

International Bloom Syndrome 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”.

The screenshot shows the 'Registration' page for the International Bloom Syndrome Registry. At the top is the logo for the 'bloom syndrome association' featuring a stylized flower. Below the logo is a progress bar with five steps: 'Terms & Conditions' (active), 'Contact Info', 'Notifications', 'Review & Submit', and 'Confirmation'. The main content area contains a paragraph about the IAMRARE Terms of Use and Privacy Guidelines, followed by a section titled 'Acknowledgements:' with four checkboxes and their corresponding text. At the bottom left is a link 'Return to login' and at the bottom right is a blue 'Next' button.

Featuring
bloom syndrome
association

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”.

The screenshot shows the 'Registration' page for the International Bloom Syndrome Registry, specifically the 'Contact Info' step. The progress bar now highlights 'Contact Info'. The form fields include a dropdown menu for 'Country of Residence', text boxes for 'First Name' and 'Last Name', and a text box for 'E-mail'. At the bottom left is a link 'Return to login' and at the bottom right are 'Previous' and 'Next' buttons.

Featuring
bloom syndrome
association

Registration

Terms & Conditions **Contact Info** Notifications Review & Submit Confirmation

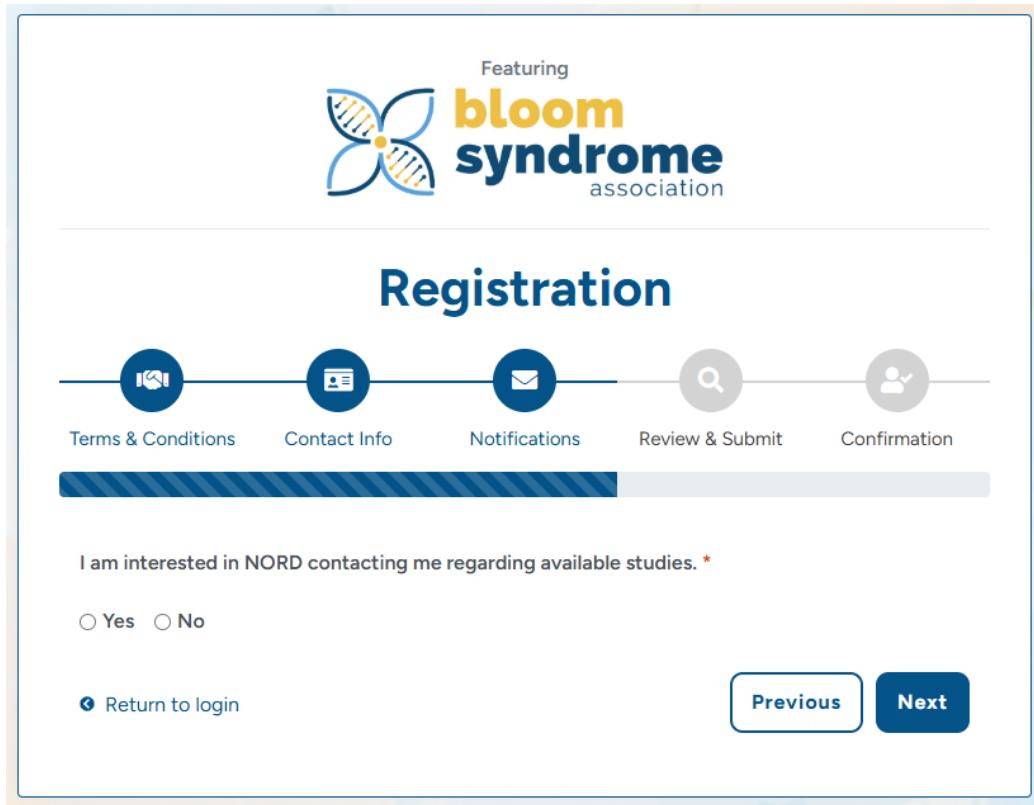
Country of Residence *

First Name * Last Name *

E-mail *

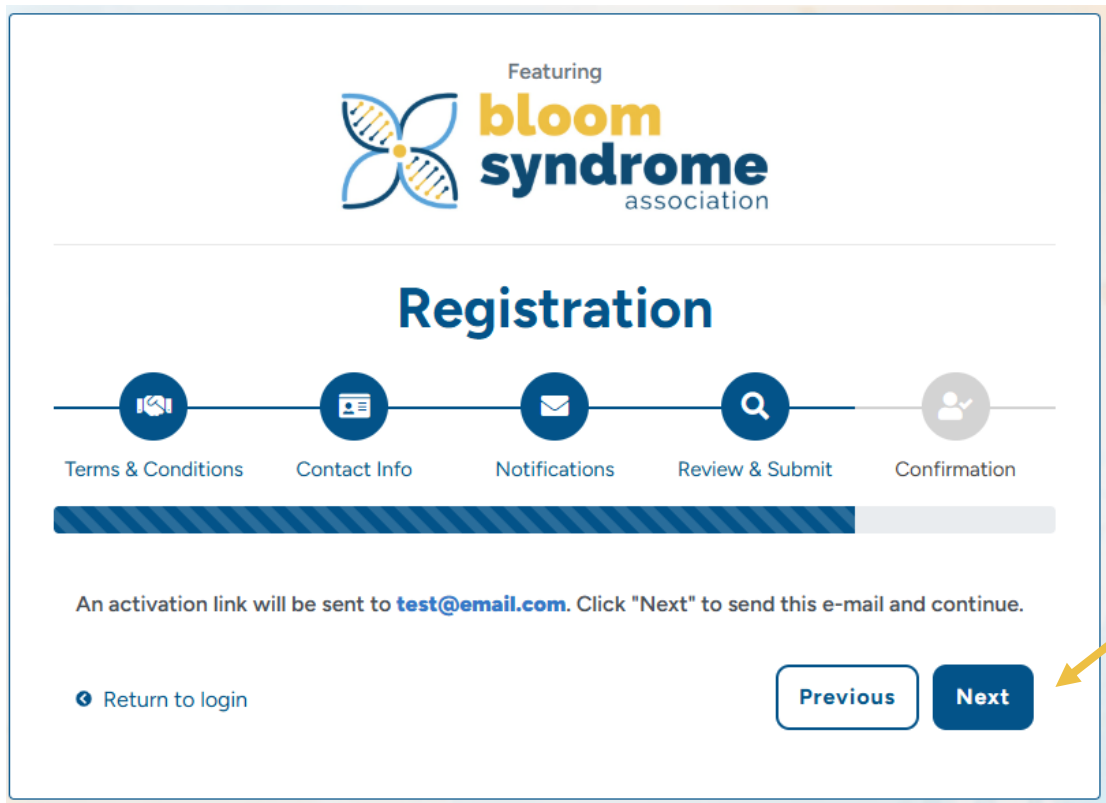
[Return to login](#) **Previous** **Next**

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



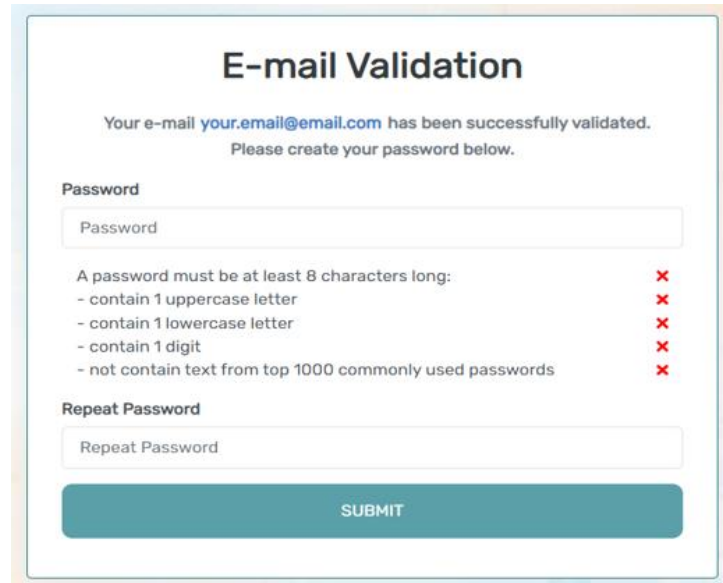
The screenshot shows the 'Registration' page for the 'Featuring bloom syndrome association'. The progress bar indicates that the 'Review & Submit' step is currently active. The form contains a question: 'I am interested in NORD contacting me regarding available studies. *'. Below the question are two radio buttons labeled 'Yes' and 'No'. At the bottom left is a link 'Return to login'. At the bottom right are two buttons: 'Previous' and 'Next'.

