




The GFPD Patient Registry for Peroxisomal Disorders 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”.

Featuring




GLOBAL
FOUNDATION
•for•
PEROXISOMAL
DISORDERS


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. *

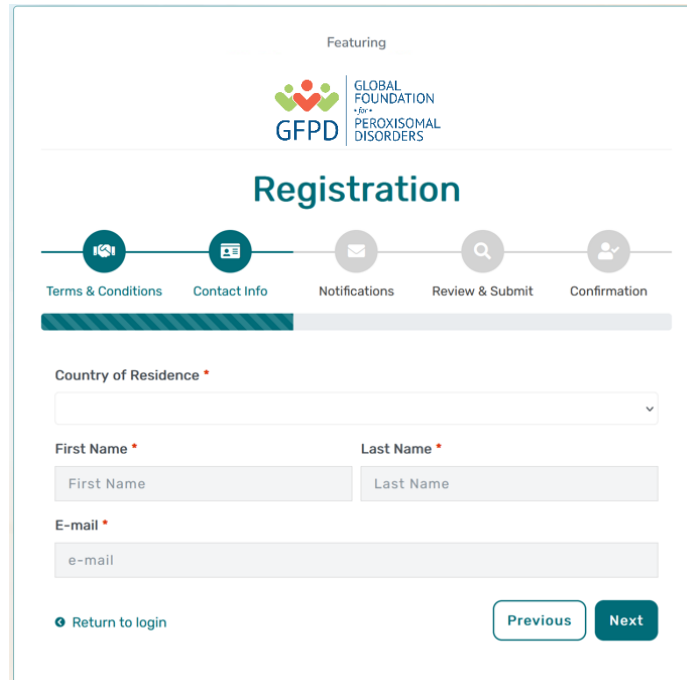
☐

You agree to the [Terms and Conditions & Privacy Policy](#) *


☐ Return to login

Next

- Step 2: Enter your personal information in the spaces provided. When you are finished with this page, click “Next”.



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Registration

Terms & Conditions Contact Info Notifications Review & Submit Confirmation

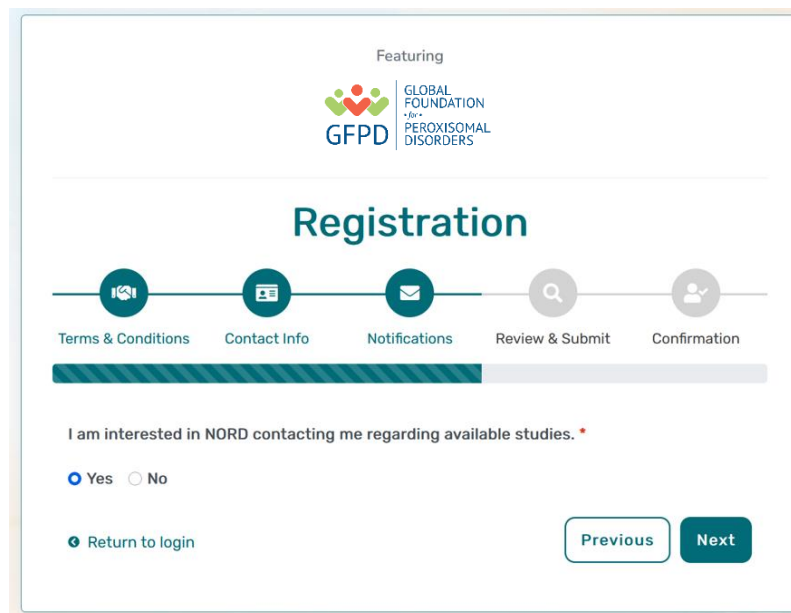
Country of Residence *

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”.



