




Participant User Guide

Register for an Account

- Step 1: Select the appropriate Account Type. If you need more information to help you choose, click “Not sure? Help me choose”.
 - If you have a diagnosis of Fanconi anemia select **Participant Account**.
 - If you are entering information for someone else who has Fanconi anemia, select **Caregiver Account**.
 - If you are entering information for a Fanconi anemia patient who has passed away, select **Caregiver Account**.

Featuring



Select Account Type

I have a rare disease, condition, and/or diagnosis.
Participant Account

I am a family member or guardian of someone with a rare disease.
Caregiver Account

[Return to login](#) [Not sure? Help me choose.](#)

- Step 2: Read the Terms and Conditions and Privacy Policy and attest to the statements provided. When you are finished with this page, click “Next”.

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Advancing Research. Supporting Families.

Participant Registration

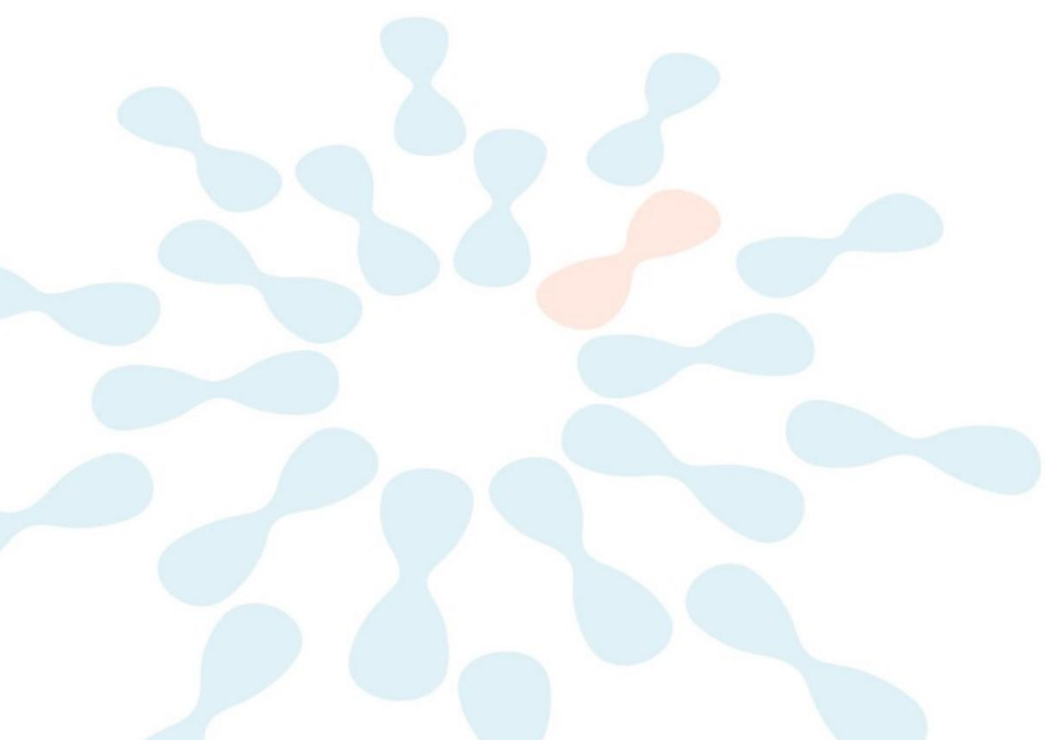
Terms & Conditions Contact Info Notifications Review & Submit Confirmation

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.


