



GLOBAL  
FOUNDATION  
•for•  
PEROXISOMAL  
DISORDERS

## The GFPD Patient Registry for Peroxisomal Disorders 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 a Peroxisomal Disorder, select **Participant Account**.
  - If you are entering information for **someone else** who has a Peroxisomal Disorder, select **Caregiver Account**.
  - If you are entering information for a Peroxisomal Disorder **patient who has passed away**, select **Caregiver Account**.

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DISORDERS

### 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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**GFPD** GLOBAL FOUNDATION for PEROXISOMAL DISORDERS

## 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 information in the spaces provided. When you are finished with this page, click “Next”.

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**GFPD** GLOBAL FOUNDATION for PEROXISOMAL DISORDERS

## Caregiver Registration

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

Country of Residence \*

First Name \*   Last Name \*

E-mail \*

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

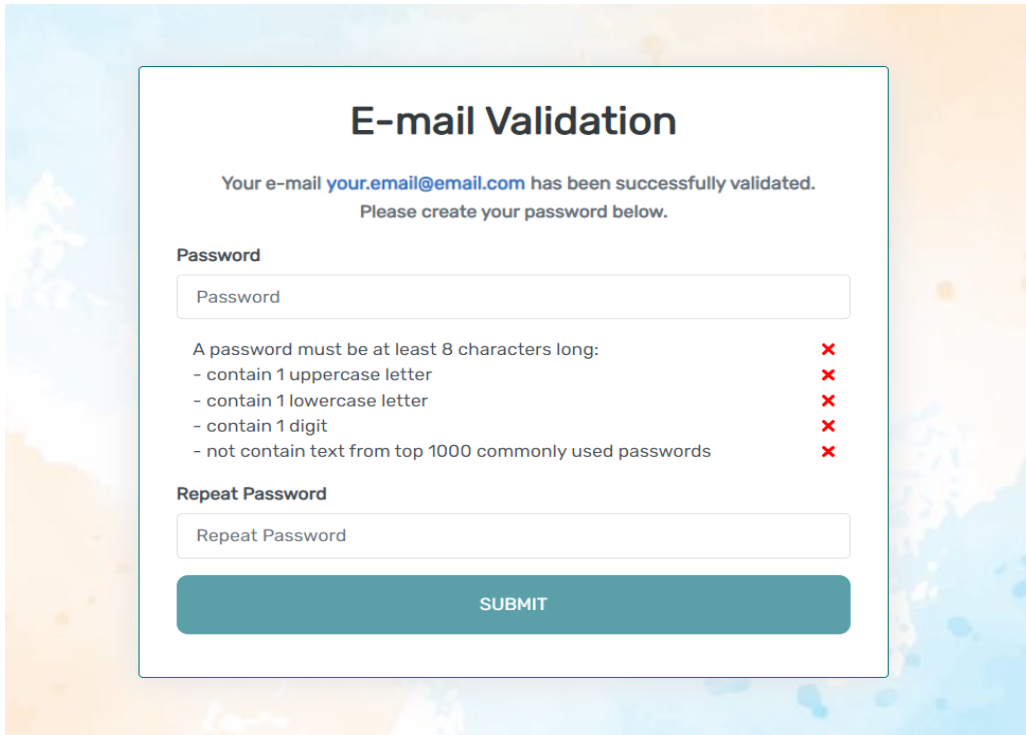
Step 4: Select whether you are interested in being contacted by NORD regarding available studies. When you are finished with this page, click “Next”.

The screenshot shows the 'Caregiver Registration' form for the Global Foundation for Peroxisomal Disorders (GFPD). The form is titled 'Featuring GLOBAL FOUNDATION for PEROXISOMAL DISORDERS GFPD'. Below the title is a progress bar with five steps: 'Terms & Conditions', 'Contact Info', 'Notifications', 'Review & Submit', and 'Confirmation'. The 'Terms & Conditions' step is currently active, indicated by a blue bar. Below the progress bar, the text reads: 'I am interested in NORD contacting me regarding available studies.\*' with radio buttons for 'Yes' (selected) and 'No'. There is also a 'Return to login' link and 'Previous' and 'Next' buttons.