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Registration

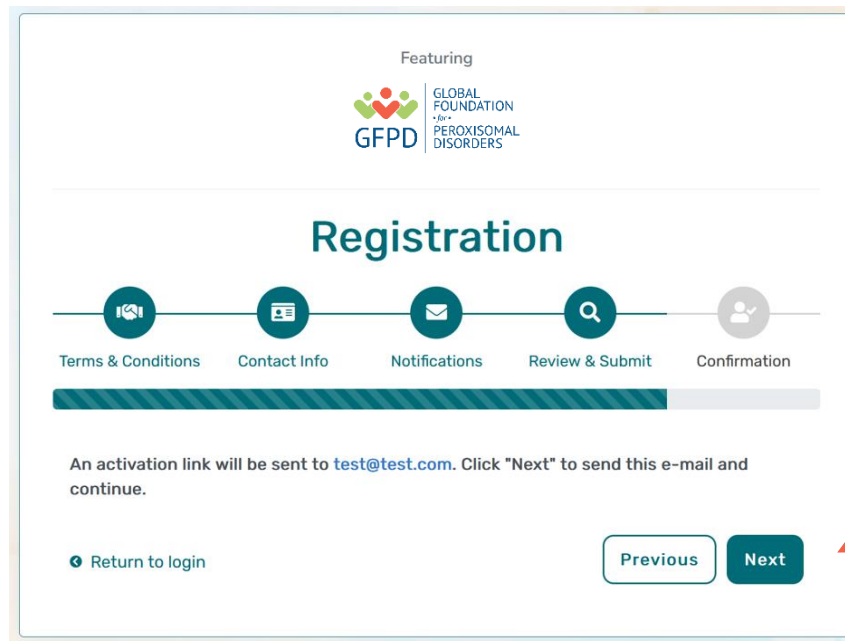
Terms & Conditions Contact Info Notifications Review & Submit Confirmation

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

☒ Yes ☐ No

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

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



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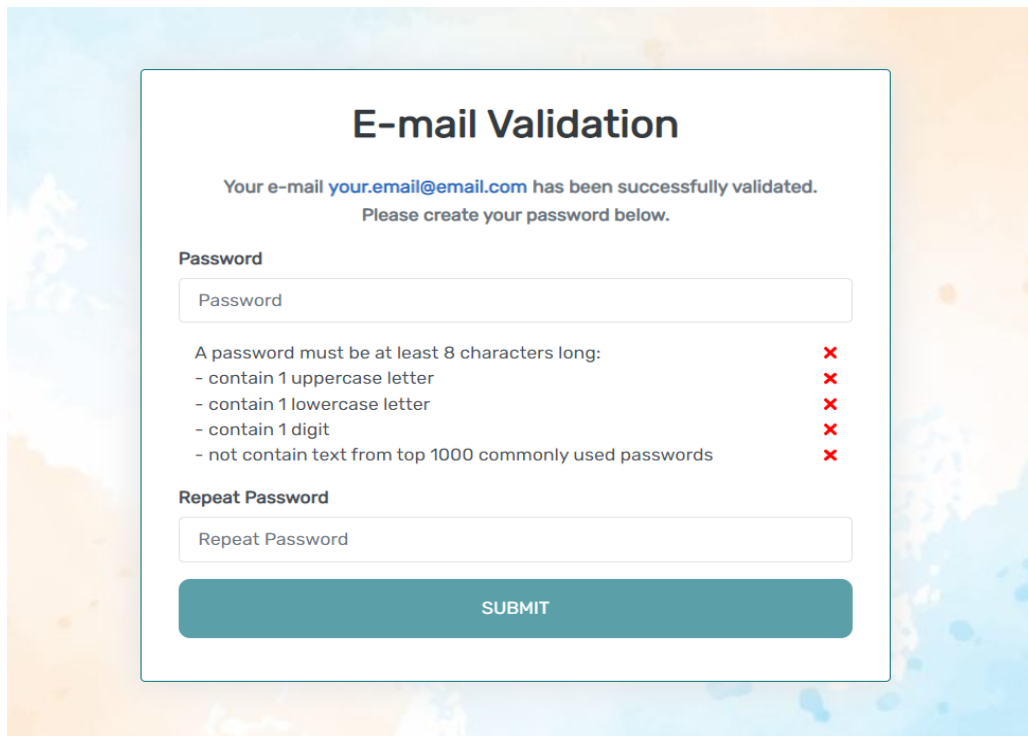
Registration

Terms & Conditions Contact Info Notifications Review & Submit Confirmation

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

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

- 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.