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



The screenshot shows the 'Registration' page for the 'Featuring bloom syndrome association'. The progress bar indicates that the 'Review & Submit' step is currently active. The form contains a message: 'An activation link will be sent to test@email.com. Click "Next" to send this e-mail and continue.' At the bottom left is a link 'Return to login'. At the bottom right are two buttons: 'Previous' and 'Next'. A yellow 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.

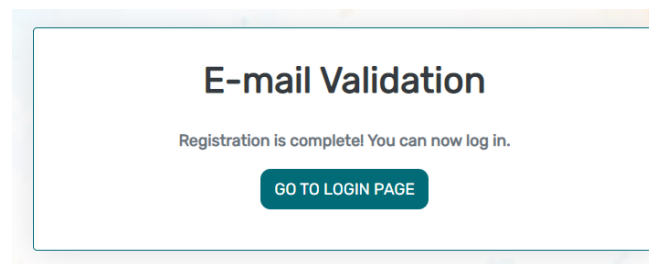
Password

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”.

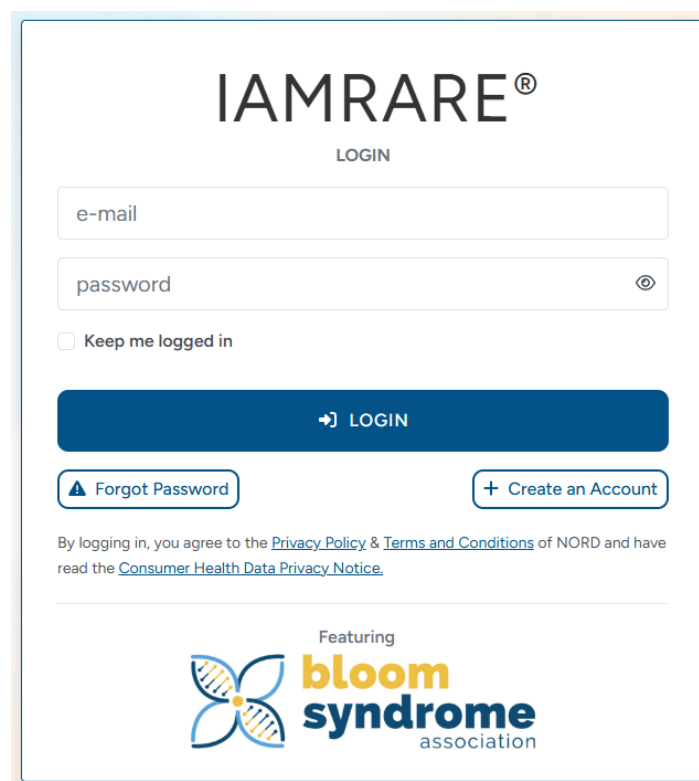


E-mail Validation

Registration is complete! You can now log in.

GO TO LOGIN PAGE

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



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](#).

Featuring

 **bloom syndrome** association

Add a Participant

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



English

 **bloom**
syndrome
association

Welcome, Jane!

Welcome to the IAMRARE® program, home of **International Bloom Syndrome Registry**.

