



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”.
 - o If you have a diagnosis of PKU, select **Participant Account**.
 - o If you are entering information for someone else who has PKU or you have PKU and are also entering information for yourself, select **Caregiver Account**.
 - o If you are entering information for a PKU 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”.

Featuring

NPKUA

national PKU alliance

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

The screenshot shows the 'Caregiver Registration' form for the NPKUA (national PKU alliance). The form is titled 'Caregiver Registration' and features a progress bar with five steps: Terms & Conditions, Contact Info, Notifications, Review & Submit, and Confirmation. The 'Contact Info' step is currently active, indicated by a teal bar under the progress bar. The form fields include: 'Country of Residence' (a dropdown menu showing 'United States'), 'First Name' (a text box with 'Jane'), 'Last Name' (a text box with 'Doe'), and 'E-mail' (a text box with 'jane@email.com'). At the bottom, there is a 'Return to login' link and two buttons: 'Previous' and 'Next'.

Featuring
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national PKU alliance

Caregiver Registration

Terms & Conditions Contact Info Notifications Review & Submit Confirmation

Country of Residence *

United States

First Name * Last Name *

Jane Doe

E-mail *

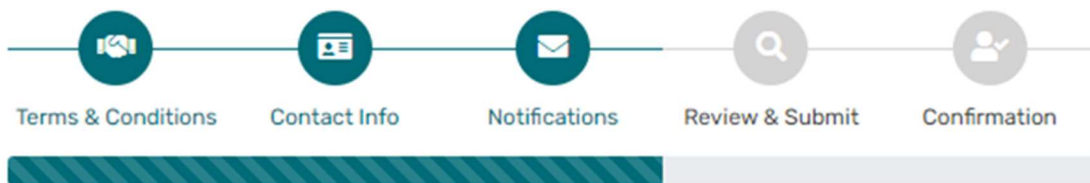
jane@email.com

[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”.



Caregiver Registration



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.



Caregiver Registration



An activation link will be sent to
mail and continue.

Click "Next" to send this e-

[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 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".

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.

Featuring
NPKUA
national PKU alliance

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

Add a Participant

- Step 1: To start, click Yes, register new participant.



Welcome to the IAMRARE® program, home of PKU Patient Registry!

Would you like to register a participant to join PKU Patient Registry?

[Not right now](#) [Yes, register new participant](#)

[Don't show this again](#)

- Step 2: Fill out the Participant's information.

Program powered by NORD. To get started, please click on the Add Participant button to add a new participant.

Add Participant

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 * ⓘ

Sex Recorded on Birth Certificate * ⓘ

Country of Residence * ⓘ

State/Province/Region of Residence * ⓘ

Country of Birth *

City/Municipality of Birth *

What Is Your Relationship to ? * ⓘ

Profile Image

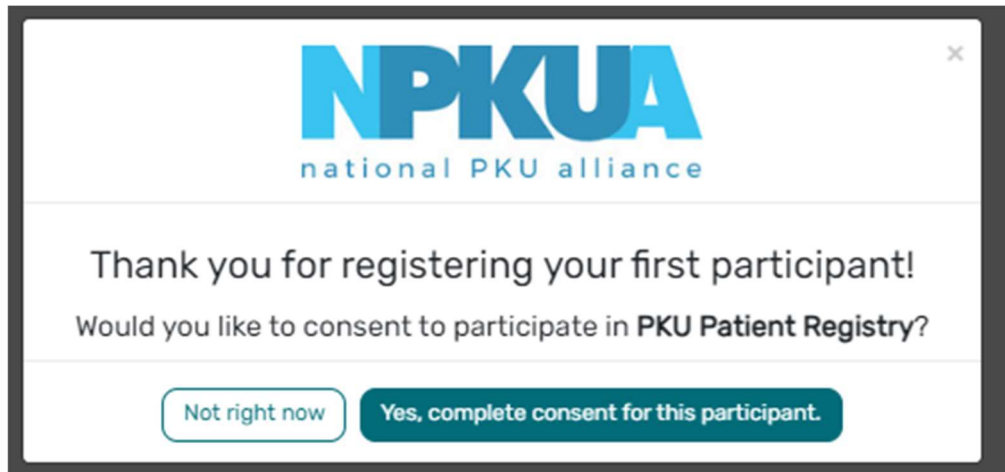
OR

No image selected

[CANCEL](#) [SUBMIT](#)

Consent to the Study

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



- Step 2: Read through the consent overview and answer any questions (for caregiver account only).