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

The screenshot shows the 'Caregiver Registration' form for the Global Foundation for Peroxisomal Disorders (GFPD). The form is titled 'Featuring GLOBAL FOUNDATION for PEROXISOMAL DISORDERS GFPD'. Below the title is a progress bar with five steps: 'Terms & Conditions', 'Contact Info', 'Notifications', 'Review & Submit', and 'Confirmation'. The 'Review & Submit' step is currently active, indicated by a blue bar. Below the progress bar, the text reads: 'An activation link will be sent to your.email@email.com. Click “Next” to send this e-mail and continue.' There is a 'Return to login' link and 'Previous' and 'Next' buttons. A red arrow points to the 'Next' button.

- 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](mailto:your.email@email.com) has been successfully validated.  
Please create your password below.

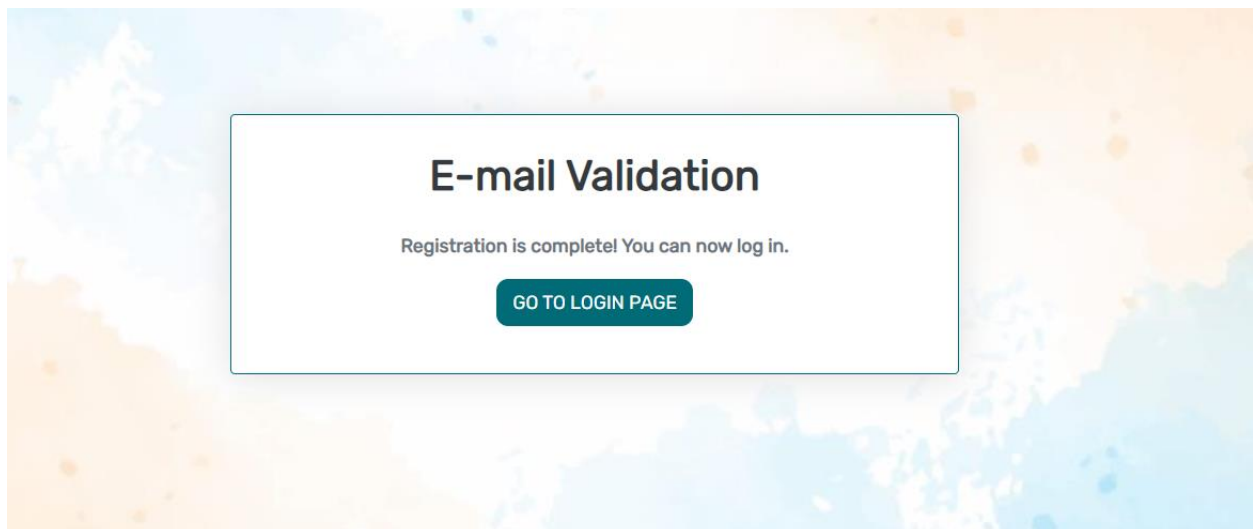
**Password**

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”.

