



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**.

🖉 RES	CONI ANEMIA EARCH FUND g Research. Supporting Families.		
Select Account Type			
l have a rare disease, condition, and/or diagnosis.	I am a family member or guardian of someone with a rare disease.		
Participant Account	Caregiver Account		
turn to login	Not sure? Help me cho		

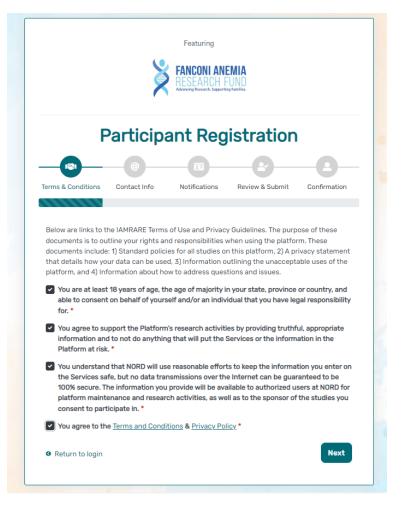
1779 MASSACHUSETTS AVENUE NW, SUITE 500 WASHINGTON, DC 20036 T 202-588-5700 • F 202-588-5701 T

55 KENOSIA AVENUE DANBURY, CT 06810 T 203-744-0100 • F 203-263-9938 1900 CROWN COLONY DRIVE, SUITE 310 QUINCY, MA 02169 T 617-249-7300 ■ F 617-249-7301

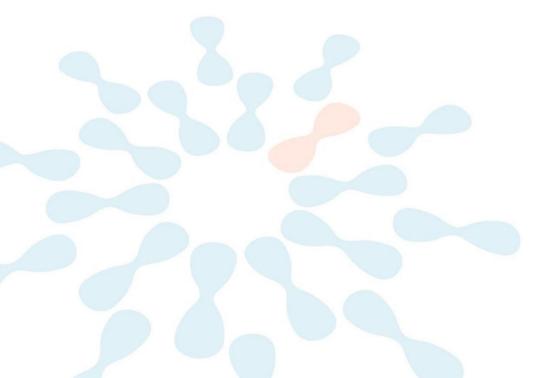
rarediseases.org orphan@rarediseases.org

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• 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".

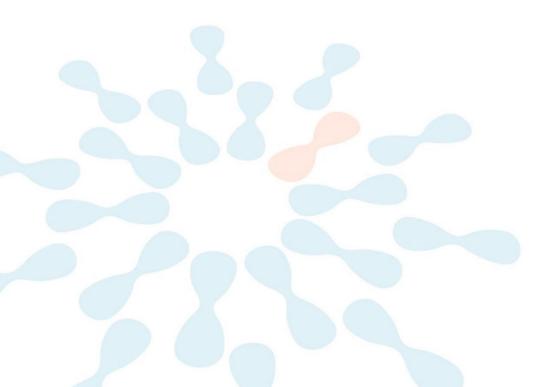


• Step 3: Enter your personal information in the spaces provided. When you are finished with this page, click "Next".



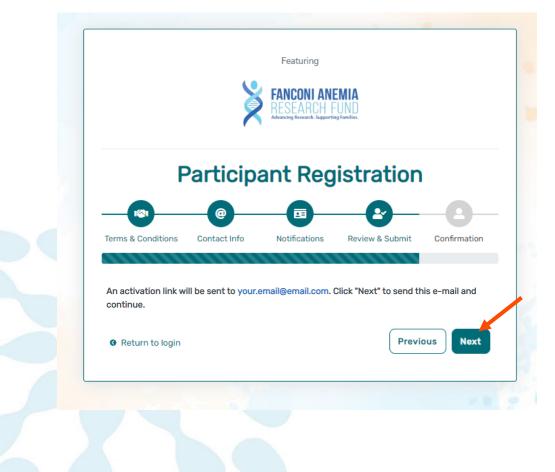
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• Step 4: Select whether you are interested in being contacted by NORD regarding available studies. When you are finished with this page, click "Next".



		FANCONI AN RESEARCH F Adrancing Research. Support	UND	
Participant Registration				
erms & Conditions	Contact Info	Notifications	Review & Submit	Confirmation
I am interested in N	IORD contacting m	ne regarding availal	ble studies. *	
● Yes ○ No				

• Step 5: Select "Next" so that an activation link is sent to your e-mail to complete registration.



• 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".

