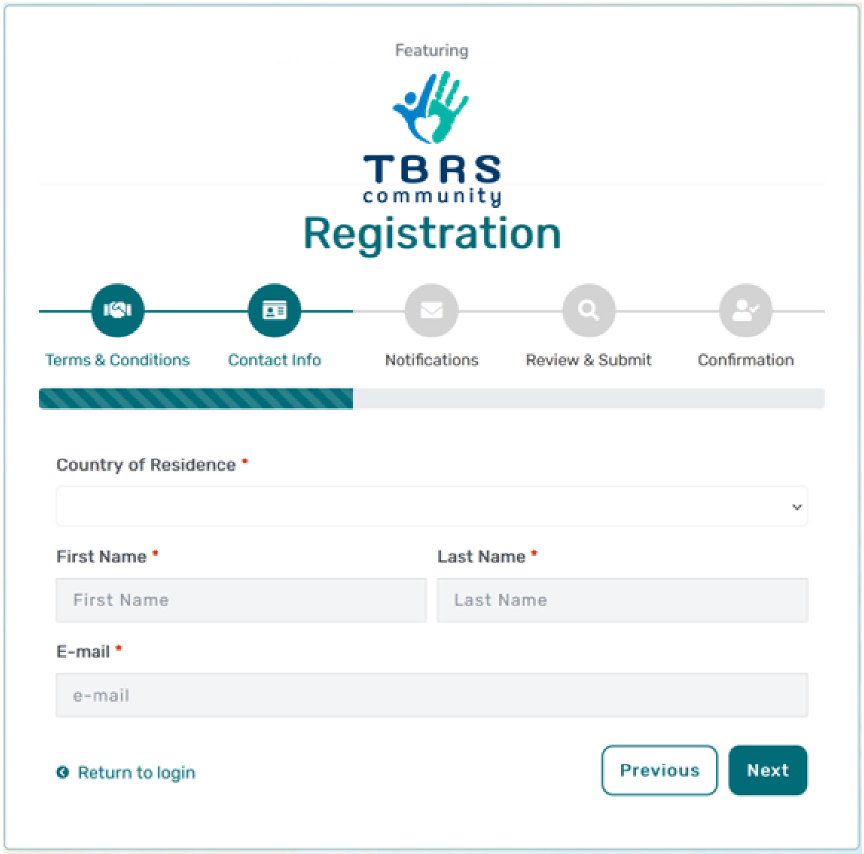
☐ You are at least 18 years of age, the age of majority in your state, province or country, and able to consent on behalf of yourself and/or an individual that you have legal responsibility for. *

☐ 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”.



Country of Residence *

First Name *

First Name

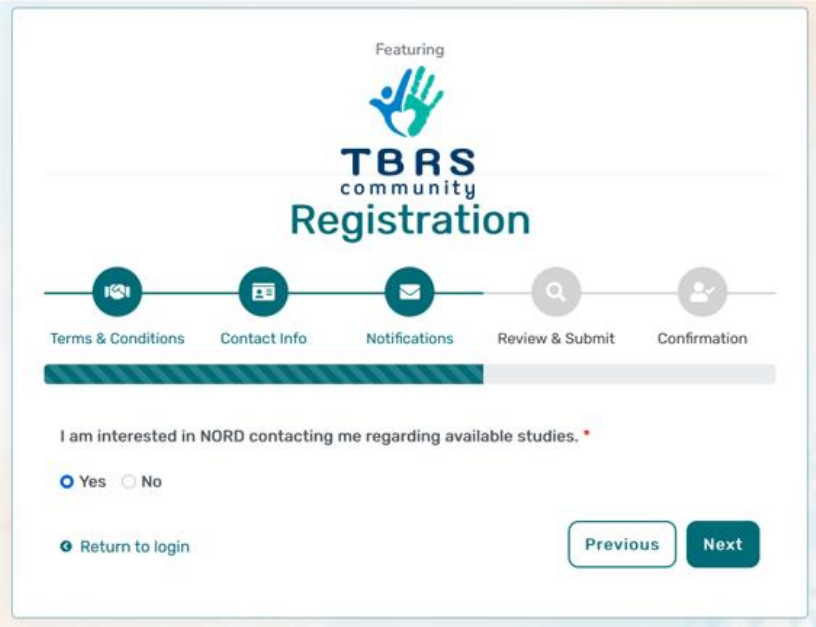
Last Name *

Last Name

E-mail *

e-mail

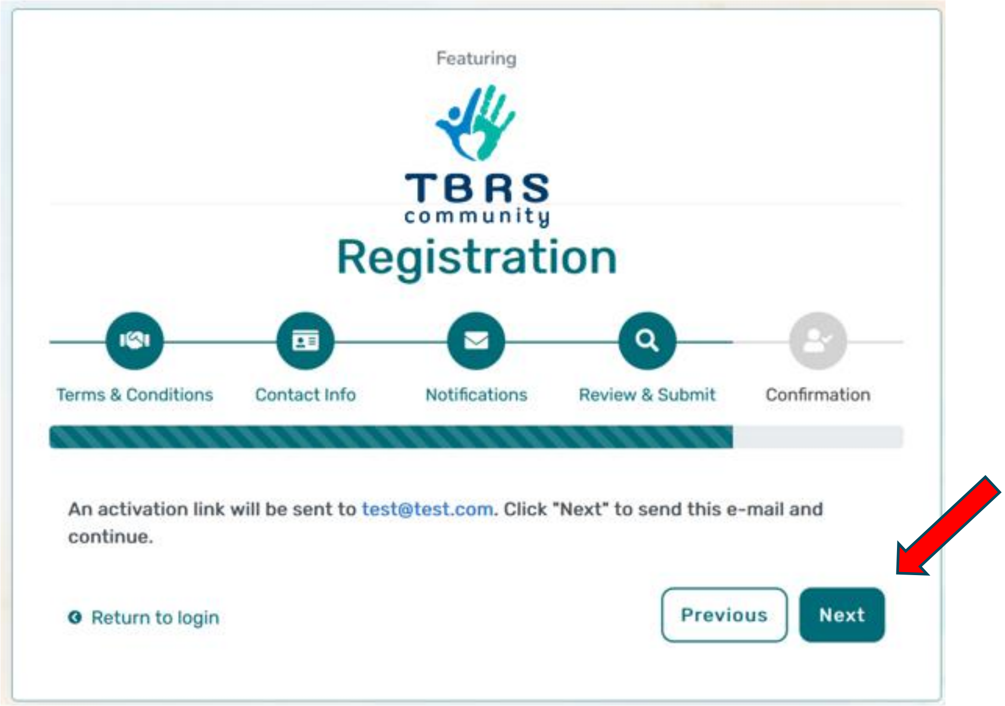
- Step 3: Select whether you are interested in being contacted by NORD regarding available studies. When you are finished with this page, click “Next”.