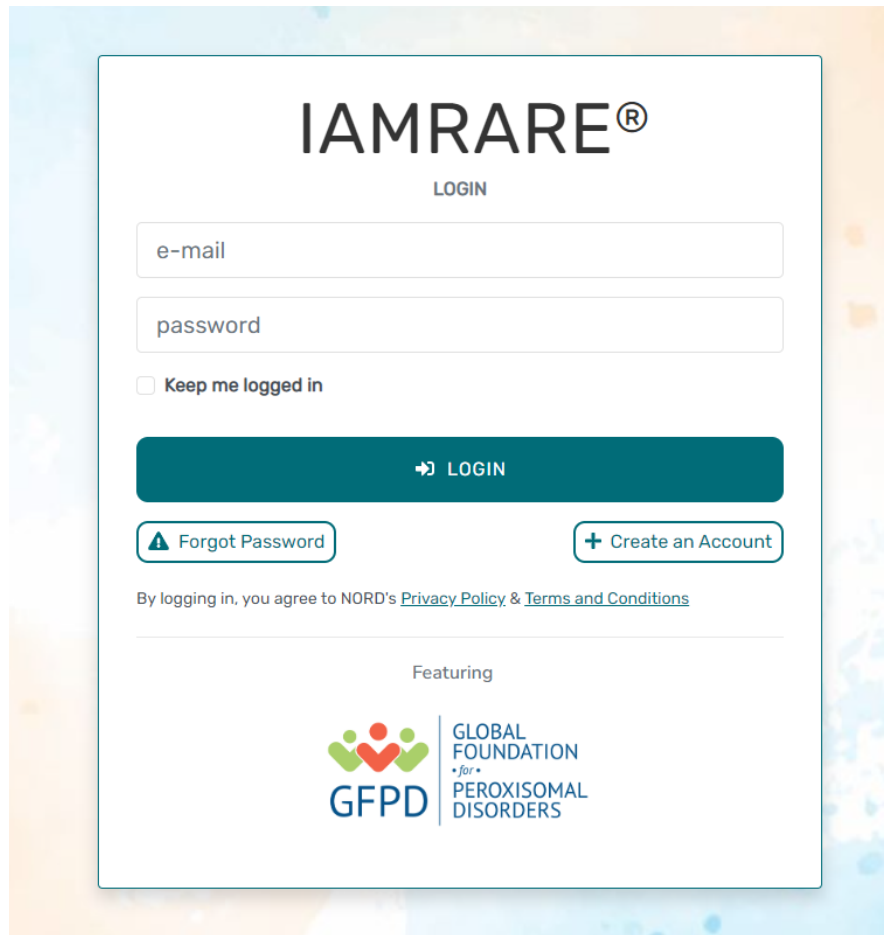


**E-mail Validation**

Registration is complete! You can now log in.

**GO TO LOGIN PAGE**

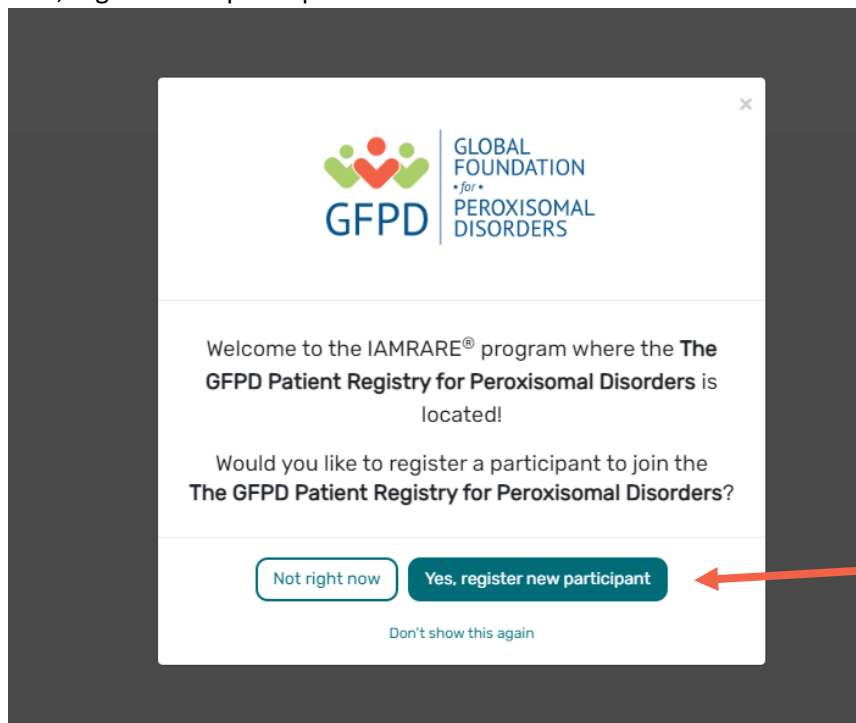
- Step 8: Log in using your new e-mail and password.