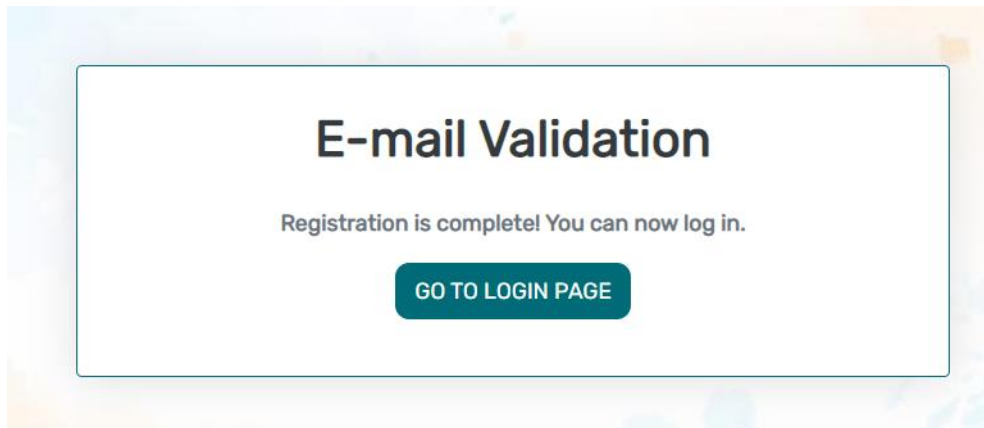
Password

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 ✗

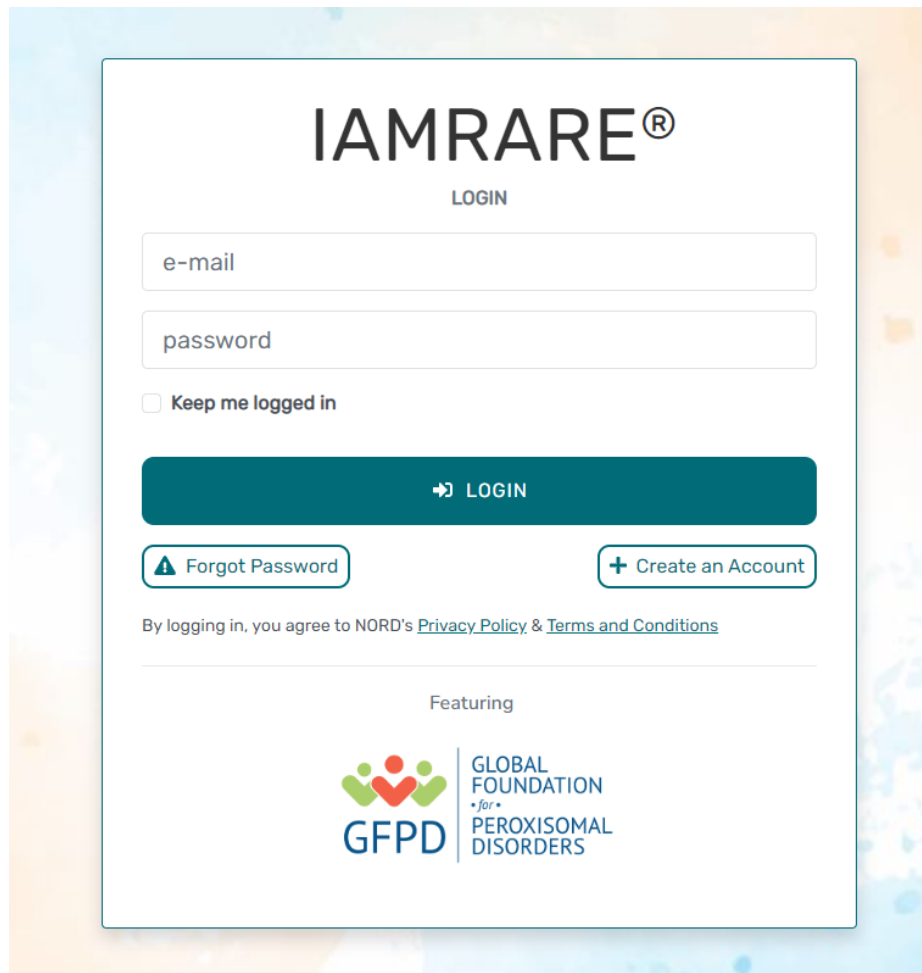
Repeat Password

[SUBMIT](#)