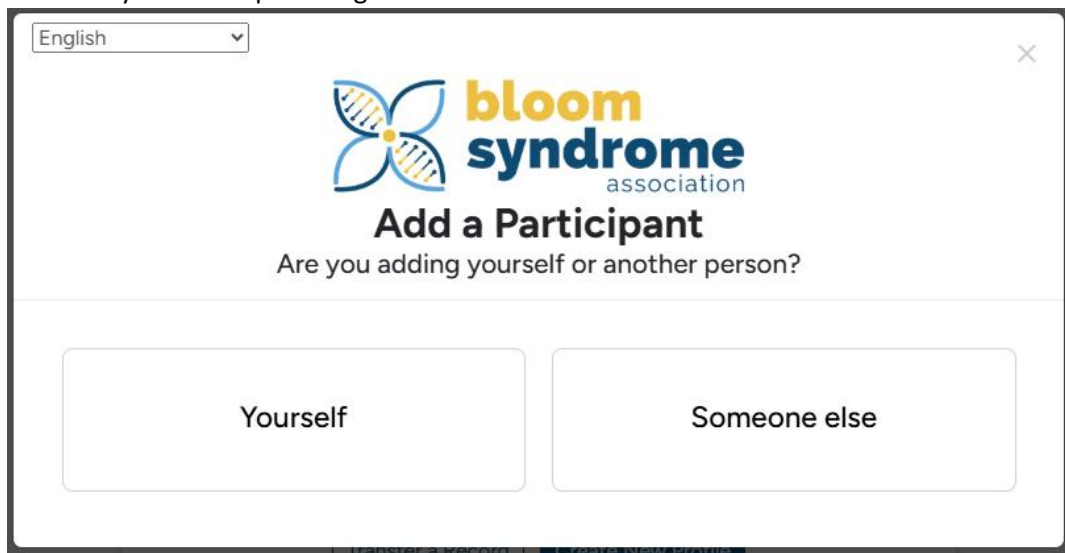
If you are a new user, click on the **Create New Profile** button below.