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

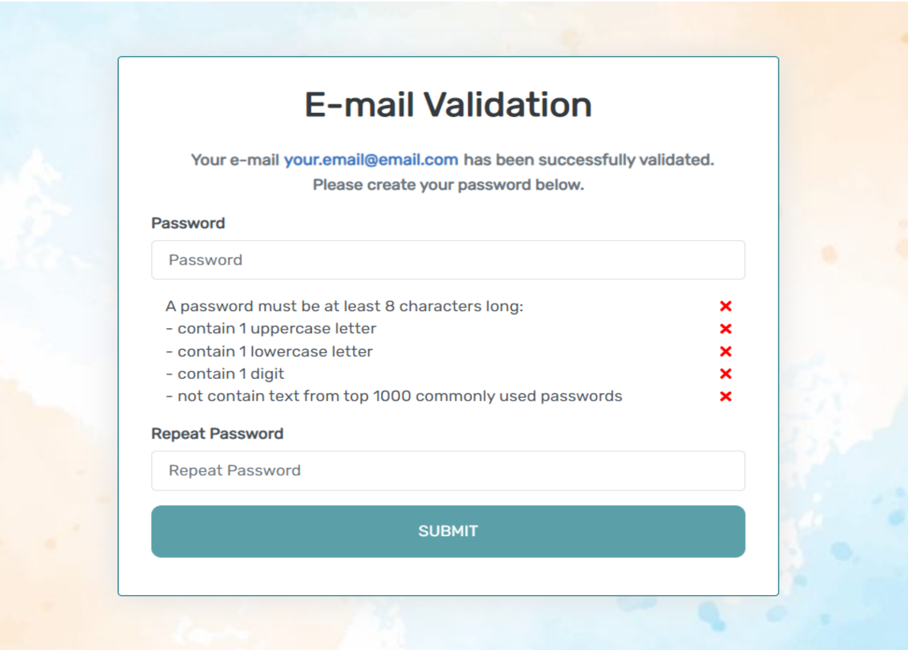
● Yes ○ No

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



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

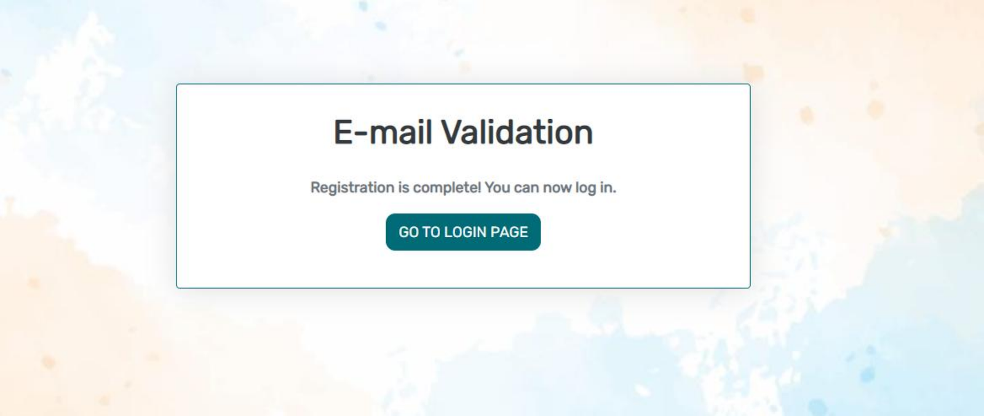
- Step 5: Click the link you are sent via e-mail. Please check your Spam folder if you do not see the e-mail. You will be taken to the following screen in a new tab within your browser. Set your password and click “Submit”.



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

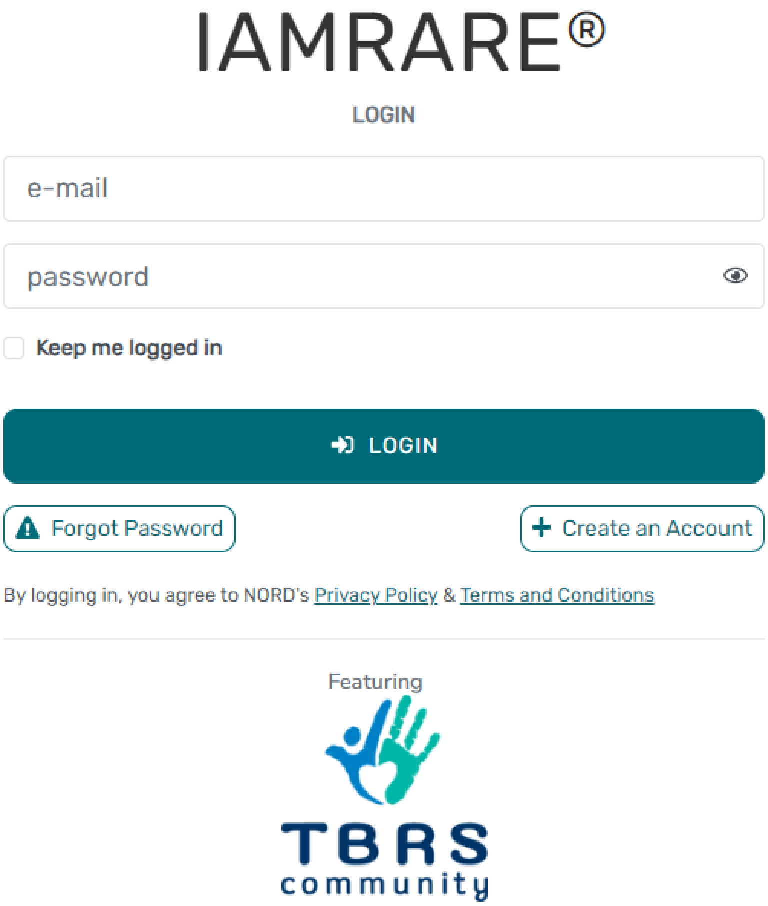
A password must be at least 8 characters long: ✗
- contain 1 uppercase letter ✗
- contain 1 lowercase letter ✗
- contain 1 digit ✗
- not contain text from top 1000 commonly used passwords ✗

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


E-mail Validation

Registration is complete! You can now log in.

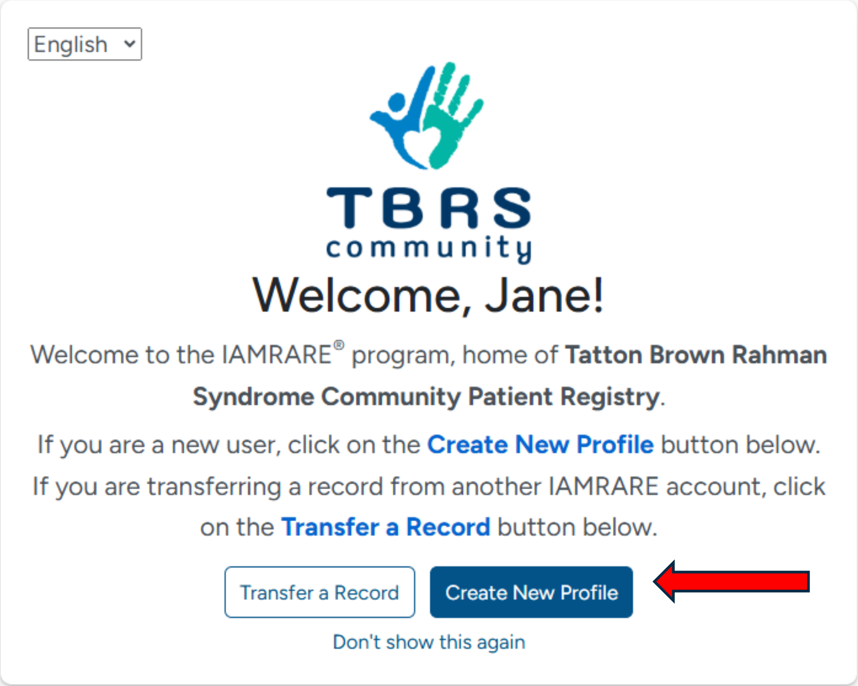
- Step 7: Log in using your new e-mail and password.