Consent to NORD Core

Consent Overview

Those eligible to participate in our study include:

Participant: An individual diagnosed with Rare Disease 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 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 Rare Disease, defined as a spouse, parent, sibling, offspring, close relative, close friend, guardian and/or significant other of the individual who had Rare Disease 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.

 **Next**

- Step 3: Scroll down and read through the consent form thoroughly. Once you finish reading, click the “Next” button.

Consent to NORD Core

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For persons who are residents of the European Union and Switzerland, transfers of your personal information outside of the European Union and/or Switzerland, if any, will be undertaken in compliance with the General Data Protection Regulation under an appropriate transfer mechanism provided for by the General Data Protection Regulation, including the use of standard data protection clauses adopted by the European Commission. Please be aware that, under the General Data Protection Regulation, the European Commission is permitted to issue a decision that the data protection laws of a third country are adequate to the protection of personal information and that, to date, the European Commission has not done so with respect to the United States.

For persons who are residents of the European Union and Switzerland, processing of personal information will also be undertaken in such a manner as to ensure the rights of data subjects provided for by the General Data Protection Regulation. Specifically, Registry participants who are residents of the European Union and Switzerland are entitled to:

- Request to obtain access to and rectification or erasure of personal data;
- To receive personal data in a portable, readily-accessible format;
- To restrict or withdraw permission for the processing of personal information;
- To lodge a complaint with an appropriate supervisory authority.

Please note that the rights to erase personal data or restrict or withdraw permission for the processing of personal information are subject to limitations provided for by Article 17 of the General Data Protection Regulation, namely, that such rights may be limited as necessary to protect the public interest in the area of public health or for archiving purposes in the public and scientific interest.

Getting Answers to Your Questions about the Registry

We have used some technical terms in this form and talked about issues in research and data sharing with which you may not have been familiar. Take as long as you need or want to consider what was presented here and whether you want to share your personal and medical information with the Registry. If you have any questions or want anything explained further, please contact the Registry Staff at: [Name and contact information]. It is our responsibility to answer your questions.

An Institutional Review Board (IRB) has reviewed this Registry to ensure that it meets ethical and regulatory standards for protecting your rights. An IRB is an independent group that reviews research proposals to make sure they properly protect participants. For questions about those protections and your rights as a Study Participant in this Registry, or to discuss other 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 are not getting answers from the research team.
- You cannot reach the research team.
- You want to talk to someone else about the research.
- You have questions about your rights as a research subject.

IMPORTANT: Please do not sign the form on the next page unless you have had all your questions answered.

Next

- Step 4: Once you click “Next” and 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 “Complete.”

Consent to NORD Core

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Authorization

The following statements are intended to ensure 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. You will be asked to acknowledge that you have:

- Read the consent form and have no further questions about the Registry and your participation
- That you wish to provide personal data to the registry for the purposes of the Study
- And that you wish to provide your pseudonymized data for future research

This is a web-based form and by answering Yes to all of the following statements, you are giving your consent to participate in the **NORD Core**, just as if you had signed your name to a paper document. After signing, a copy of the consent form will be emailed to you.

If you cannot comfortably answer “Yes” to these three statements and you have no further questions, please do not check the boxes below:

☒ I have read (or someone has read to me) 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 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 NORD Core for the purposes described above under Study Aims.

☒ I wish to provide my research data that has been pseudonymized to the NORD Core for future research within recognized ethical standards for scientific research, as described under How We Use Your Data.

Previous

Complete

- Step 5: Click Continue to Opt-ins.