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

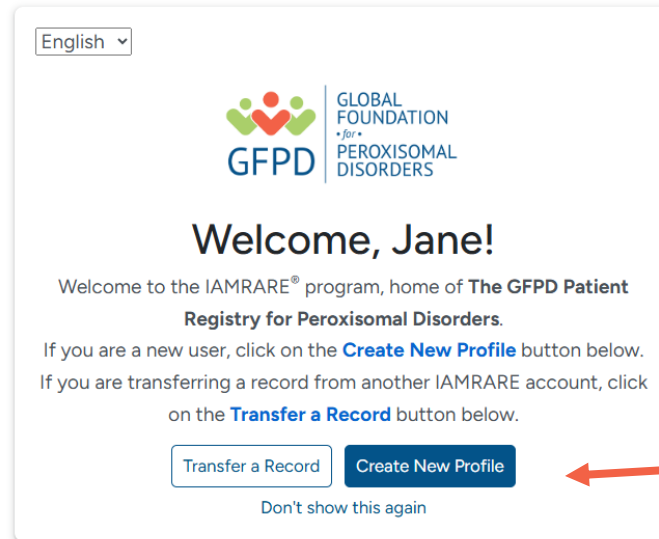


- Step 7: Log in using your new e-mail and password.




Add a Participant

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



English ▾

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Welcome, Jane!

Welcome to the IAMRARE® program, home of **The GFD Patient Registry for Peroxisomal Disorders**.

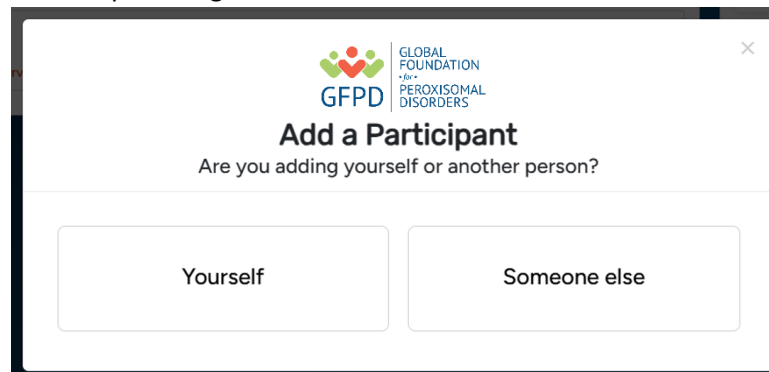
If you are a new user, click on the [Create New Profile](#) button below.


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.



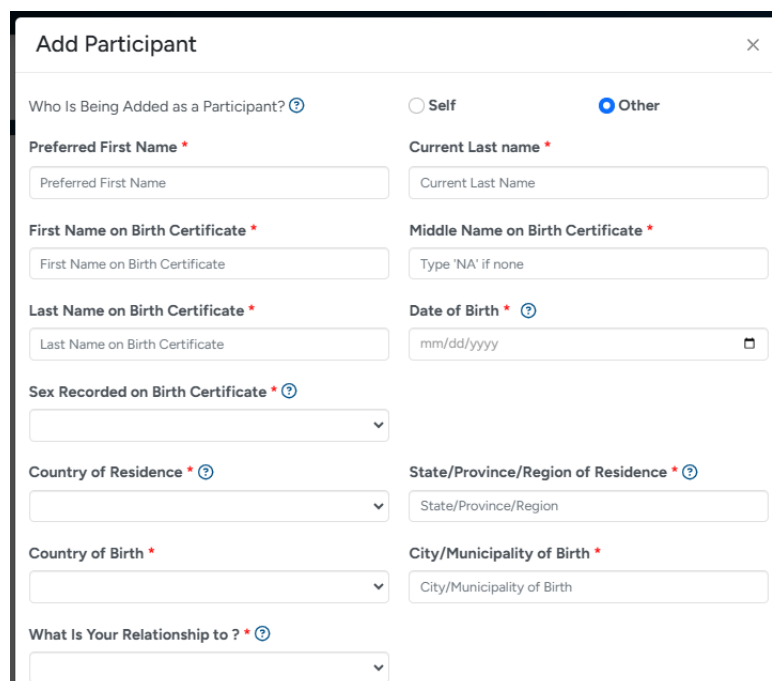
 GLOBAL FOUNDATION
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PEROXISOMAL DISORDERS

Add a Participant

Are you adding yourself or another person?

