

# KAT6A Patient Registry

## *Procedure for Registering, Consenting and completing Surveys*

1. Go to the **KAT6A Patient Registry** website at: [kat6a.iamrare.org](http://kat6a.iamrare.org).

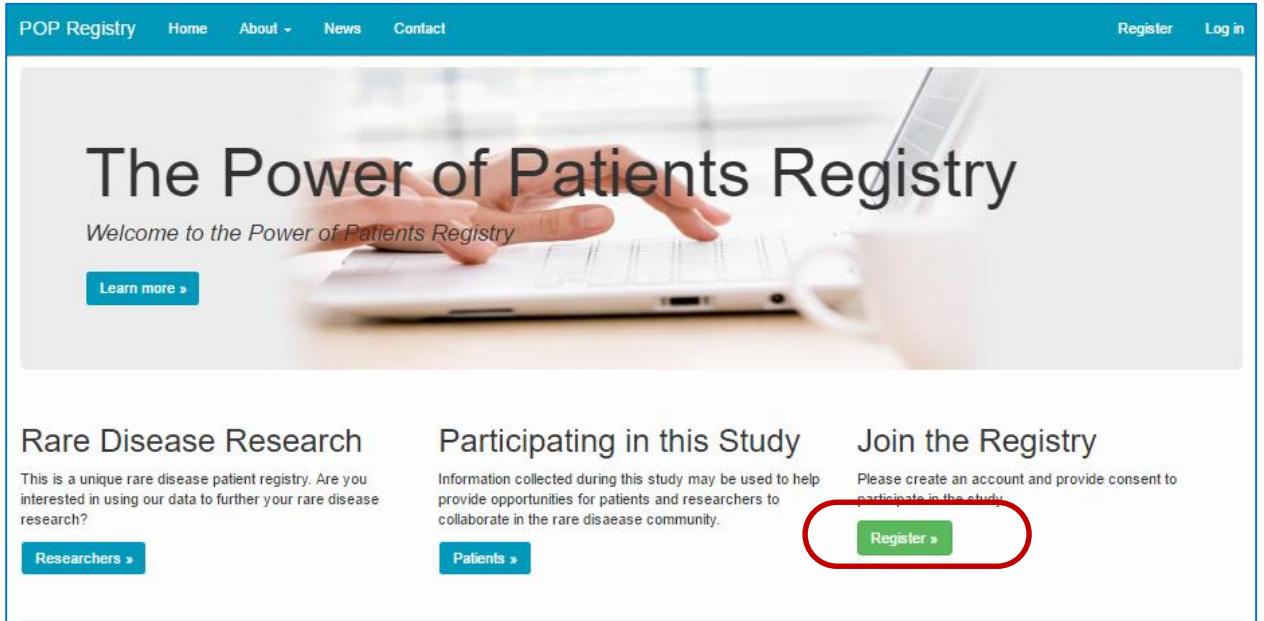


Figure 1. Landing Page

2. Click on the green **Register** button.
3. Complete the age attestation

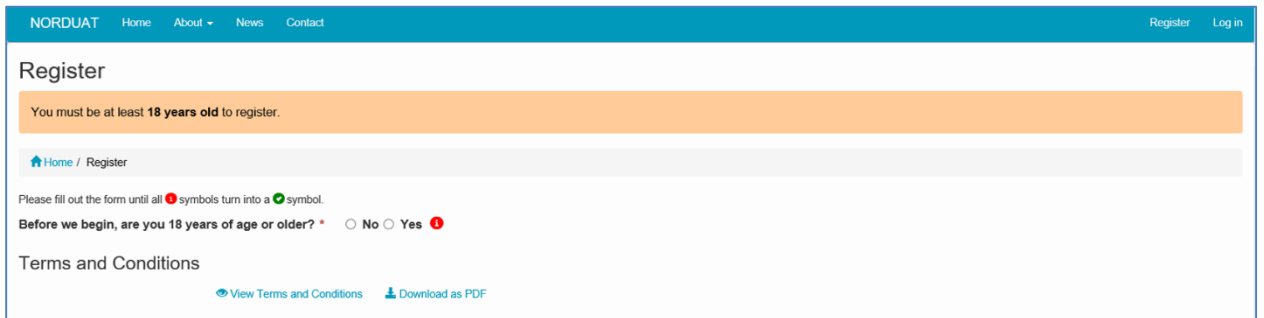


Figure 2. Age attestation

4. Read the "**Terms and Conditions**" document.

**Register**

[Home](#) / [Register](#)