The image shows a login form for IAMRARE. At the top, it says "IAMRARE®" and "LOGIN". Below that are two input fields: "e-mail" and "password". There is a checkbox labeled "Keep me logged in". A large teal button with a right arrow and the word "LOGIN" is centered. Below the button are two smaller buttons: "Forgot Password" with a warning icon and "Create an Account" with a plus icon. At the bottom, there is a line of text: "By logging in, you agree to NORD's [Privacy Policy](#) & [Terms and Conditions](#)". Below this is a section titled "Featuring" with the logo for the Global Foundation for Peroxisomal Disorders (GFPD). The logo consists of three stylized figures in green and red above the text "GFPD" and "GLOBAL FOUNDATION for PEROXISOMAL DISORDERS".

### Add a Participant

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



The image shows a dialog box with the GFPD logo at the top. The text inside reads: "Welcome to the IAMRARE® program where the **The GFPD Patient Registry for Peroxisomal Disorders** is located!" followed by "Would you like to register a participant to join the **The GFPD Patient Registry for Peroxisomal Disorders**?" At the bottom, there are two buttons: "Not right now" and "Yes, register new participant". A red arrow points to the "Yes, register new participant" button. Below the buttons is a link that says "Don't show this again".

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

Add Participant x

**Acknowledgement\***

By checking this box, you acknowledge that information collected on this platform will only be used for research purposes by NORD and in ways that will not reveal who you are. Federal or state laws may require us to show information to university or government officials (or sponsors) who are responsible for monitoring the safety of any studies running on this platform. You will not be identified in any publications.

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 of Residence \*

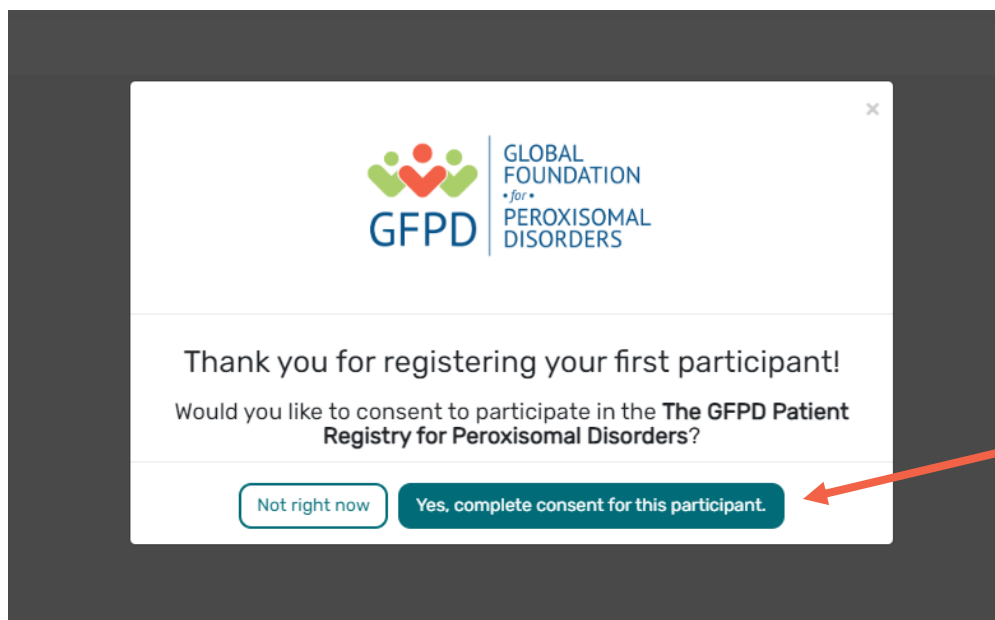
Country of Birth \*

City/Municipality of Birth \*

What Is Your Relationship to ? \*

## Consent to the Study

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



- 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 themself.