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

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



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 * ⓘ

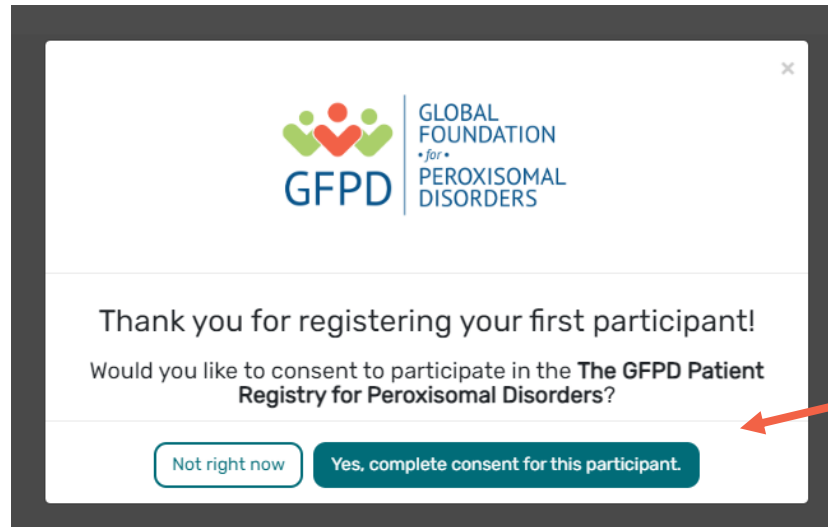
Country of Birth *

City/Municipality of Birth *

What Is Your Relationship to ? * ⓘ

Consent to the Study

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



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DISORDERS


GFPD

Thank you for registering your first participant!

Would you like to consent to participate in the **The GFPD Patient Registry for Peroxisomal Disorders?**

Not right now Yes, complete consent for this participant.

- 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 **The GFPD Patient Registry for Peroxisomal Disorders**

Consent Overview

Those eligible to participate in our study include:

Participant: An individual diagnosed with a peroxisomal 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 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.

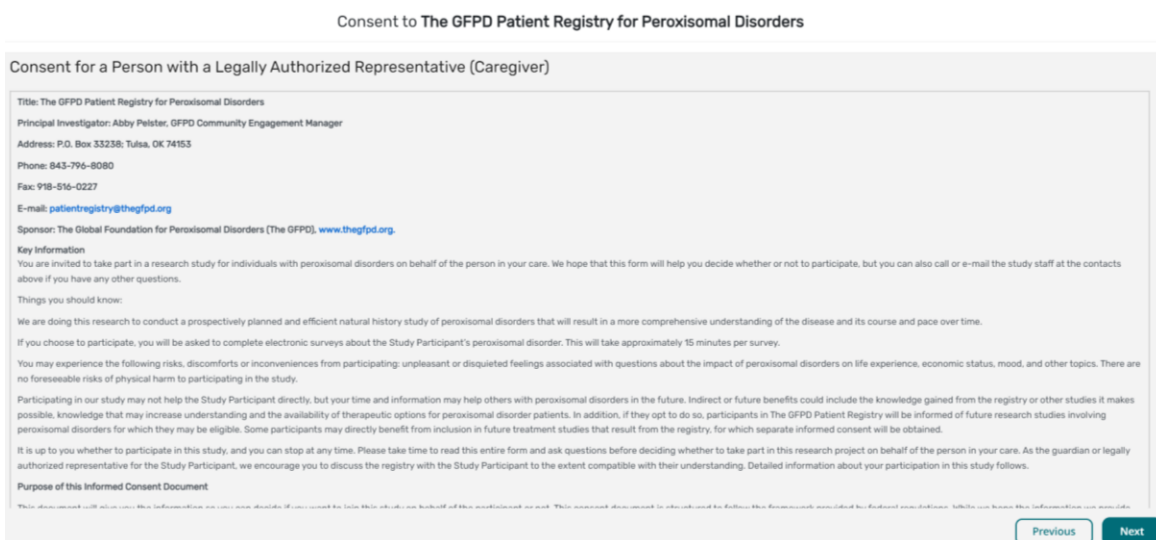
Designated Representative: A legal adult who was the caretaker of an individual who passed away from a peroxisomal disorder, defined as a spouse, parent, sibling, offspring, close relative, close friend, guardian and/or significant other of the individual who had a peroxisomal disorder and who had knowledge 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 a peroxisomal disorder. I participated in their medical care.

Next



Consent to **The GFPD Patient Registry for Peroxisomal Disorders**

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

Title: The GFPD Patient Registry for Peroxisomal Disorders

Principal Investigator: Abby Pelster, GFPD Community Engagement Manager

Address: P.O. Box 33238; Tulsa, OK 74153

Phone: 843-796-8080

Fax: 918-516-0227

E-mail: patientregistry@thegfpd.org

Sponsor: The Global Foundation for Peroxisomal Disorders (The GFPD), www.thegfpd.org.