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



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Participant Registration

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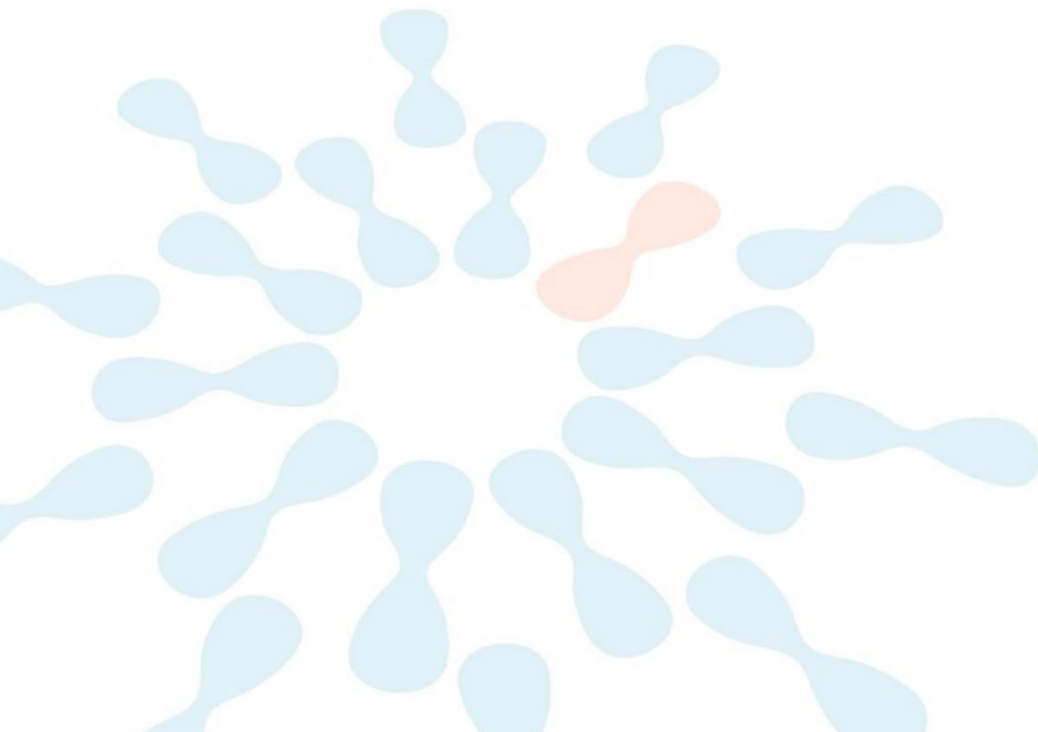
Country of Residence *
United States

First Name * Last Name *
Jane Smith


E-mail *
youremail@email.com

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

- Step 4: 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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Participant 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 5: Select “Next” so that an activation link is sent to your e-mail to complete registration.

Featuring



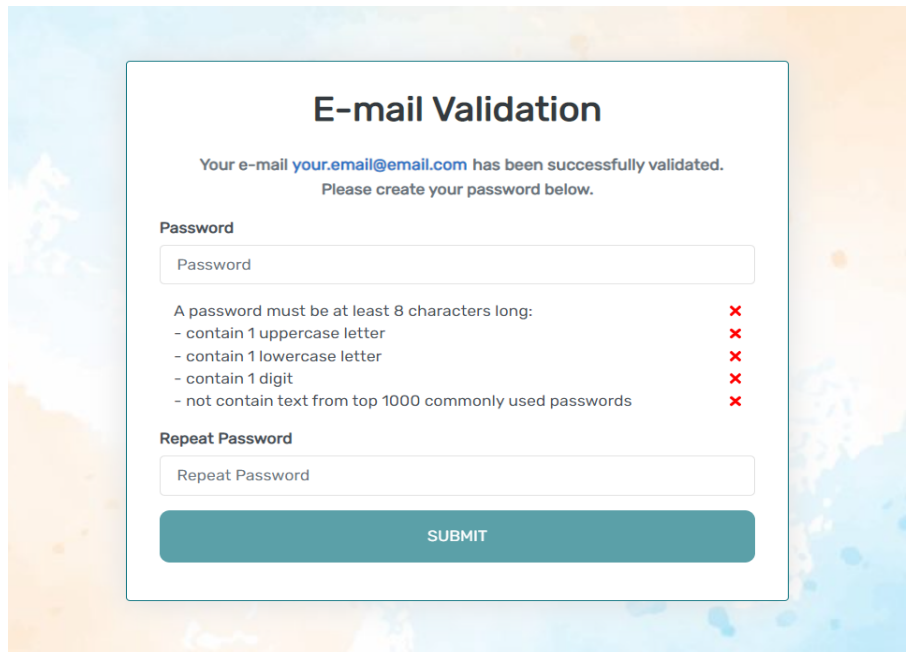
Participant Registration

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An activation link will be sent to your.email@email.com. Click “Next” to send this e-mail and continue.

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

- Step 6: 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.