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

 **bloom**
syndrome
association

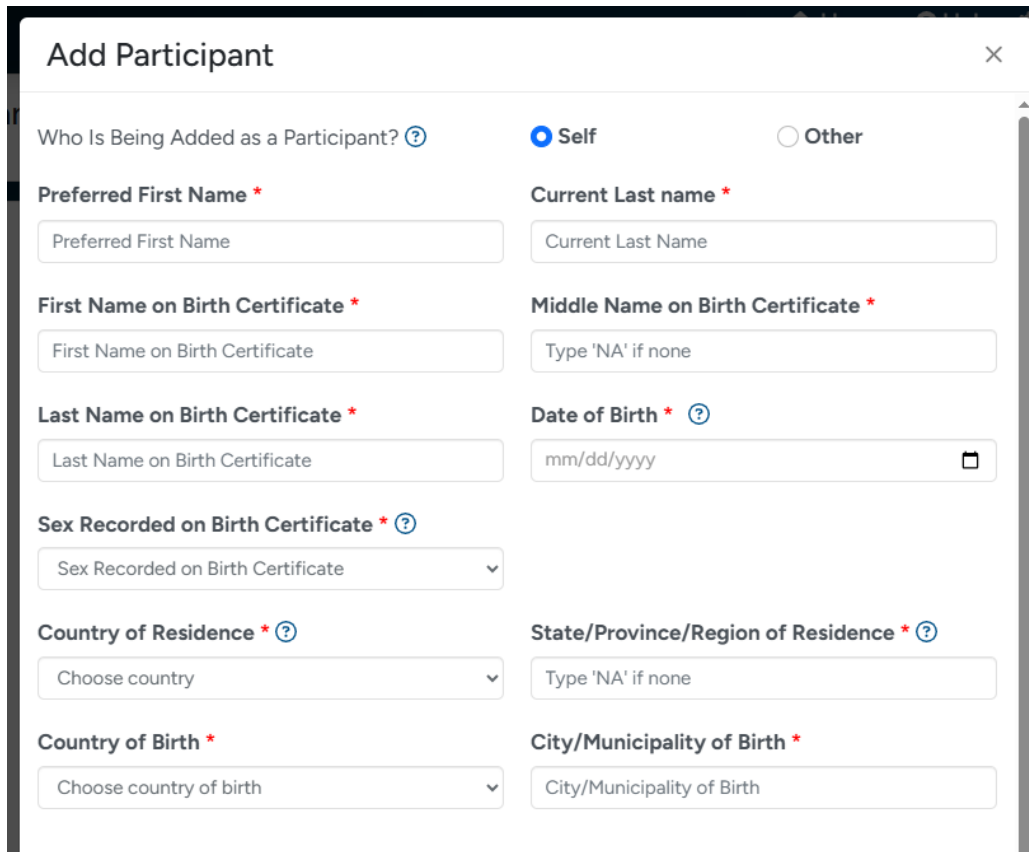
Add a Participant

Are you adding yourself or another person?

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

[Transfer a Record](#) [Create New Profile](#)

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



Add Participant [X]

Who Is Being Added as a Participant? [?] ☒ Self ☐ 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 arrow]

Country of Residence * [?] [dropdown arrow]

State/Province/Region of Residence * [?]

Country of Birth * [dropdown arrow]

City/Municipality of Birth *

Consent to the Study

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



 **bloom**
syndrome
association

Thank you for registering your first participant!
Would you like to consent to participate in **International Bloom Syndrome 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 International Bloom Syndrome Registry

Jane Smith

Consent Overview

Those eligible to participate in our study include:
Participant: An individual diagnosed with Bloom syndrome, or Bloom-like syndrome 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 Bloom syndrome, or Bloom-like 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 Bloom syndrome, or Bloom-like syndrome, defined as a spouse, parent, sibling, offspring, close relative, close friend, guardian and/or significant other of the individual who had Bloom syndrome, or Bloom-like syndrome and who had knowledge and participated in their medical care. The Designated Representative must also be at least 18 years of age and the age of majority in their state, province or country.

Next

Consent to International Bloom Syndrome Registry

Jane Smith

Adult Consent

Consent to Participate in the International Bloom Syndrome Registry ("IBSR" or "Registry") and to Allow Your Data to be Shared for Future Research

Title: International Bloom Syndrome Registry
Principal Investigators: Chris Brunger, M.D. and Mary Elizabeth Campbell, Ph.D.
Phone: +1 (619) 492-9144
E-mail: chris2@bloomsyndromeassociation.org; marybeth@bloomsyndromeassociation.org
International Bloom Syndrome Registry Coordinator
E-mail: ibsr@bloomsyndromeassociation.org
Sponsor: Bloom Syndrome Association

PreviousNext

Consent to International Bloom Syndrome 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 the International Bloom Syndrome 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 International Bloom Syndrome Registry have been answered to my satisfaction, and I understand the purpose of the registry and the risks of participation.

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

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

Consent to International Bloom Syndrome 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.

[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 International Bloom Syndrome Registry