**TERMS AND CONDITIONS**

PLEASE READ THE FOLLOWING INFORMATION CAREFULLY. IN UTILIZING THIS SERVICE, YOU REPRESENT THAT YOU ARE AT LEAST EIGHTEEN (18) YEARS OF AGE, 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 Power of Patients Registry ("POP Registry") is a project of the Power of Patients 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 Power of Patients Registry website (the "Website") and the services associated with the Power of Patients Registry website (the "Services") is governed by the following terms and conditions herein (the "Terms and Conditions") and a privacy policy (the "Privacy Policy"), both of which you must read before using the Registry Website and the Services. All pages within the Website are owned and operated by Power of Patients together with its members, directors, and affiliated entities are referred to collectively herein as "Power of Patients") or with the permission and cooperation of approved and trusted third-party partners.

b. **Purpose.** The purpose of the Website is to allow individuals, families, and medical and research providers to enter certain information to the Power of Patients Registry. The voluntary information provided by the registrant, during registration, is maintained in a secured database and identifiable data will not be shared outside Power of Patients without the registrants express consent. However, Power of Patients 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, the Privacy Policies, and the Informed Consent documents, understand them, and that you agree to and have the legal capacity to be bound by them. These Terms and Conditions constitute a legal agreement between you and Power of Patients. Power of Patients reserves the right to modify these Terms and Conditions at any time in its sole discretion, and without prior notice, by posting amended terms on this Website. We encourage you to review the Terms and Conditions periodically for any updates or changes. If you do not agree to be bound by the Terms and Conditions and the Privacy Policy, you may not use the Website.

**2. Ownership**

All Power of Patients Registry-generated content available at the Website, including without limitation, any information, software, photographs, images, video, audio, graphics, or text on the Website ("Content"), and all patent, copyright, trademark, trade dress, domain name, trade secret, and other proprietary rights therein are the sole property of Power of Patients or used by Power of Patients with the permission of the owner of such content. You agree to abide by all intellectual property and copyright laws protecting those property rights and any additional restrictions set forth on the Website in relation to the content, source code, and other elements of the Website.

**3. Use of the Website**

a. **Legal Capacity.** You may use the Website to register to be included in the Power of Patients Registry, if you are at least eighteen (18) years old or older or possess legal parental or guardian consent; that you are fully able and competent to enter into the terms and conditions set forth in these Terms and Conditions and are otherwise capable of forming legally binding agreements under applicable law; and that you agree to be bound by these Terms and Conditions. If you are not competent to form legally binding agreements, do not use this Website.

b. **True, accurate and complete information.** If you register to use the Website, you agree to provide true, accurate, and complete registration information.

Figure 3: Terms and conditions for use of the IAMRARE™ Platform

5. Fill in the requested information.
6. Agree to the Terms and Conditions
7. **Opt-in or out** of reasons to be contacted by study personnel
8. Click **Create Account** button

## Register

You must be at least 18 years old to register.

[Home](#) / Register

Please fill out the form until all ● symbols turn into a ● symbol.

Before we begin, are you 18 years of age or older? \* **Yes** ●

First Name \*  ●

Middle Name

Last Name \*  ●

Country of Residence \*  ●

Username (Email Address) \*  ●

Confirm Username \*  ●

A password must be at least 8 characters long: ●

- contain 1 uppercase letter ●
- contain 1 lowercase letter ●
- contain 1 digit ●
- contain 1 special character ●
- not contain text from top 1000 commonly used passwords ●

Password \*  ●

Confirm Password \*  ●

**Additional Contact Information (Optional)**

Home Phone

Work Phone

Mobile Phone

Contact Preferences

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

Reminders to update my survey responses

Clinical trials I may be eligible for †

Potentially donating biospecimen and/or DNA for future research studies ††

Figure 4. Creating an account

9. 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.