Key Information

You are invited to take part in a research study for individuals with peroxisomal 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 conduct a prospectively planned and efficient natural history study of peroxisomal disorders that will result in a more comprehensive understanding of the disease and its course and pace over time.

If you choose to participate, you will be asked to complete electronic surveys about the Study Participant's peroxisomal disorder. This will take approximately 15 minutes per survey.

You may experience the following risks, discomforts or inconveniences from participating: unpleasant or disquieted feelings associated with questions about the impact of peroxisomal disorders on life experience, economic status, mood, and other topics. There are no foreseeable risks of physical harm to participating in the study.

Participating in our study may not help the Study Participant directly, but your time and information may help others with peroxisomal disorders in the future. Indirect or future benefits could include the knowledge gained from the registry or other studies it makes possible, knowledge that may increase understanding and the availability of therapeutic options for peroxisomal disorder patients. In addition, if they opt to do so, participants in The GFPD Patient Registry will be informed of future research studies involving peroxisomal disorders for which they may be eligible. Some participants may directly benefit from inclusion in future treatment studies that result from the registry, for which separate informed consent will be obtained.

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 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 allow you to make informed decisions about whether to take part in this study on behalf of the individual in your care. This document also serves to inform you of the risks, benefits, and procedures associated with your participation in this study.

Previous Next

Consent to The GFPD Patient Registry for Peroxisomal Disorders

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 GFPD Patient Registry for Peroxisomal Disorders 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 GFPD Patient Registry for Peroxisomal Disorders 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 GFPD Patient Registry for Peroxisomal Disorders for the purposes described above under Study Aims.

☒ I wish to provide the Study Participant's research data to The GFPD Patient Registry for Peroxisomal Disorders for future research within recognized ethical standards for scientific research, as described under How We Use Your Data.

Previous

Next

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

Consent to The GFPD Patient Registry for Peroxisomal Disorders

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 The GFPD Patient Registry for Peroxisomal Disorders

Select Opt-Ins for this study

- ☐ Interest in hearing about other studies from [Global Foundation for Peroxisomal Disorders](#)
- ☐ Interest in hearing about clinical trials you may be eligible for
- ☐ Interest in donating specimens or DNA (biobanking) for future research
- ☐ Interest in genetic testing
- ☐ Interest in learning more about [Global Foundation for Peroxisomal Disorders](#)
- ☐ Interest in signing up for [Global Foundation for Peroxisomal Disorders's](#) newsletter
- ☐ Support from [Global Foundation for Peroxisomal Disorders](#) Ambassador / Care Coordinator

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 on your Participant.

The screenshot shows the IAMRARE® dashboard. At the top, there's a navigation bar with 'Home', 'Help', 'Settings', and a user greeting 'Hi, Jane!'. Below this, a 'Good Morning, Jane!' banner includes a '+ Add Participant' button. The main section is titled 'Participants' and contains a list of participants. The first participant is 'Jane Smith', with a date '5-May-2020' and a status '7 pending surveys'. A red arrow points to the 'Add Participant' button in the top right corner.

- Step 2: Click on the appropriate study.

This screenshot shows the 'Enrolled Studies' section for Jane Smith. It includes a 'Search Studies' button and a list of studies. The first study is 'The GFPD Patient Registry for Peroxisomal Disorders', which is marked as 'Consented' and has '1 pending surveys'. A red arrow points to this study card.

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

This screenshot shows the 'Getting Started' survey progress for Jane Smith. It displays a progress bar at 0% and a 'Take Survey' button. A red arrow points to this button.

View Responses

- Step 1: Once you have submitted a survey, you are able to view your responses to that survey. Click “View Responses” to see your completed survey.

The screenshot shows the 'View Responses' page for a study titled 'The GFPD Patient Registry for Peroxisomal Disorders'. At the top, there is a 'Back to study list' link. Below that, the user's name 'Jane Smith' and the date '5-May-2020' are displayed. The study title is followed by a 'Surveys' section showing '1 pending' survey. A green checkmark icon indicates the survey is 'Getting Started' and 'Completed on 1-Apr-2025'. On the right, there are two buttons: 'View Responses 1' (highlighted with a red arrow) and 'Reports'.

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

The screenshot shows the 'View Consent and Opt-Ins' page for a study titled 'The GFPD Patient Registry for Peroxisomal Disorders'. At the top, there is a 'Back to participant list' link. Below that, the user's name 'Jane Smith' and the date '5-May-2020' are displayed. The study title is followed by a 'Consents/Opt-Ins' section. A table lists the study details, including the 'Consent Status' (Consented) and the 'Consented On' date (1-Apr-2025). In the 'Actions' column, there are three buttons: 'View Consent', 'Revoke', and 'Opt-Ins' (highlighted with a red arrow). A 'Search Studies' button is also visible in the top right corner.