By logging in, you agree to NORD's Privacy Policy & Terms and Conditions

Add a Participant

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

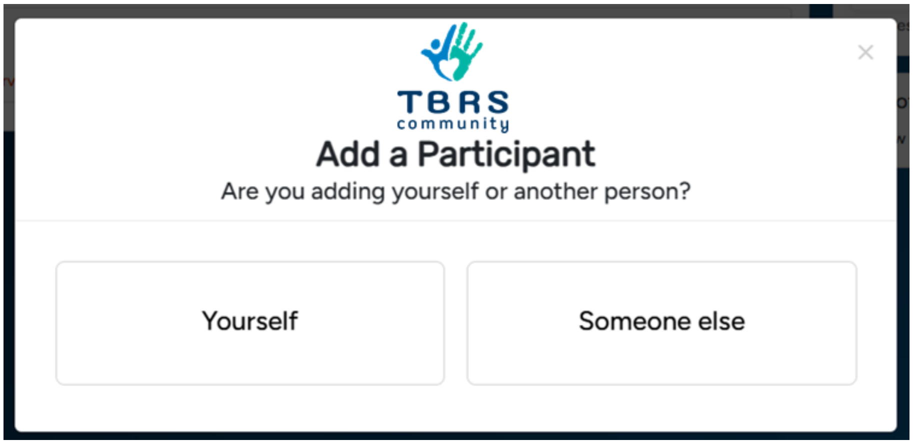


Welcome, Jane!

Welcome to the IAMRARE® program, home of **Tatton Brown Rahman Syndrome Community 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.

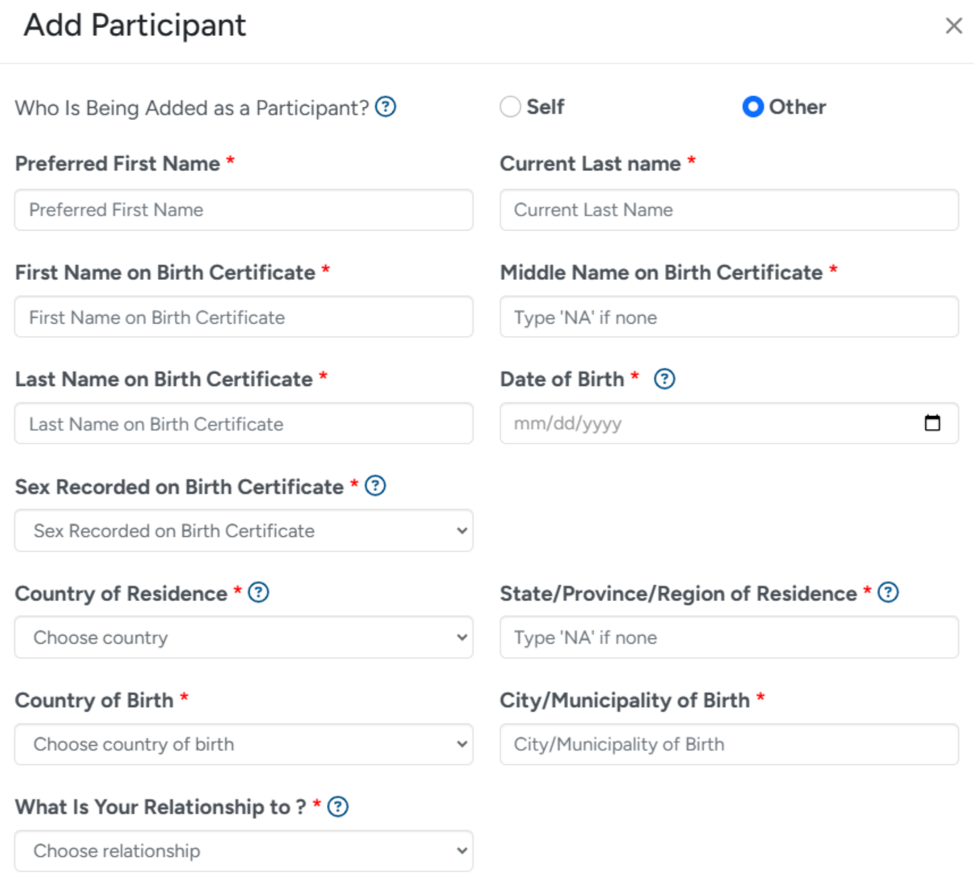
- Step 2: Select who you will be providing information about.



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 *
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

Country of Residence * ⓘ
Choose country

State/Province/Region of Residence * ⓘ
Type 'NA' if none

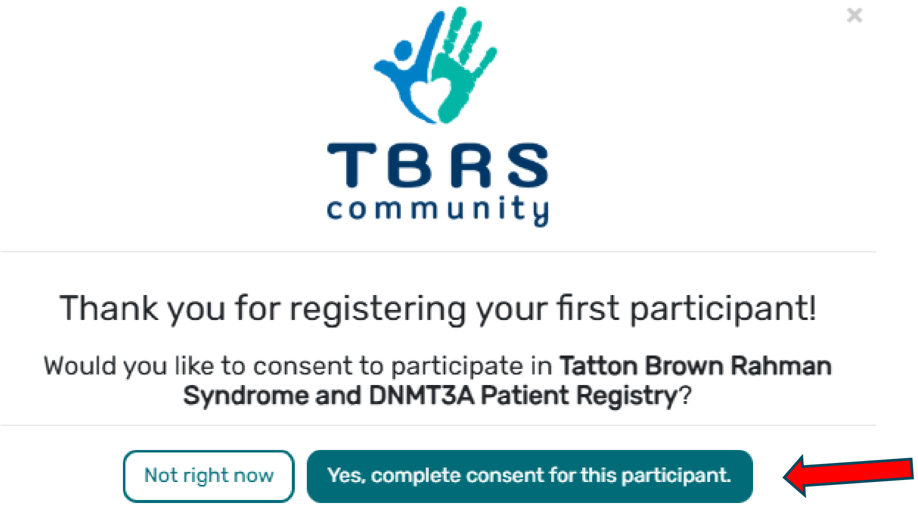
Country of Birth *
Choose country of birth

City/Municipality 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.”