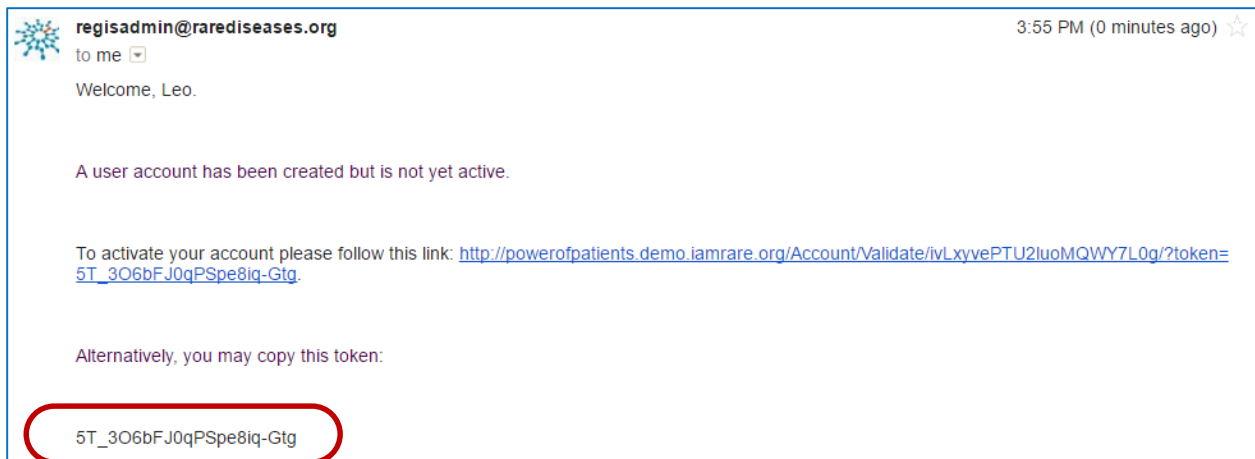


Figure 5. Registration confirmation email

10. 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.

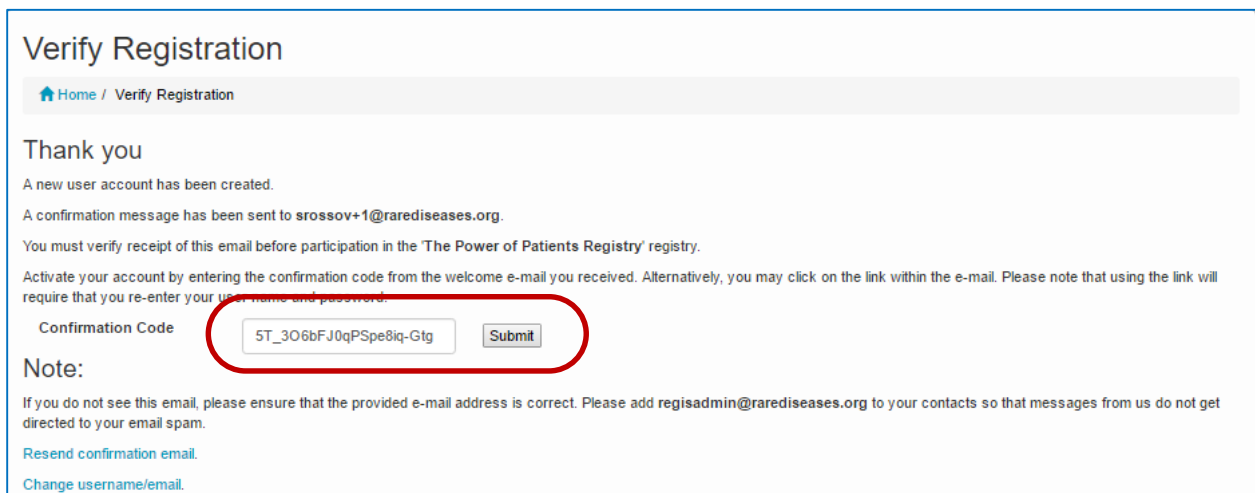


Figure 6. Entering the confirmation code into the registry to complete registration.