Select Opt-Ins for this study

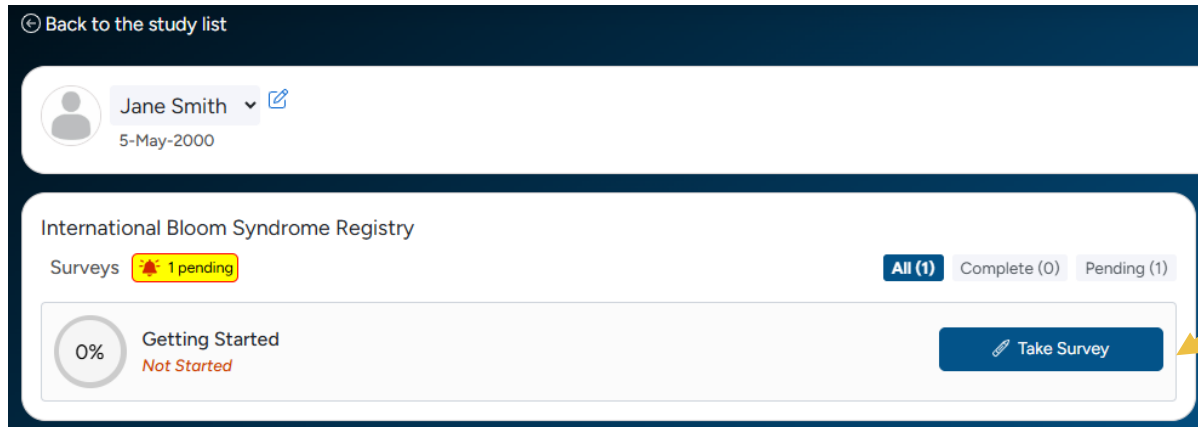
- ☐ Interest in learning more about **Bloom Syndrome Association**
- ☐ Interest in signing up for a **Bloom Syndrome Association** newsletter
- ☐ Support from **Bloom Syndrome Association** Ambassador / Care Coordinator
- ☐ If eligible, I have interest in receiving **Bloom Syndrome Association** merchandise that would be sent via electronic or postal mail
- ☐ Interest in learning about upcoming events such as webinars and conferences
- ☐ Interest in hearing about other relevant research studies and clinical trials from **Bloom Syndrome Association**
- ☐ Interest in regional family support groups
- ☐ Interest in donating tissue, specimens, or DNA (biobanking) for future research
- ☐ Interest in receiving information about **Bloom syndrome** clinics

[Save and Review](#)