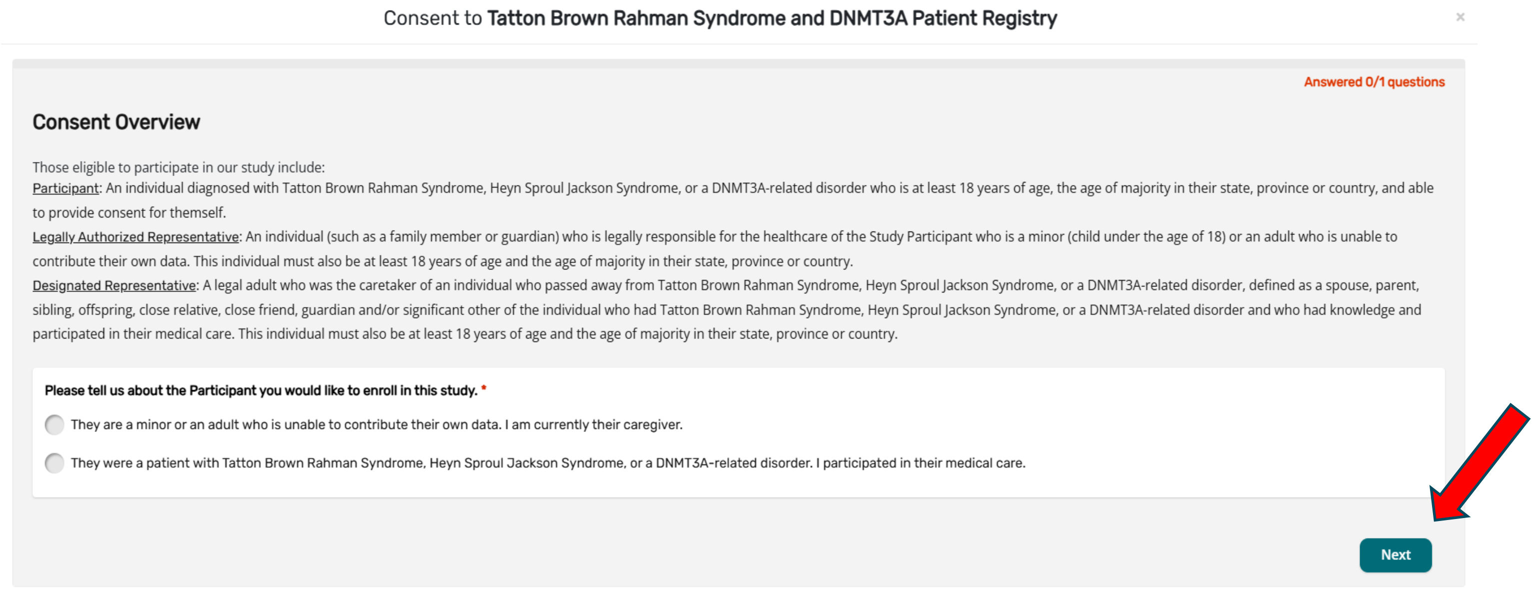


TBRS community

Thank you for registering your first participant!

Would you like to consent to participate in **Tatton Brown Rahman Syndrome and DNMT3A Patient 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 **Tatton Brown Rahman Syndrome and DNMT3A Patient Registry**

Answered 0/1 questions

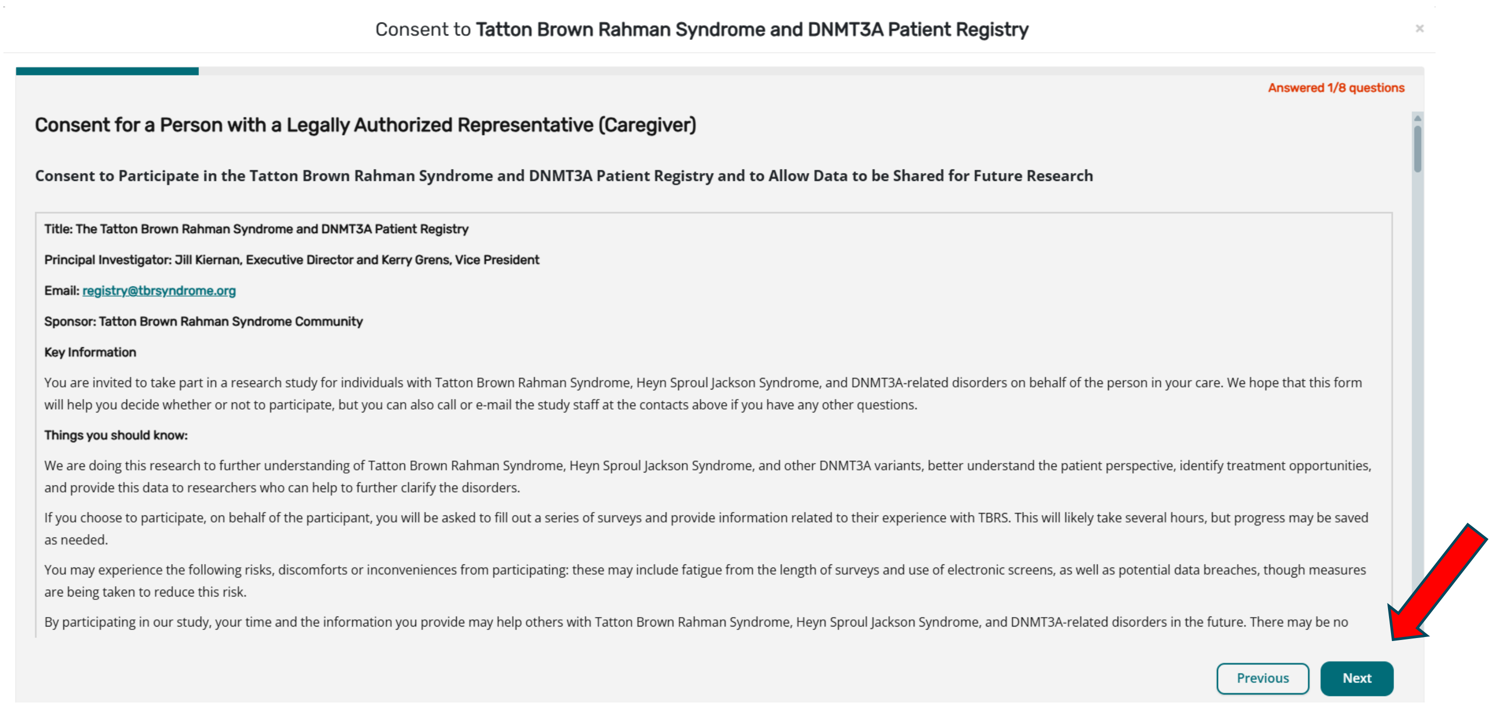
Consent Overview

Those eligible to participate in our study include:
Participant: An individual diagnosed with Tatton Brown Rahman Syndrome, Heyn Sproul Jackson Syndrome, or a DNMT3A-related disorder 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.
Designated Representative: A legal adult who was the caretaker of an individual who passed away from Tatton Brown Rahman Syndrome, Heyn Sproul Jackson Syndrome, or a DNMT3A-related disorder, defined as a spouse, parent, sibling, offspring, close relative, close friend, guardian and/or significant other of the individual who had Tatton Brown Rahman Syndrome, Heyn Sproul Jackson Syndrome, or a DNMT3A-related disorder and who had knowledge 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.

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 Tatton Brown Rahman Syndrome, Heyn Sproul Jackson Syndrome, or a DNMT3A-related disorder. I participated in their medical care.



Consent to **Tatton Brown Rahman Syndrome and DNMT3A Patient Registry**

Answered 1/8 questions

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

Consent to Participate in the Tatton Brown Rahman Syndrome and DNMT3A Patient Registry and to Allow Data to be Shared for Future Research

Title: The Tatton Brown Rahman Syndrome and DNMT3A Patient Registry

Principal Investigator: Jill Kiernan, Executive Director and Kerry Grens, Vice President

Email: registry@tbrsyndrome.org

Sponsor: Tatton Brown Rahman Syndrome Community

Key Information

You are invited to take part in a research study for individuals with Tatton Brown Rahman Syndrome, Heyn Sproul Jackson Syndrome, and DNMT3A-related disorders 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.