**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.

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### 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](mailto:patientregistry@thegfpd.org)

Sponsor: The Global Foundation for Peroxisomal Disorders (The GFPD), [www.thegfpd.org](http://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 explain the information you need to decide if you want to take this study on behalf of the individual in your care. This consent document is structured to follow the framework provided by federal regulations. While we have the information we provide

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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.

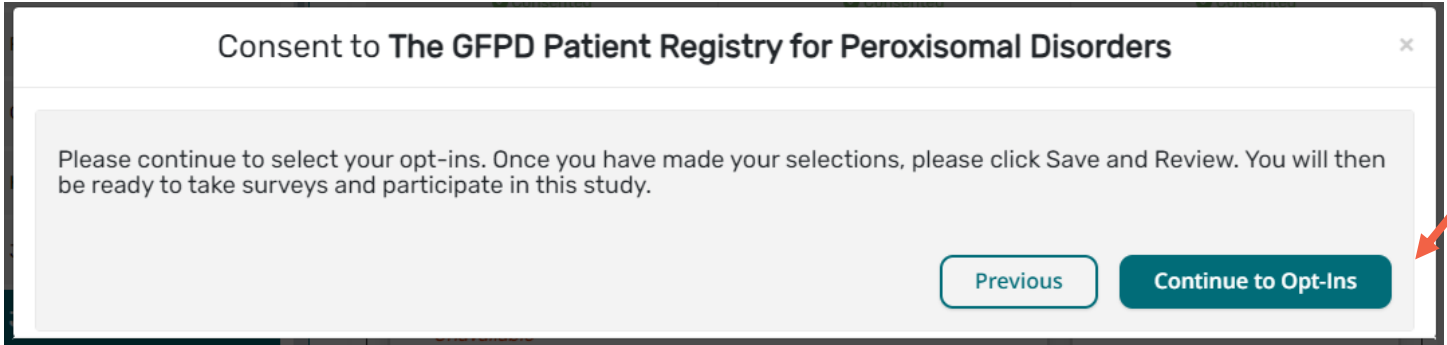
I wish to provide the Study Participant's research data to The GFPD Patient Registry for Peroxisomal Disorders for the purposes described above under Study Aims.

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.

