

PKU Patient Registry

Procedure for Registering, Consenting and completing Surveys

1. Go to the **PKU Patient Registry** website at: pku.iamrare.org.

POP Registry Home About News Contact Register Log in

The Power of Patients Registry

Welcome to the Power of Patients Registry

Learn more »

Rare Disease Research

This is a unique rare disease patient registry. Are you interested in using our data to further your rare disease research?

Researchers »

Participating in this Study

Information collected during this study may be used to help provide opportunities for patients and researchers to collaborate in the rare disease community.

Patients »

Join the Registry

Please create an account and provide consent to participate in the study

Register »

2. Click on the green **Register** button.
3. Read the "**Terms and Conditions**" document.

Register

Home / Register

TERMS AND CONDITIONS

APBDRF FAN NATURAL HISTORY STUDY REGISTRY ON THE NORD NATURAL HISTORY PLATFORM

PLEASE READ THE FOLLOWING INFORMATION CAREFULLY. IN UTILIZING THIS SERVICE, YOU REPRESENT THAT YOU ARE AT LEAST EIGHTEEN (18) YEARS OF AGE, OR HAVE THE EXPRESS LEGAL AUTHORITY TO ACT ON BEHALF OF A MINOR, AND YOU ACKNOWLEDGE THAT YOU UNDERSTAND AND ACCEPT THE FOLLOWING TERMS AND CONDITIONS. IN COMPLIANCE WITH THE CHILDREN'S ONLINE PRIVACY PROTECTION ACT, YOU MUST BE EIGHTEEN (18) YEARS OF AGE OR OLDER TO SUBMIT PERSONAL MEDICAL DATA AND INFORMATION. IF YOU DO NOT ACCEPT THESE TERMS AND CONDITIONS, YOU MAY NOT ACCESS THIS SITE OR UTILIZE ANY OF THE SERVICES PROVIDED ON OR THROUGH THIS SITE.

The APBDRF FAN Natural History Study Registry ("APBDRF FAN/NHS Registry") is a project of the Adult Polyglucosan Body Disease Research Foundation (APBDRF) organization to collect patient information and medical information concerning rare diseases in order to accelerate research and find better treatments and ultimately a cure for these conditions.

1. General, Purpose, and Acceptance of Terms and Conditions

a. General. Use of the APBDRF FAN/NHS Registry website (the "Website") and the services associated with the APBDRF FAN/NHS Registry website (the "Services") is governed by the following terms and conditions herein (the "Terms and Conditions") and the NORD Natural History Study Platform Service and Use Agreement ("Agreement") to which APBDRF is a signatory. All pages within the Website are owned by the National Organization for Rare Disorders, Inc. ("NORD") and APBDRF owns and retains ownership of all data submitted to the APBDRF FAN/NHS Registry.

b. Purpose. The purpose of the Website is to allow individuals, families, and medical and research providers to enter certain information to the APBDRF FAN/NHS Registry. The voluntary information provided by the registrant, during registration, is maintained in a secured database and identifiable data will not be shared outside APBDRF without the registrant's express consent. However, APBDRF may allow researchers and other approved third parties to search and access *de-identified* information.

c. Acceptance of Terms and Conditions. By using the Website, you represent that you accept and agree that you have read all of the Terms and Conditions, and been informed of the Agreement, and that you agree to accept these terms. If you do not agree to be bound by the Terms and Conditions and the Agreement, you may not submit data to the Website.

4. Fill in the requested information.
5. Agree to the Terms and Conditions

6. **Opt-in or out** of reasons to be contacted by study personnel
7. Click **Create Account** button

If you have questions about the APBDFE PAN/NHS Registry, or to report violations of these Terms and Conditions, please email the Registry Coordinator at: apbdfan@apbdf.org.

First name *

Middle name

Last name *

User name (e-mail address) *

Confirm user name *

Password *

Confirm password

I have read and agree to the terms and conditions.

Contact preferences

Yes, I would like to be contacted about...

Clinical trials I may be eligible for †

Donations of a sample of blood, tissue, or other biospecimens

Reminders to update my survey responses

8. A confirmation email will be sent to the email address that was provided during registration. Confirm registration by copying the **Confirmation Token** from your email.



regisadmin@rarediseases.org

3:55 PM (0 minutes ago) ☆

to me ▾

Welcome, Leo.

A user account has been created but is not yet active.

To activate your account please follow this link: http://powerofpatients.demo.iamrare.org/Account/Validate/ivLxyvePTU2luoMQWY7L0g/?token=5T_3O6bFJ0qPSpe8iq-Gtg.

Alternatively, you may copy this token:

5T_3O6bFJ0qPSpe8iq-Gtg

9. Paste the confirmation token into the “**Confirmation Code**” field. Click **Submit**.
 - a. If the confirmation email has not been received after a few minutes, click “**Resend confirmation email**” at the bottom of the page. Be sure to check spam folders for the email confirmation.

Verify Registration

[Home](#) / [Verify Registration](#)

Thank you

A new user account has been created.

A confirmation message has been sent to srossov+1@rarediseases.org.

You must verify receipt of this email before participation in the 'The Power of Patients Registry' registry.

Activate your account by entering the confirmation code from the welcome e-mail you received. Alternatively, you may click on the link within the e-mail. Please note that using the link will require that you re-enter your user name and password.

Confirmation Code

Note:

If you do not see this email, please ensure that the provided e-mail address is correct. Please add regisadmin@rarediseases.org to your contacts so that messages from us do not get directed to your email spam.

[Resend confirmation email.](#)

[Change username/email.](#)

10. Click on “**Participant Enrollment.**”
11. Select the appropriate **Option** for granting consent.

Participant Enrollment

[Home](#) / [Participant Enrollment](#)

I would like to answer surveys for myself.

[Add yourself as a participant](#)

I am a parent, or other authorized representative, and would like to answer surveys for someone else.

[Add someone else as a participant](#)

You haven't added any survey participants yet.

12. Fill in the fields as they apply to the **Study Participant**.

Add a new survey participant

[Home](#) / [Participant Enrollment](#) / Add a new survey participant

If you are entering someone other than yourself as a participant in the registry, please ensure you are legally able to do so as the caregiver or legally authorized representative.

Your relationship to the participant *

First name *

Middle name

Last name *

Birthdate (MM/DD/YYYY) *

Can we contact the Participant or Reporter directly? Yes No

Preferred contact method

Preferred contact language

E-mail

Address line 1

Address line 2

13. Access Surveys by clicking on “**Take Surveys.**”

Participant Enrollment

[Home](#) / [Participant Enrollment](#)

I am a parent, or other authorized representative, and would like to answer surveys for someone else.

[Add another participant](#)

| Name | Consent granted | Actions |
|--------------|-----------------|-----------------------------------------------------------------------------------------------------------------------------------------------------------------|
| Katie Singer | Yes | Take Surveys Edit Archive Transfer Email Consent Revoke Consent |

14. Complete the **surveys** applicable to the **Study Participant**. For example, and adult would not complete the Quality of Life Pediatric survey.
- a. **NOTE: The Reporter is listed in the top right hand corner of the page and the Study Participant is listed on the left side of the page.** If someone is answering surveys for him or herself, both the Reporter and Study Participant fields will reflect the same name.

15. Under “**Survey Title**” click on the name of the survey to open the survey. Complete the survey. Questions marked with a red * are require a response.

16. When each Survey has been completed, click on the **Submit as Final Response** button. If not completed, Surveys can be saved as drafts by clicking the **Save as Draft** button.