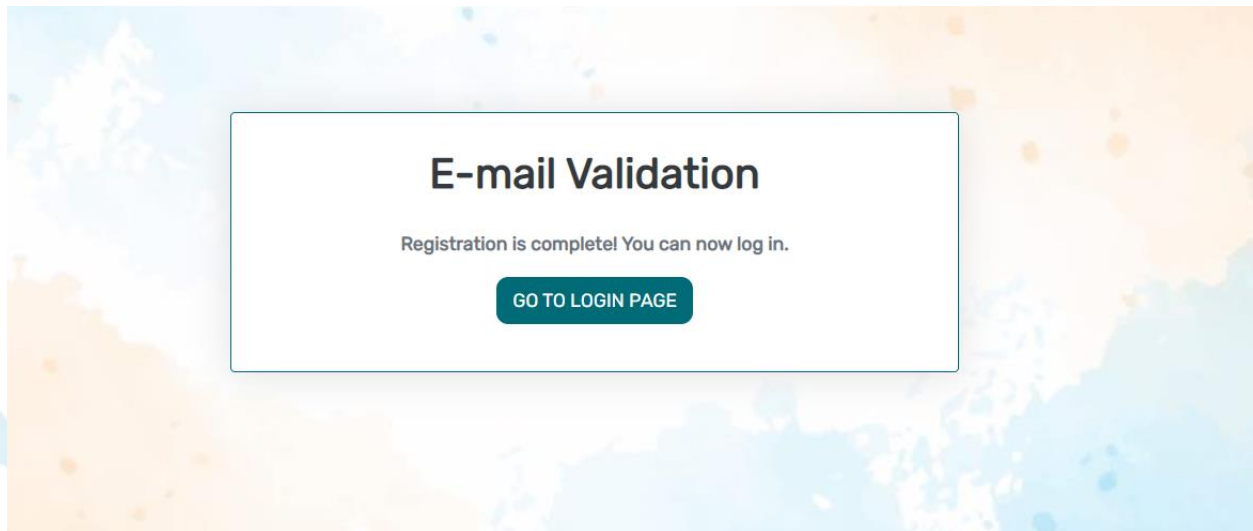
Password

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 7: 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 8: Log in using your new e-mail and password.

IAMRARE[®]

LOGIN

e-mail

password

Keep me logged in


➔ LOGIN

⚠️ Forgot Password

+ Create an Account

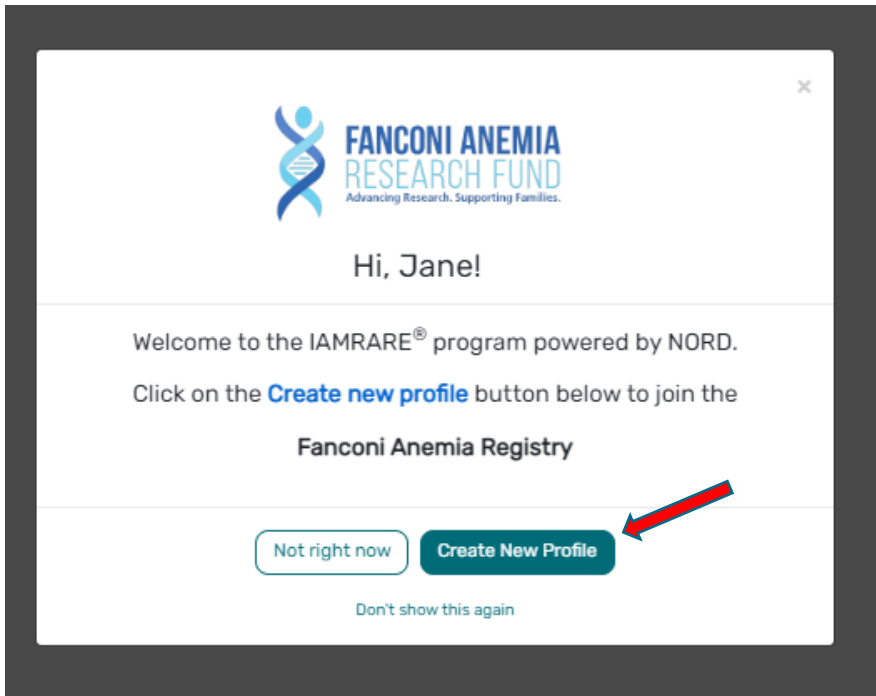
By logging in, you agree to NORD's [Privacy Policy](#) & [Terms and Conditions](#)