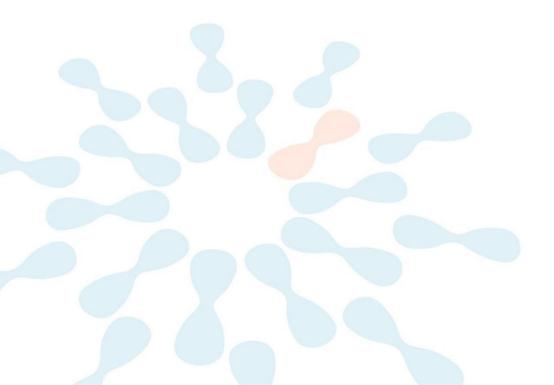
E-mail Validation	
Your e-mail your.email@email.com has been success Please create your password below.	fully validated.
assword	
Password	
A password must be at least 8 characters long:	×
- contain 1 uppercase letter	×
- contain 1 lowercase letter	×
- contain 1 digit - not contain text from top 1000 commonly used passwor	ds ×
apeat Password	
Repeat Password	
SUBMIT	

• Step 7: Your validation is now complete. Select "Go to Login Page".

	E-mail Validation	
7	Registration is complete! You can now log in.	
	GO TO LOGIN PAGE	Con S
		-

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

IA	
e-mail	
password	
Keep me logged in	
	→) LOGIN
▲ Forgot Password	→ LOGIN + Create an Account
Forgot Password	+ Create an Account



Create Your Profile

• Step 1: To start, click Create New Profile

FANCONI ANEMIA RESEARCH FUND Advancing Research. Supporting Families. Hi, Jane!	×
Welcome to the IAMRARE [®] program powered by NORD. Click on the Create new profile button below to join the Fanconi Anemia Registry	
Not right now Create New Profile Don't show this again	

• Step 2: Fill out your information.

Preferred First Name *	Current Last Name *	
Jane	Smith	
First Name on Birth Certificate *	Middle Name on Birth Certif	ficate *
First Name on Birth Certificate	Type 'NA' if none	
Last Name on Birth Certificate *	Date of Birth *	
Last Name on Birth Certificate	mm/dd/yyyy	
	State/Province/Region of F	Residence •
United States	×	Residence *
United States		Residence •
Country of Residence • United States Country of Birth • Choose country of birth	×	~

Consent to the Study

• Step 1: Click on "Yes, complete consent for this study."

FANCONI ANEMIA RESEARCH FUND Advancing Research. Supporting Families.	
Would you like to consent to participate in the Fanconi Anemia Registry?	
Not right now Yes, complete consent for this study.	

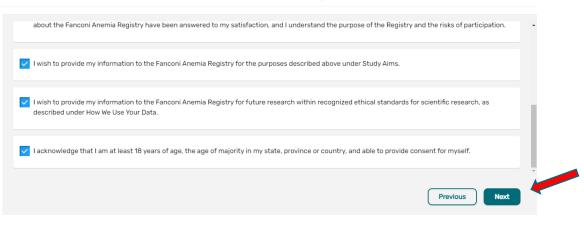
• Step 2: Scroll down and read through the consent form thoroughly. Once you finish reading, click Next.