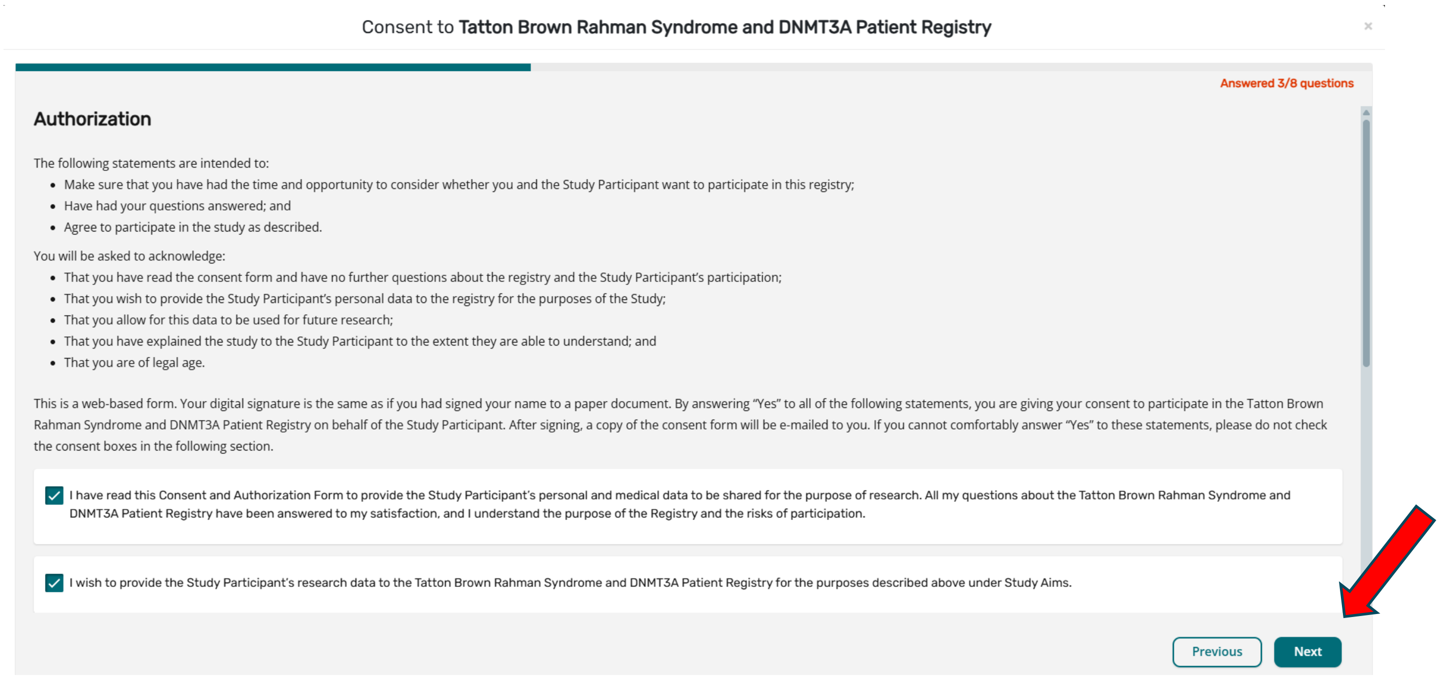
Things you should know:

We are doing this research to further understanding of Tatton Brown Rahman Syndrome, Heyn Sproul Jackson Syndrome, and other DNMT3A variants, better understand the patient perspective, identify treatment opportunities, and provide this data to researchers who can help to further clarify the disorders.

If you choose to participate, on behalf of the participant, you will be asked to fill out a series of surveys and provide information related to their experience with TBRS. This will likely take several hours, but progress may be saved as needed.

You may experience the following risks, discomforts or inconveniences from participating: these may include fatigue from the length of surveys and use of electronic screens, as well as potential data breaches, though measures are being taken to reduce this risk.

By participating in our study, your time and the information you provide may help others with Tatton Brown Rahman Syndrome, Heyn Sproul Jackson Syndrome, and DNMT3A-related disorders in the future. There may be no



Consent to **Tatton Brown Rahman Syndrome and DNMT3A Patient Registry**

Answered 3/8 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:

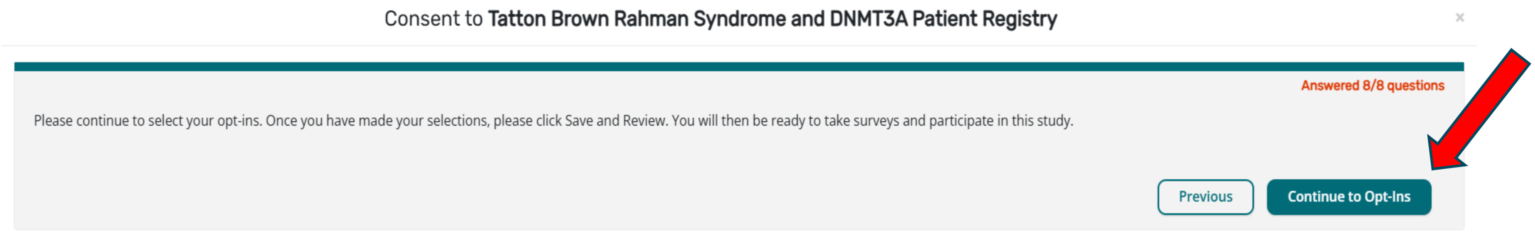
- That you have read the consent form and have no further questions about the registry and the Study Participant's participation;
- That you wish to provide the Study Participant's personal data to the registry for the purposes of the Study;
- That you allow for this data to be used for future research;
- 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 Tatton Brown Rahman Syndrome and DNMT3A Patient 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 Tatton Brown Rahman Syndrome and DNMT3A 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 the Study Participant's research data to the Tatton Brown Rahman Syndrome and DNMT3A 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".

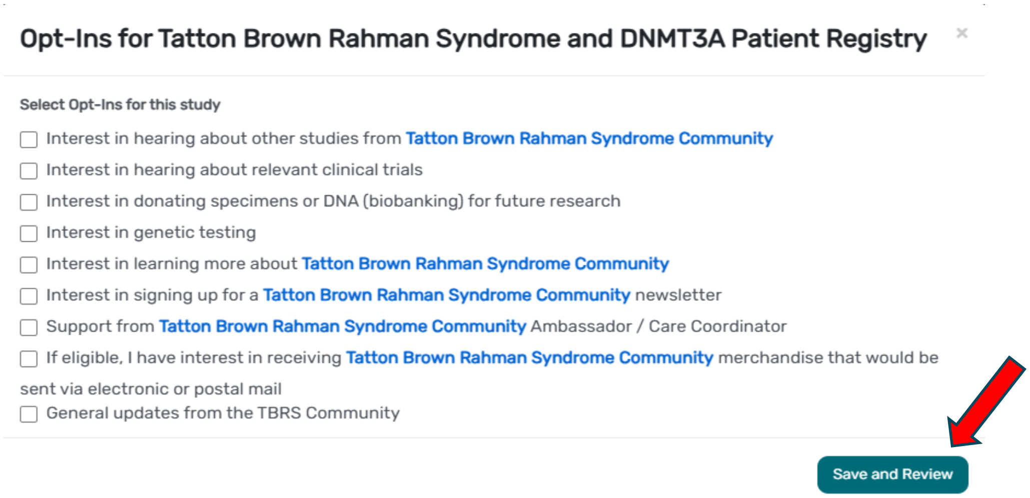


Consent to **Tatton Brown Rahman Syndrome and DNMT3A Patient Registry**

Answered 8/8 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.