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

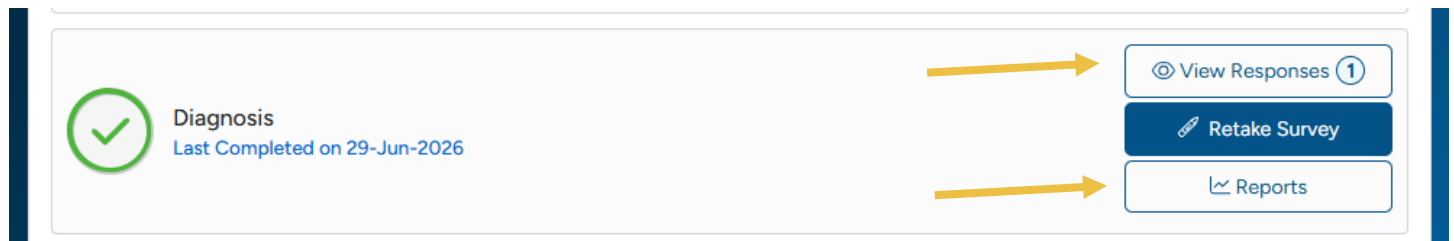
Taking Surveys

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



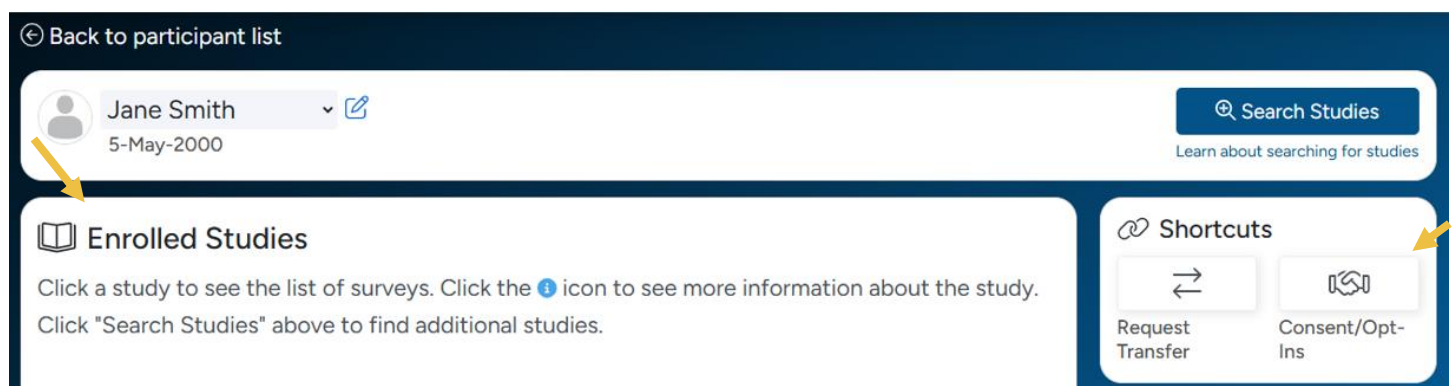
View Responses and Reports

- 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. Note that graphs are only visible once at least ten people have answered the question.

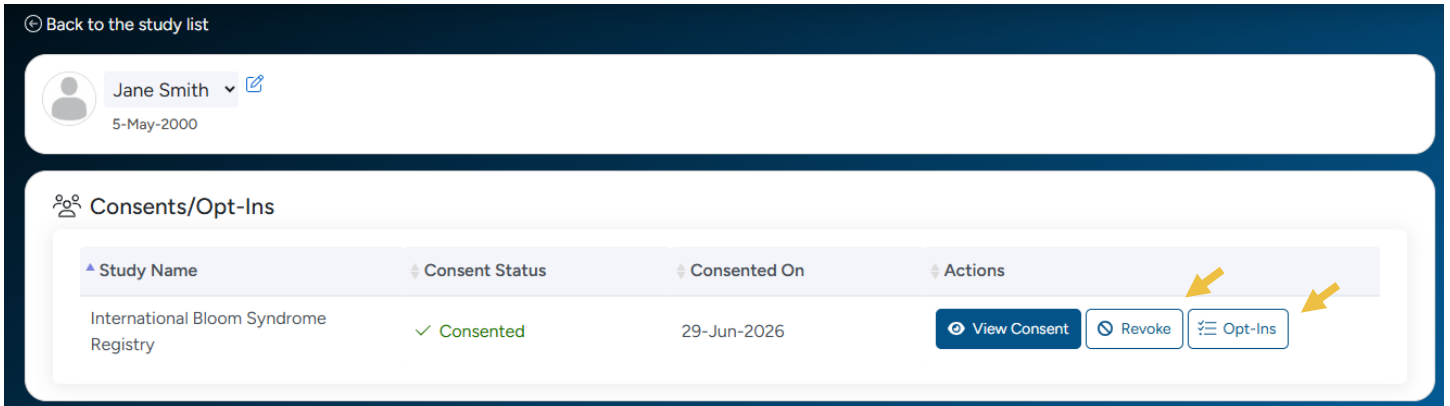


View Consent and Opt-Ins

- 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.



- Step 2: You may revoke your consent at any time by clicking “Revoke”. You may also edit your Opt-Ins by clicking “Opt-Ins”.