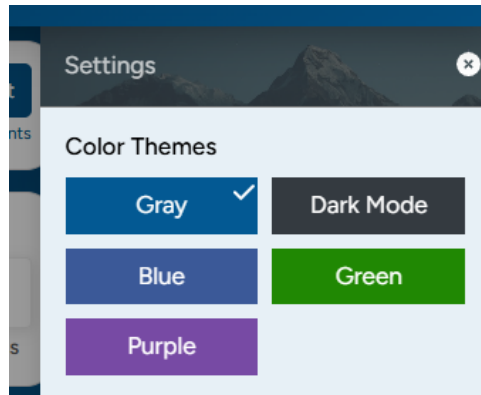
Study Name	Consent Status	Consented On	Actions
The GFPD Patient Registry for Peroxisomal Disorders	✓ Consented	1-Apr-2025	View Consent Revoke Opt-Ins

Dark Mode Settings

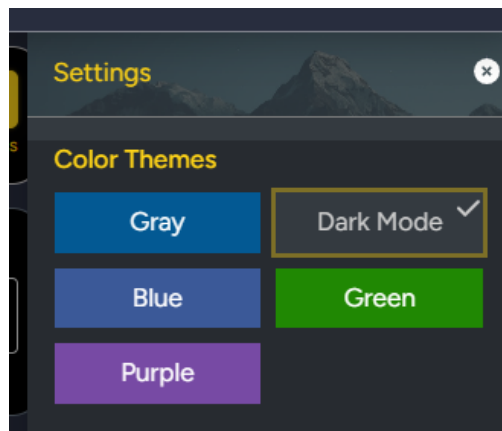
- Step 1: You can view the platform in Dark Mode. First, click Settings.



- Step 2: Select Dark Mode.



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

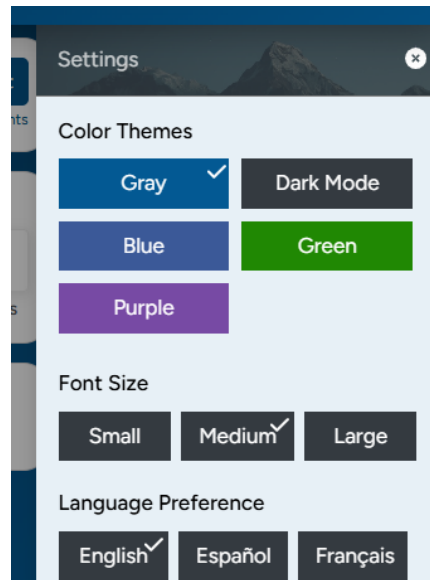


Display Settings

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



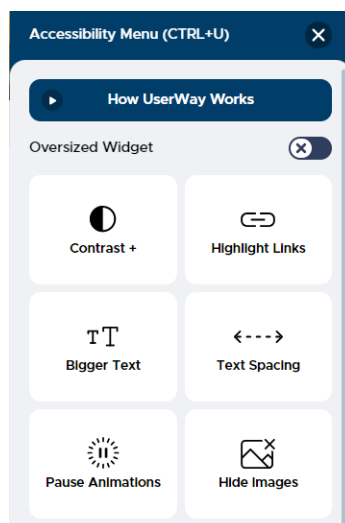
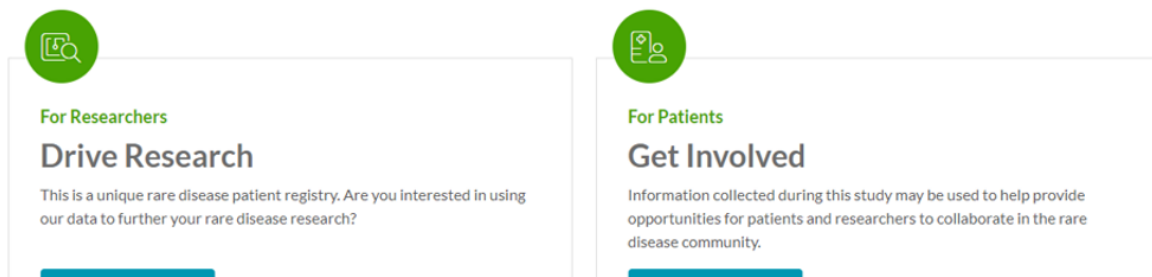
- Step 2: Select a color theme, a font size, or language preference.