- 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 Tatton Brown Rahman Syndrome and DNMT3A Patient Registry

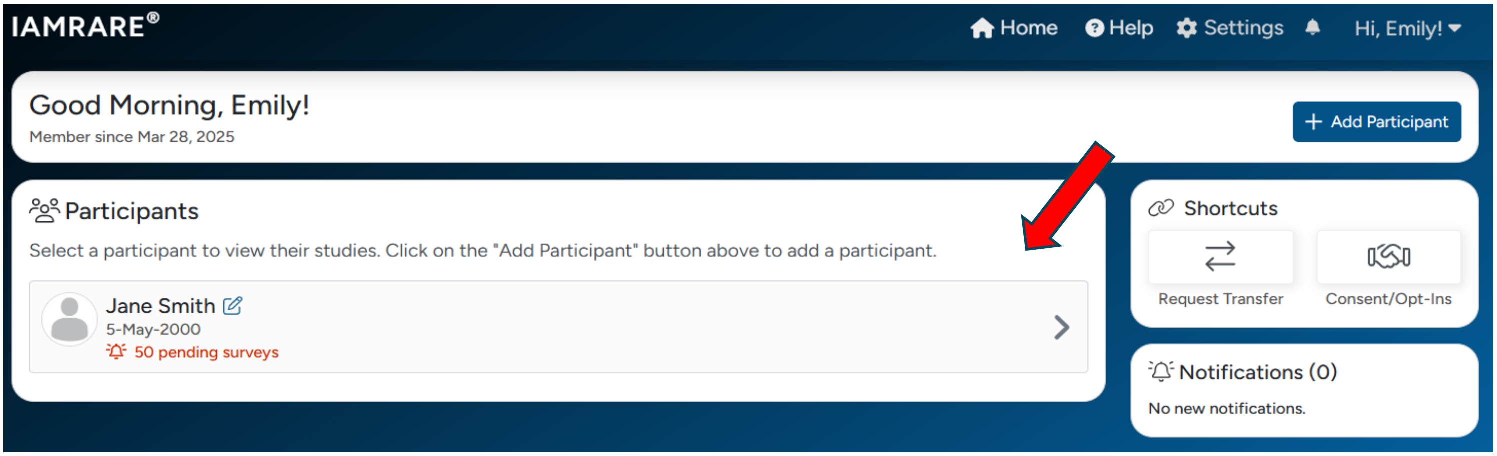
Select Opt-Ins for this study

☐ Interest in hearing about other studies from **Tatton Brown Rahman Syndrome Community**
☐ 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 **Tatton Brown Rahman Syndrome Community**
☐ Interest in signing up for a **Tatton Brown Rahman Syndrome Community** newsletter
☐ Support from **Tatton Brown Rahman Syndrome Community** Ambassador / Care Coordinator
☐ If eligible, I have interest in receiving **Tatton Brown Rahman Syndrome Community** merchandise that would be sent via electronic or postal mail
☐ General updates from the TBRS Community

- 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 Morning, Emily!

Member since Mar 28, 2025

Participants

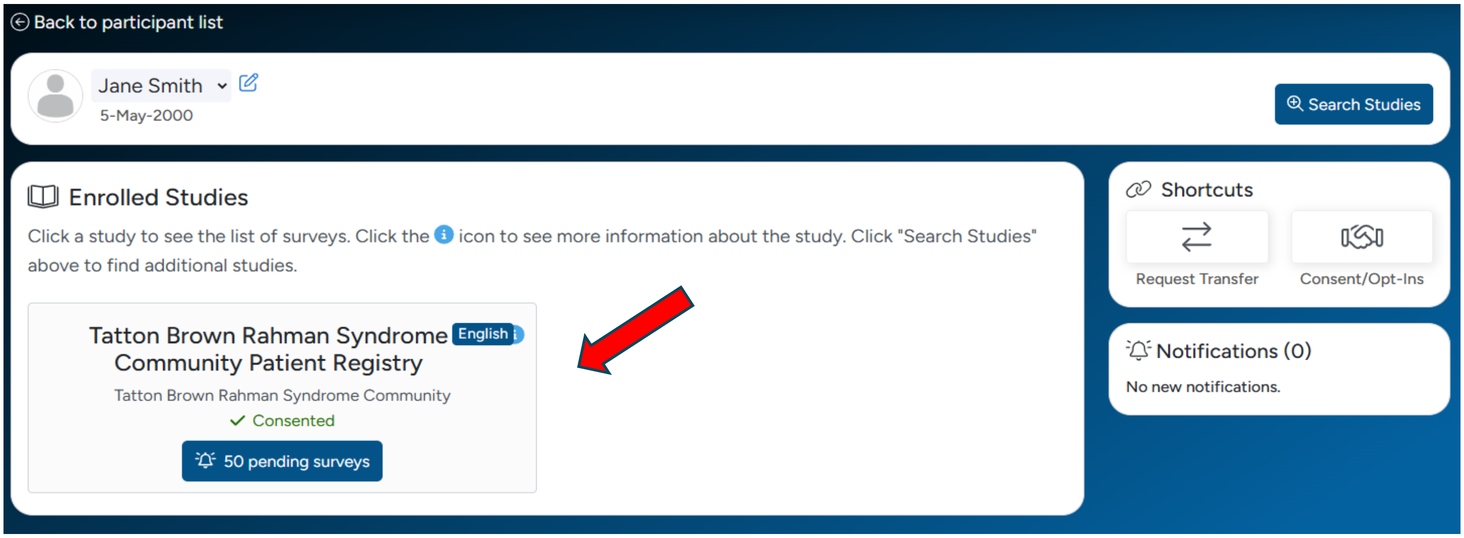
Select a participant to view their studies. Click on the "Add Participant" button above to add a participant.

Jane Smith
5-May-2000
50 pending surveys

Notifications (0)

No new notifications.

- Step 2: Click on the appropriate study.



Jane Smith
5-May-2000

Enrolled Studies

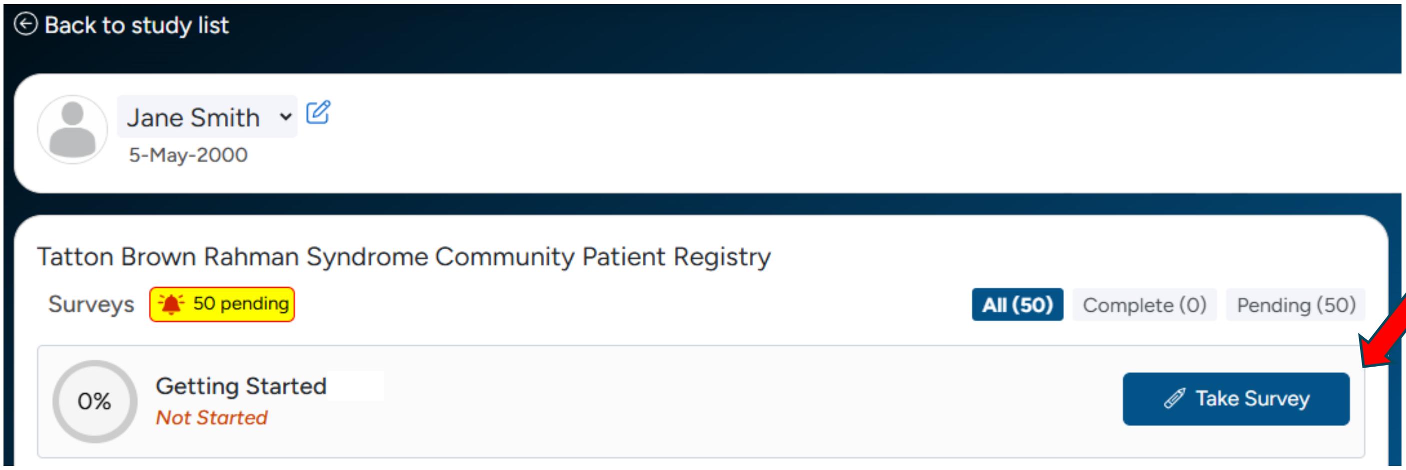
Click a study to see the list of surveys. Click the ℹ icon to see more information about the study. Click "Search Studies" above to find additional studies.