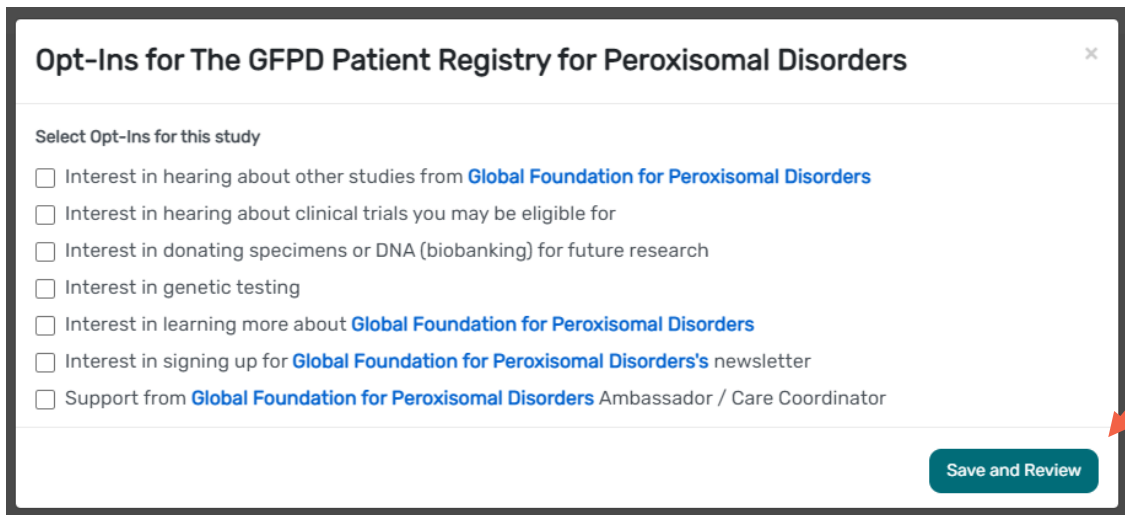
Previous

Next

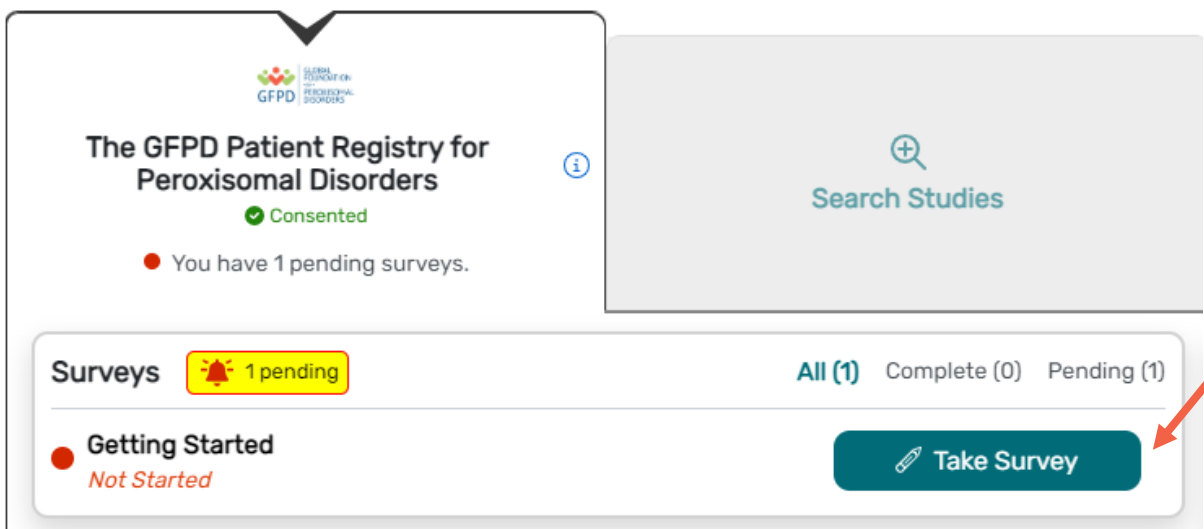
- Step 3: Once you click “Next” and reach the Thank You page, click “Continue to Opt-Ins”.



- 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”.



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





## 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 user's profile for 'The GFD Patient Registry for Peroxisomal Disorders'. The user has 'Consented' and has '3 pending surveys'. A 'Search Studies' button is visible. Below, a 'Surveys' section shows two completed surveys: 'Getting Started' and 'Demographics', both completed on 5-Jun-2023. For each survey, there are 'View Responses' and 'Reports' buttons. A red arrow points to the 'View Responses' button for the 'Demographics' survey.

## View Consent and Opt-Ins

- Step 1: Once you have consented to the study, you are able to view your consent at any time. 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 'CONSENTS/OPT-INS' page for Jane Smith. The left sidebar shows navigation options: 'Enrolled Studies', 'Reminders', 'Consents/Opt-Ins' (highlighted), and 'Reports'. The main content area shows a table with the following data:

Study Name	Consent Status	Consented On	Actions
The GFD Patient Registry for Peroxisomal Disorders	Consented	5-Jun-2023	View Consent, Revoke, Opt-Ins

Page 1 of 1

A red arrow points to the 'View Consent' button in the Actions column.