Consent to |

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 6: Select your Opt-ins and click Save and Review.

Opt-Ins for

Select Opt-Ins for this study

☐ Interest in hearing about other studies from |

☐ Interest in hearing about relevant clinical trials

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

Save and Review

- Step 7: Download a copy of your consent or click Close.

View Consent/Assent

Review consent: Fa

John NORD
15 Jan 2025
Consented on: 1 Jan 2025

Phone: 541-687-4458

Email: |

Sponsor:

Key Information

You are invited to take part in a research study for individuals with Fanconi anemia on behalf of the person with Fanconi anemia in your care. We hope that this form will help you decide whether to participate, but you can also call or e-mail the study staff using the contact information above if you have any other questions.

Things you should know:

We are doing this research to gain a better understanding of individuals with Fanconi anemia, facilitate the development of best practice guidelines and recommendations to optimize care, and support clinical trial recruitment. If you choose to participate on behalf of the participant, you will be asked to provide the participant's personal and medical information in an online questionnaire format by answering surveys and uploading medical information. The information you will be asked to provide includes demographics, medical history, laboratory reports, the participant's experience with living with FA, and cancer screening, diagnosis, and treatment. It will take approximately 30 minutes to complete all surveys. It is not a requirement to complete all surveys in one sitting; you have the option to save your progress and return to finish the surveys at a later time.

You may experience the following risks, discomforts, or inconveniences from participating. Putting the participant's data in the registry does not put you or the participant at any risk of physical harm. As with any information you provide electronically, there is a risk that the participant's privacy could be compromised if their data is inappropriately disclosed or misused. The registry is designed to make the chance of this happening very small.

Participating in our study may not help the Study Participant directly, but your time and information may help others with Fanconi anemia in the future. There are no direct benefits associated with participation in the Fanconi Anemia Registry.

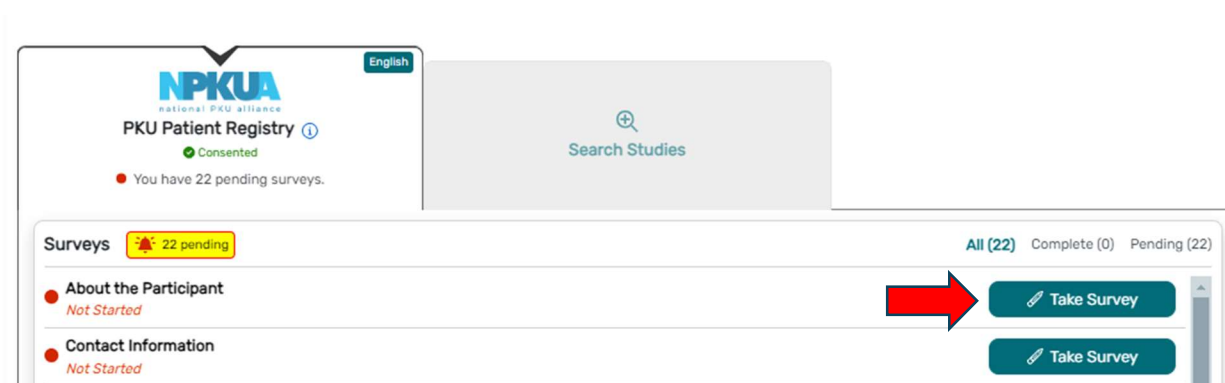
It is up to you whether to participate in this study, and you can stop at any time. Please take time to read this entire form and ask questions before deciding whether to take part in this research project on behalf of the person with Fanconi anemia in your care. As the guardian or legally authorized representative for the Study Participant, we encourage you to discuss the registry with the Study Participant to the extent compatible with their understanding. Detailed information about your participation in this study follows.

Purpose of this Informed Consent Document

This document will give you information about the Fanconi Anemia Registry so you can decide if you want to join this study on behalf of the participant or not. This consent document is structured to follow the framework provided

Download PDF Close

- Step 8: 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.