Tatton Brown Rahman Syndrome Community Patient Registry
Tatton Brown Rahman Syndrome Community
✓ Consented

Notifications (0)

No new notifications.

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



Jane Smith
5-May-2000

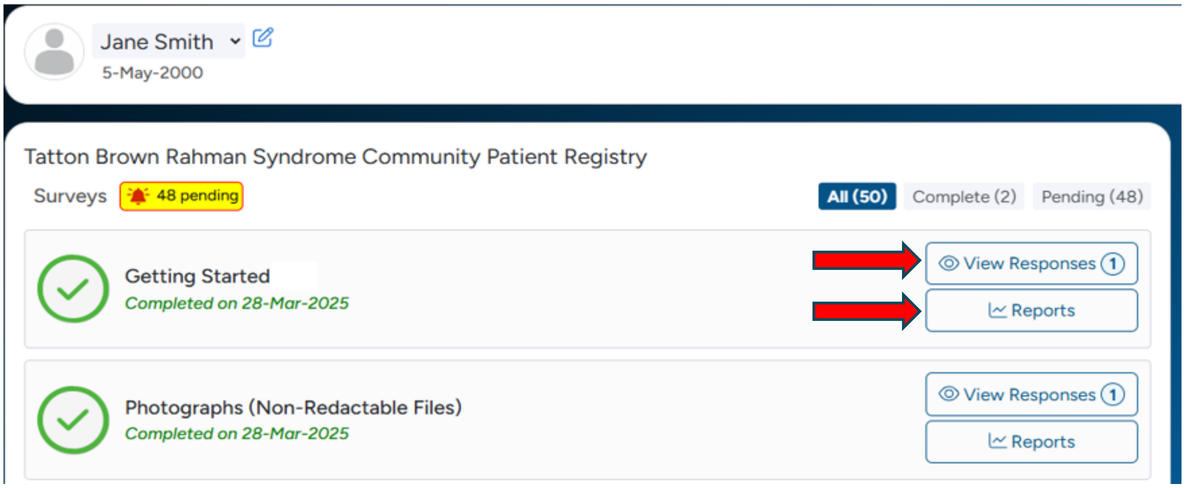
Tatton Brown Rahman Syndrome Community Patient Registry

Surveys 50 pending

0% Getting Started
Not Started

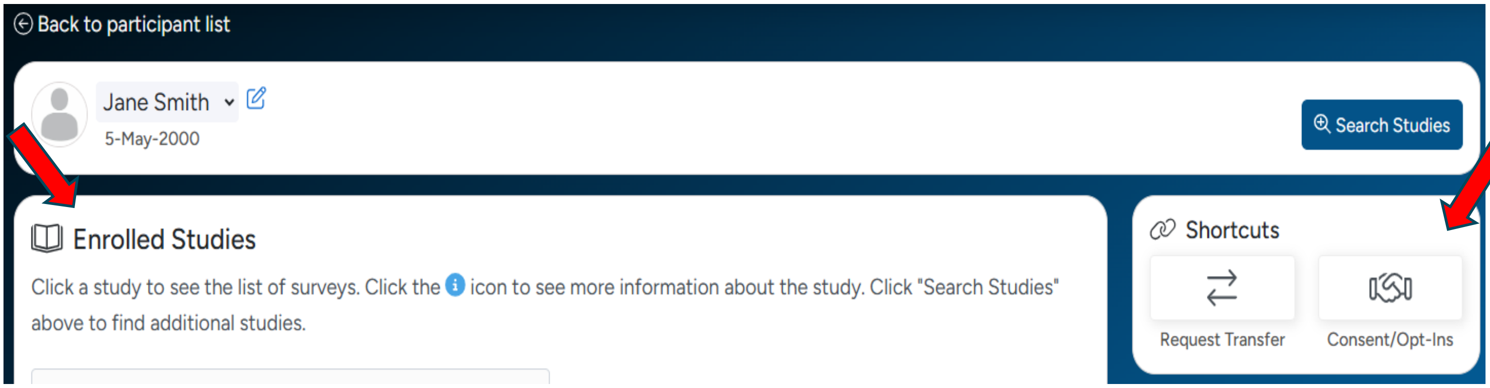
View Responses and Reports

- 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.



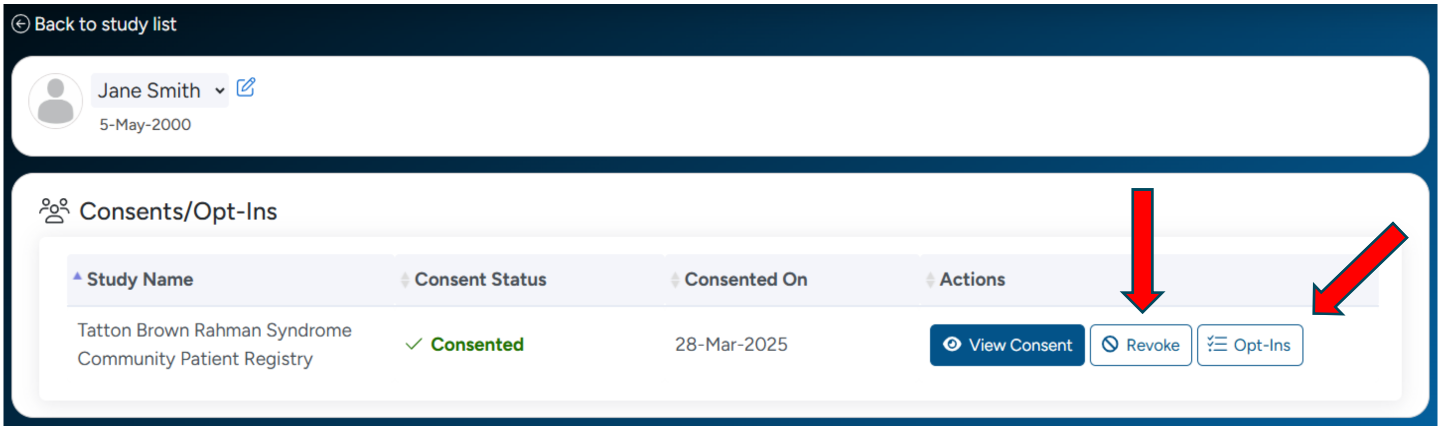
View Consent and Opt-Ins

- 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
Tatton Brown Rahman Syndrome Community Patient Registry	✓ Consented	28-Mar-2025	View Consent, Revoke, Opt-Ins

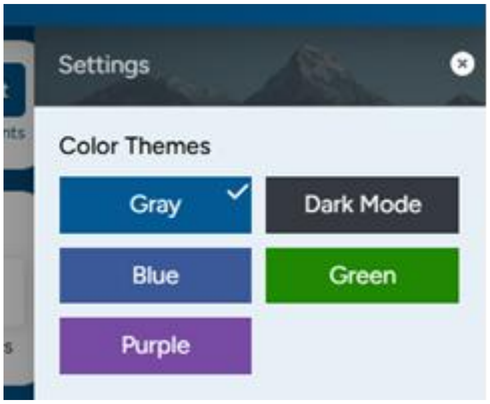
Dark Mode Settings

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

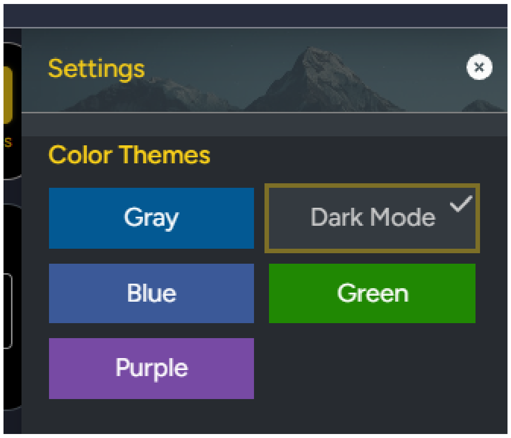
Good Afternoon, Jane!