Consent to Fanconi Anemia Registry

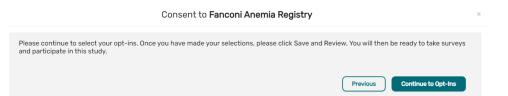
 responsibility to answer your questions. An IRB has reviewed this registry to ensure that it meets ethical and regulatory standards for protecting your rights. An IRB is an independent board that reviews research proposals to make sure they properly protect participants. To discuss study-related concerns or complaints with someone who is not part of this registry team, please contact North Star Review Board at 877-673-8439 (toll free) or info@northstarreviewboard.org. You may want to contact the IRB if: You have questions about your rights as a Study Participant in this registry; You are questions, concerns, or complaints that are not being answered by the research team; You are not getting answers from the research team; or You cannot reach the research team; or You want to talk to someone else about the research. 	An IRB has reviewed this registry to ensure that it meets ethical and regulatory standards for protecting your rights. An IRB is an independent board that reviews research proposals to make sure they properly protect participants. To discuss study-related concerns or complaints with someone who is not part of this registry team, please contact North Star Review Board at 877-673-8439 (toll free) or info@northstarreviewboard.org. You may want to contact the IRB if: • You have questions about your rights as a Study Participant in this registry: • You have questions, concerns, or compalinst that are not being answered by the research team: • You are not getting answers from the research team; • You cannot reach the research team; or • You want to talk to someone else about the research.	An IRB has reviewed this registry to ensure that it meets ethical and regulatory standards for protecting your rights. An IRB is an independent board that reviews research proposals to make sure they properly protect participants. To discuss study-related concerns or complaints with someone who is not part of this registry team, please contact North Star Review Board at 877-673-8439 (toll free) or info@northstarreviewboard.org. You may want to contact the IRB if: You have questions, concerns, or complaints that are not being answered by the research team: You have questing answers from the research team; You cannot reach the research team; or You want to talk to someone else about the research.	as you need to consider this monimator and decide in you want to share you personal and meaned informator want t want anything explained further, please contact the Fanconi Anemia Registry staff at: Andrea Ronan, 541–687-4658, Income and the second statement of the second statement of the second statement of the second statement of the	ö , , , , , , , , , , , , , , , , , , ,
 You have questions about your rights as a Study Participant in this registry; You have questions, concerns, or complaints that are not being answered by the research team; You are not getting answers from the research team; You cannot reach the research team; or 	 You have questions about your rights as a Study Participant in this registry; You have questions, concerns, or complaints that are not being answered by the research team; You are not getting answers from the research team; You cannot reach the research team; or You want to talk to someone else about the research. 	 You have questions about your rights as a Study Participant in this registry: You have questions, concerns, or complaints that are not being answered by the research team: You cannot reach the research team; or You want to talk to someone else about the research. 	An IRB has reviewed this registry to ensure that it meets ethical and regulatory standards for protecting your rights. A reviews research proposals to make sure they properly protect participants. To discuss study-related concerns or con	plaints with someone who is not part of
	MPORTANT: Please do not sign the form on the next page unless you have had all your questions answered.		 You have questions about your rights as a Study Participant in this registry; You have questions, concerns, or complaints that are not being answered by the research team; You are not getting answers from the research team; You cannot reach the research team; or 	rg. You may want to contact the IRB if:

• 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

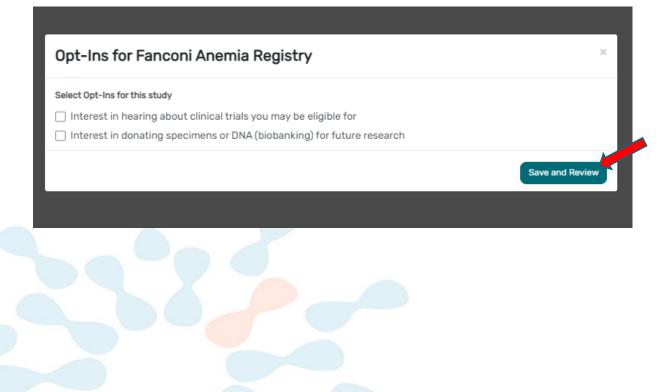
Consent to Fanconi Anemia Registry



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



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



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

	View Consent/Assent Fancon Anema Repstry	Jane Smith × 11-Jan-2000 Conserted on: 13 Apr. 2003
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Be given a disclosure of any appropriate admenting procedures, drags or devices that night in advantagement in the subject, and their risks and bareaffex be advanted of the annexes of medical headers, if any subsides to the subject after the experiment of complications advast atmas. To adjuste an appropriately to ask any subsides increasing the appointent of the procedures.	3. Be given a description of any attendant decomforts and mixer reasonably to be expected from the experiment.	
 c the informed of the announce of medical trustment, if any annihile to the adjust after the experiment if complications about arise. 7 the given an approximative to ask any specificant scenarios (the approximative about arise). 	4. Be given an explanation of any banefits to the subject reasonably to be expected from the experiment, if applicable.	
7. Be given an experimenty to ask any quantizers scinnering the experiment on the procedures involved.	5 the given a discissor of any appropriate attenuitive procedures, drugs or devices that might be advantageous to the subject, and their relative risks and benefits.	
	4. Be informed of the services of medical institution, if any, available to the subject after the experiment if complications should arise.	
8. Be instructed that consent to participate in the medical experiment may be withdress at any time and the subject may discontinue participation in the medical experiment without prov	7. Be given an opportunity to set any questions concerning the experiment or the procedures involved.	
(A. Download POT) O Chee		

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

© Consented • You have 18 pending surveys.	€ Search Studies	
Surveys : 18 pending		All (18) Complete (0) Pending (18)
Participant Profile Not Started		🖉 Take Survey
Cancer Survey Not Started		🖉 Take Survey
Cancer Medications		A 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

Fanconi Anemia Registry () © Consented • You have 17 pending surveys.	€ Search Studies	
Surveys 17 pending Participant Profile Completed on 13-Apr-2023		All (18) Complete (1) Pen View Responses Reports