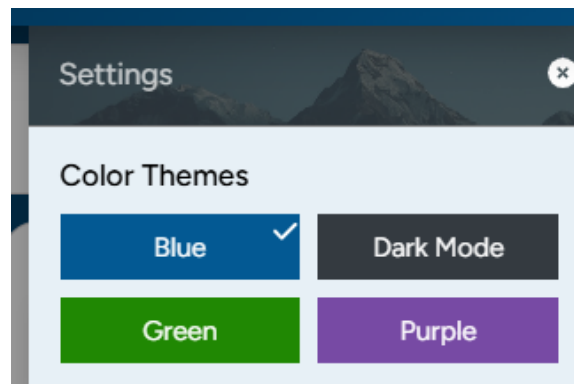


Dark Mode Settings

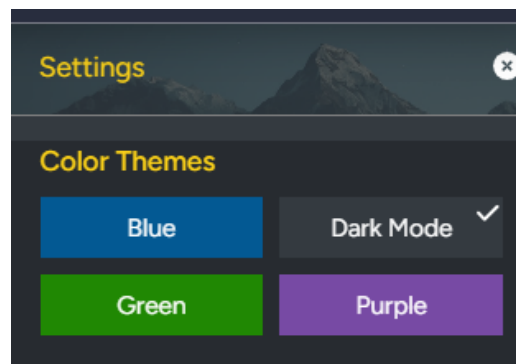
- Step 1: You can view the platform in Dark Mode. First, click Settings.



- Step 2: Select Dark Mode.



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

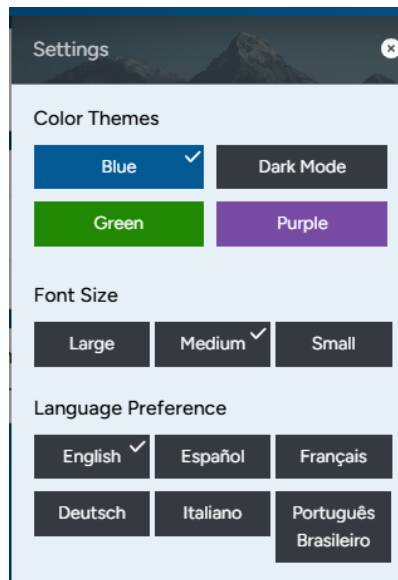


Display Settings

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



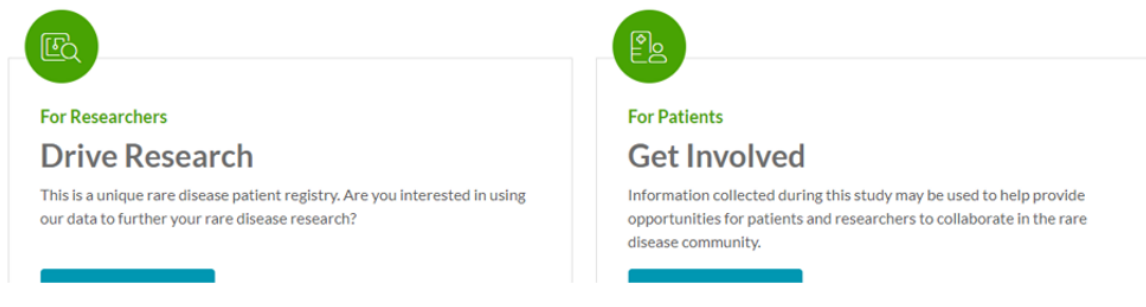
- Step 2: Select a color theme, a font size, or language preference. Note that the IBSR is currently only available in English.

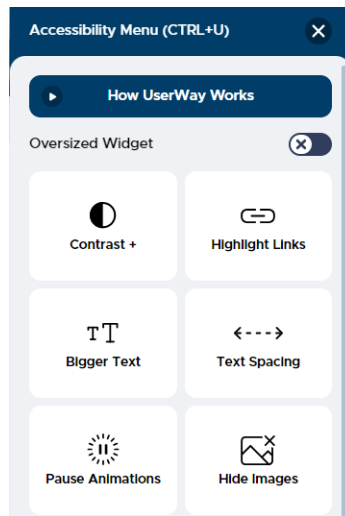


- Step 3: Exit the Settings menu, and your selection will be saved.

Microsite Visibility

- Step 1: You can change how you view the microsite (ibsr.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.





Need Assistance?

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

 A screenshot of a "Have a question?" form. At the top, there are "Home" and "Help" links. The form has a title bar with a close button. Below the title, there's a paragraph of 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 is a dropdown menu for "Inquiry Type" with the placeholder text "-- Select Inquiry Type --". Underneath is a text input field for "Message" with the placeholder text "Your message". At the bottom, there 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.