Member since Nov 16, 2024

- Step 2: Select Dark Mode.



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



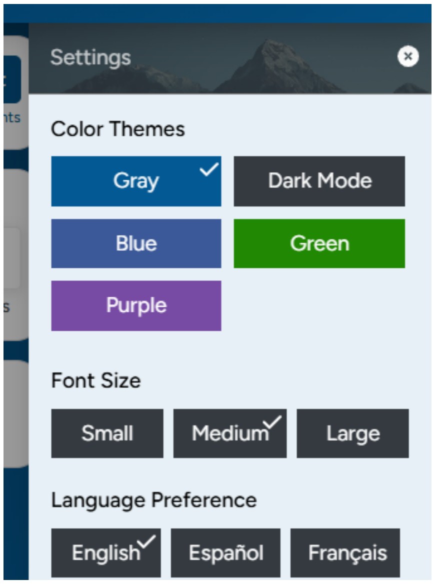
Display Settings

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

Good Afternoon, Jane!

Member since Nov 16, 2024

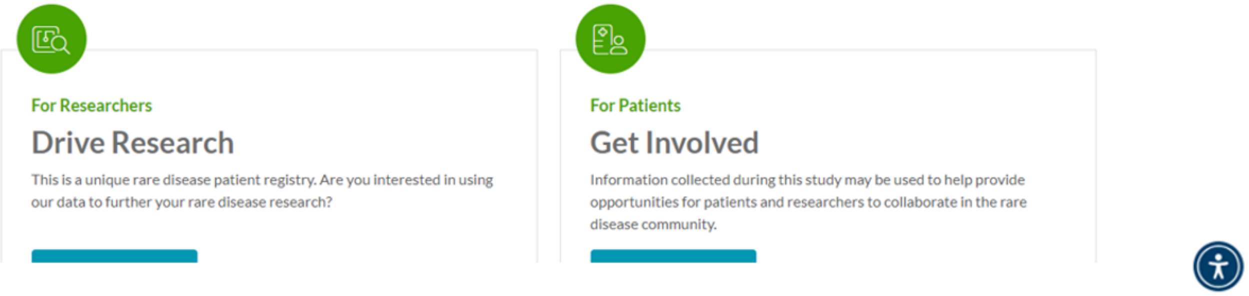
- Step 2: Select a color theme, a font size, or language preference.



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

Microsite Visibility

- Step 1: You can change how you view the microsite (https://tbrsregistry.iamrare.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 Researchers

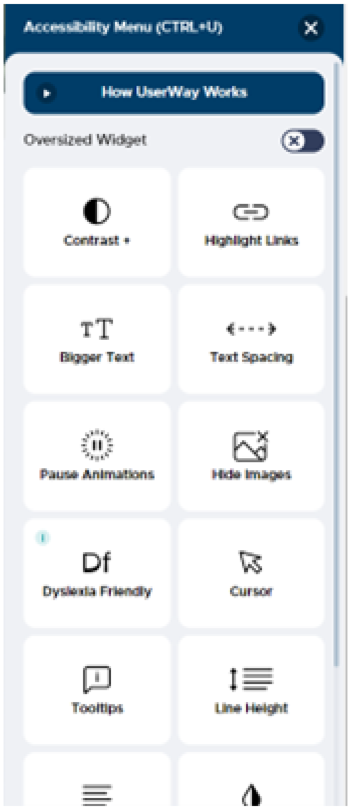
Drive Research

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

For Patients

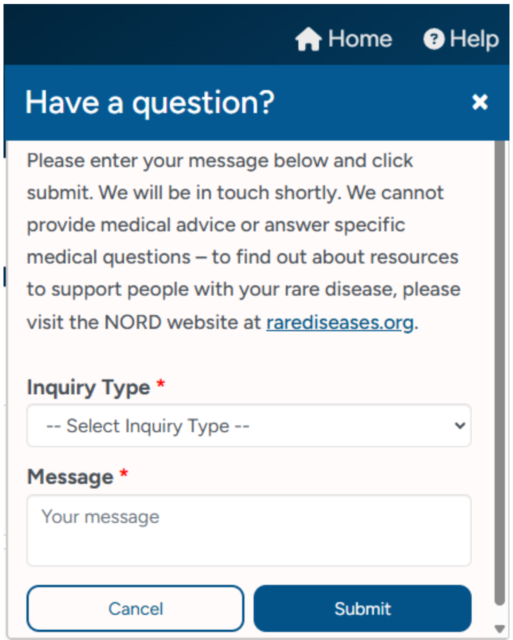
Get Involved

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.



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 *

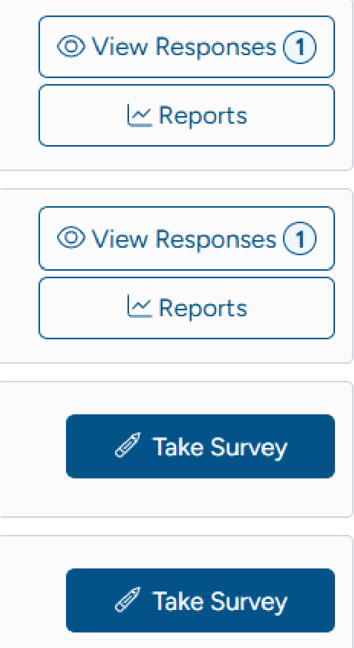
-- Select Inquiry Type --

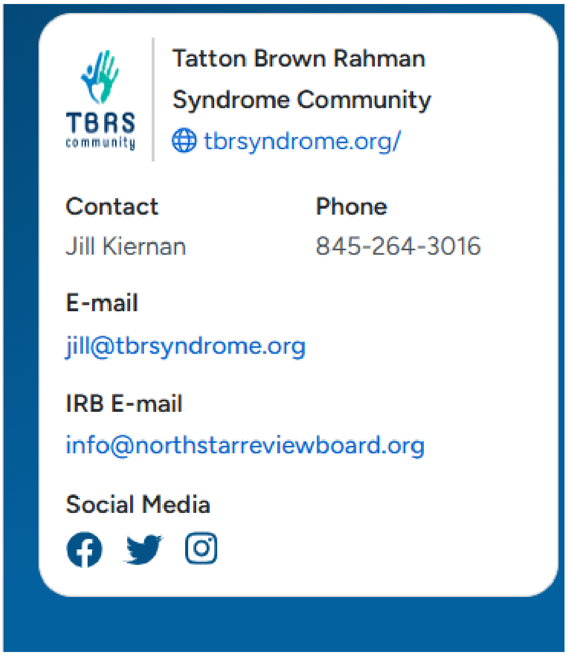
Message *

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.





Tatton Brown Rahman Syndrome Community

tbrsyndrome.org/

Contact	Phone
Jill Kiernan	845-264-3016

E-mail

jill@tbrsyndrome.org

IRB E-mail

info@northstarreviewboard.org

Social Media