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Create Your Profile

- Step 1: To start, click Create New Profile

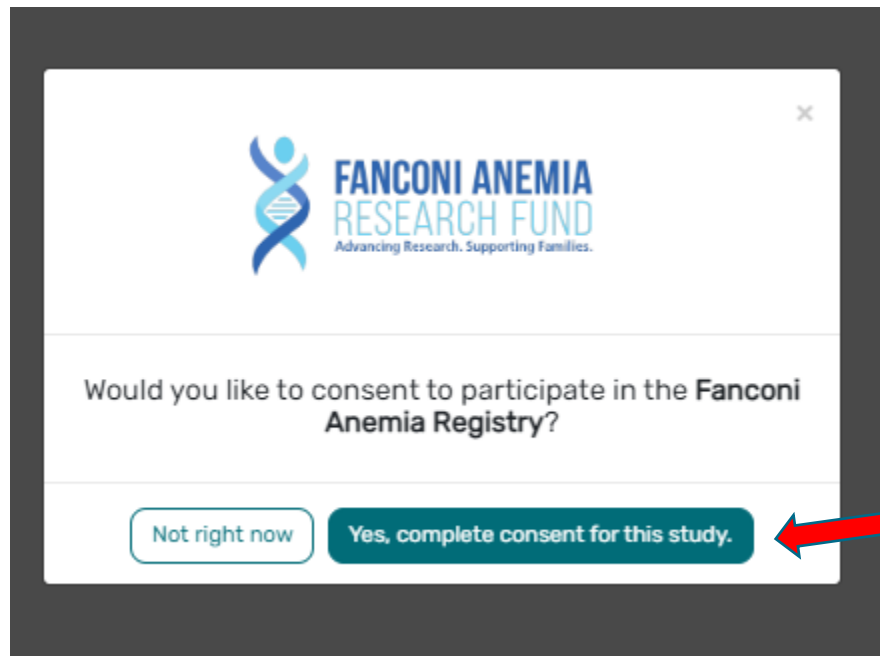


- Step 2: Fill out your information.

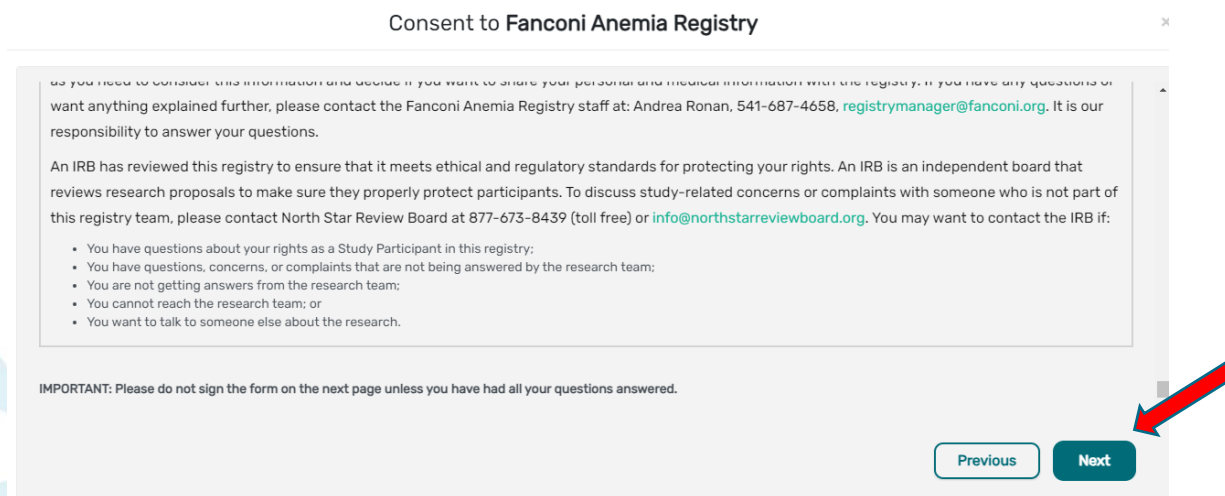
A screenshot of a web form titled 'Complete Participant Profile'. The form is organized into two columns. The left column contains: 'Preferred First Name' (text input with 'Jane'), 'First Name on Birth Certificate' (text input with 'First Name on Birth Certificate'), 'Last Name on Birth Certificate' (text input with 'Last Name on Birth Certificate'), 'Sex Recorded on Birth Certificate' (dropdown menu), 'Country of Residence' (dropdown menu with 'United States'), and 'Country of Birth' (dropdown menu with 'Choose country of birth'). The right column contains: 'Current Last Name' (text input with 'Smith'), 'Middle Name on Birth Certificate' (text input with 'Type NA if none'), 'Date of Birth' (calendar icon and text input with 'mm/dd/yyyy'), and 'State/Province/Region of Residence' (dropdown menu). Below these columns is the 'Profile Image' section, which has two options: 'Choose Avatar' (with a person icon) and 'Upload Your Own Image' (with a camera icon). Below the options, it says 'No image selected'. At the bottom of the form are two buttons: 'CANCEL' and 'SUBMIT'.