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

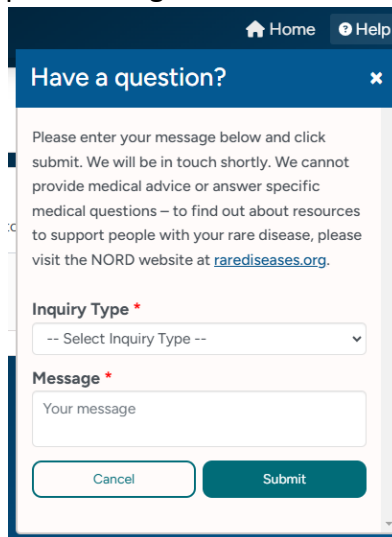
Microsite Visibility

- Step 1: You can change how you view the microsite [insert URL] 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.



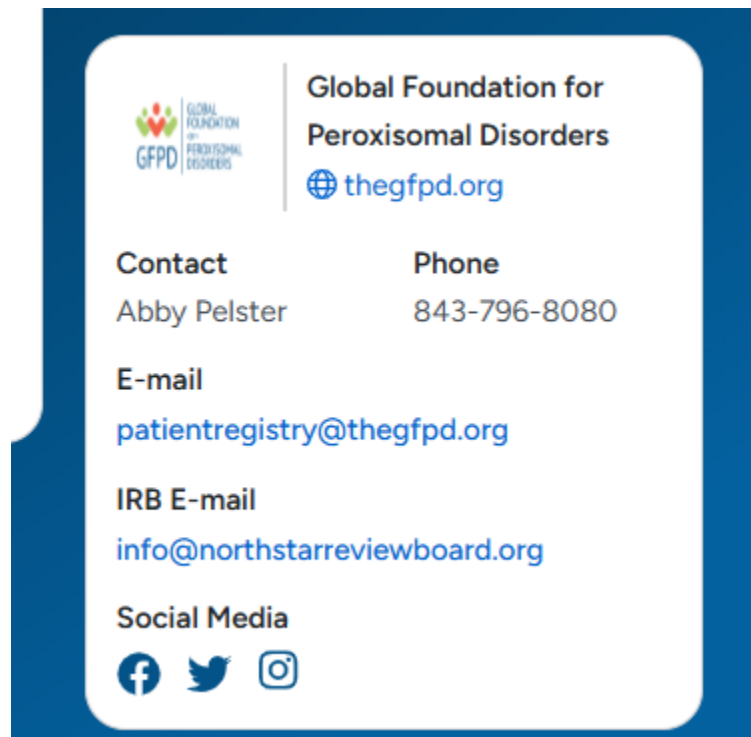
Need Assistance?

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



The screenshot shows a mobile application interface with a dark blue header containing 'Home' and 'Help' icons. Below the header is a white modal window titled 'Have a question?' with a close button (X). The modal contains the following 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.' Below this text is a dropdown menu labeled 'Inquiry Type *' with the placeholder '-- Select Inquiry Type --'. Underneath is a text input field labeled 'Message *' with the placeholder 'Your message'. At the bottom of the modal 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.



The image shows a contact information card for the Global Foundation for Peroxisomal Disorders (GFPD). The card has a white background with a blue border. At the top left is the GFPD logo, which consists of three stylized figures in red, green, and blue. To the right of the logo is the text 'GLOBAL FOUNDATION FOR PEROXISOMAL DISORDERS'. Below the logo and text is the website address 'the GFPD.org' with a globe icon. The card is divided into sections by horizontal lines. The first section is titled 'Contact' and lists 'Abby Pelster' as the contact person. The second section is titled 'Phone' and lists the number '843-796-8080'. The third section is titled 'E-mail' and lists the email address 'patientregistry@the GFPD.org'. The fourth section is titled 'IRB E-mail' and lists the email address 'info@northstarreviewboard.org'. The fifth section is titled 'Social Media' and includes icons for Facebook, Twitter, and Instagram.

Global Foundation for Peroxisomal Disorders
the GFPD.org

Contact	Phone
Abby Pelster	843-796-8080
E-mail	
patientregistry@the GFPD.org	
IRB E-mail	
info@northstarreviewboard.org	
Social Media	