Consent to the Study

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



- Step 2: Scroll down and read through the consent form thoroughly. Once you finish reading, click Next.



- Step 3: 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 **Fanconi Anemia Registry** ×

about the Fanconi Anemia 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 information to the Fanconi Anemia Registry for the purposes described above under Study Aims.

I wish to provide my information to the Fanconi Anemia Registry for future research within recognized ethical standards for scientific research, as described under How We 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.

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

- Step 4: On the next screen, click Continue to Opt Ins.

Consent to **Fanconi Anemia 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.

[Previous](#) [Continue to Opt-Ins](#)


- Step 5: Select your opt ins, then click Save and Review.

Opt-Ins for Fanconi Anemia Registry ×

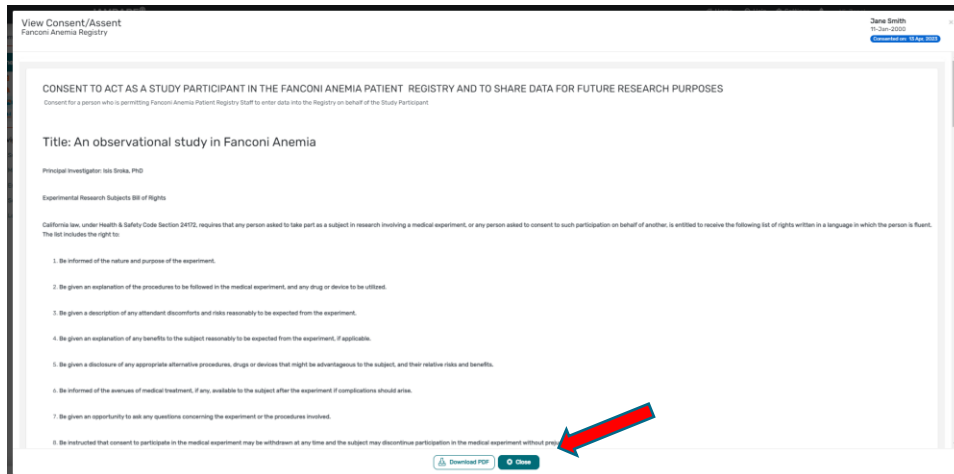
Select Opt-Ins for this study

Interest in hearing about clinical trials you may be eligible for

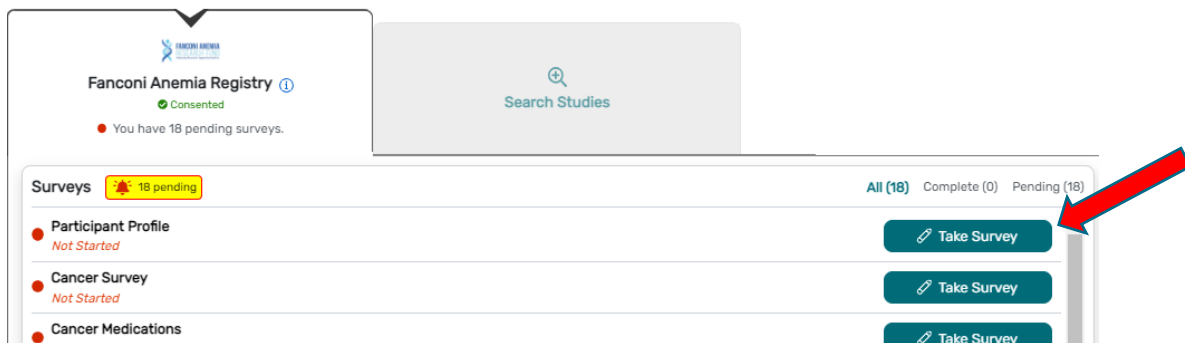
Interest in donating specimens or DNA (biobanking) for future research

[Save and Review](#) 

- Step 6: Download a copy of your consent, or click Close to continue.



- Step 7: You will now have access to start taking surveys.



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