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

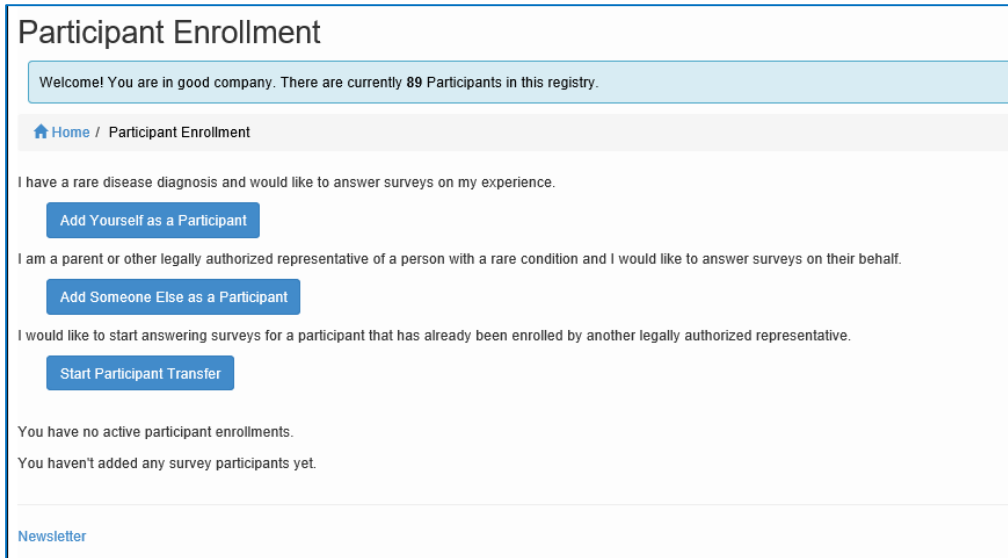


Figure 7. Providing consent

Alternatively, you can begin the process of transferring a participant from one party to another. Speak to your registry administrator if you have questions.

13. Once consent has been granted, fill in the fields as they apply to the **Study Participant**.

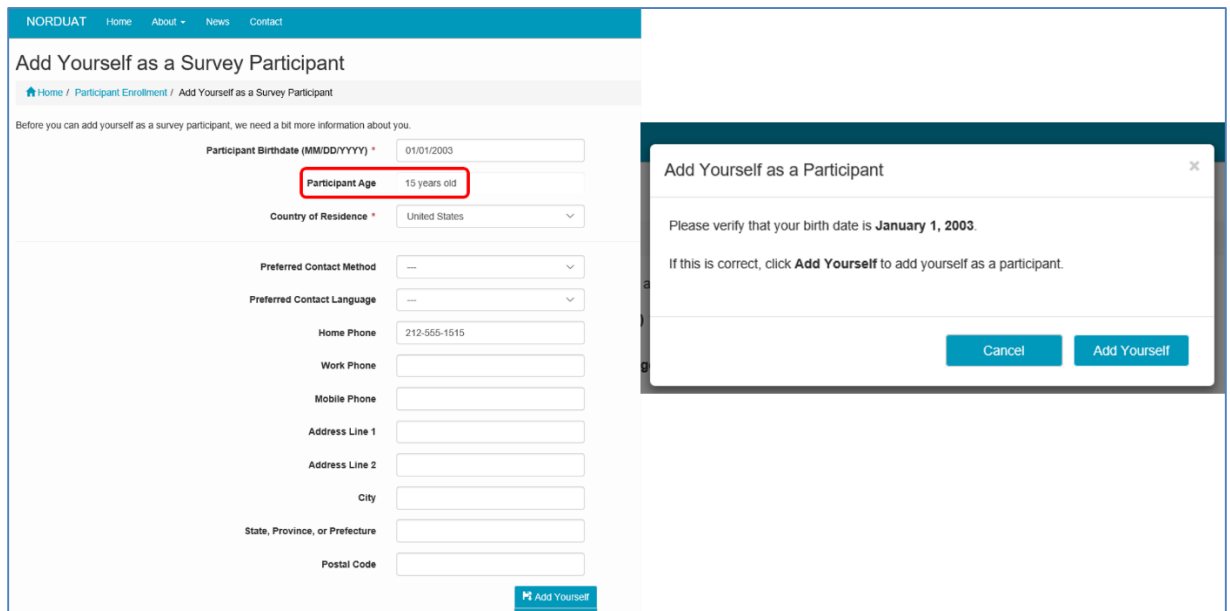


Figure 8a. Adding Participants – Adding yourself as a participant

### Add a New Survey Participant

[Home](#) / [Participant Enrollment](#) / Add a New Survey Participant

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

Your relationship to the participant \*

Participant First Name \*

Participant Middle Name

Participant Last Name \*

Participant Birthdate (MM/DD/YYYY) \*

Participant Date of Death (MM/DD/YYYY) (if applicable)

Country of Residence \*

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Can we contact the participant directly?  Yes  No

Preferred Contact Method

Preferred Contact Language

Email

Home Phone

Figure 8b. Adding participants - Adding another person as a participant.

14. Access Surveys by clicking on “Take Surveys.”

### Participant Enrollment

Welcome! You are in good company. There are currently 9 Participants in this registry.

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

#### Active Participants

[+ Add Participant](#) [⇌ Start Transfer](#)

Name	Consent Granted	Actions
Jed Clampett	Yes	<a href="#">Take Surveys</a> <a href="#">Edit</a> <a href="#">Delete</a> <a href="#">Manage Consent</a>

Figure 9. Participant Dashboard

15. 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.

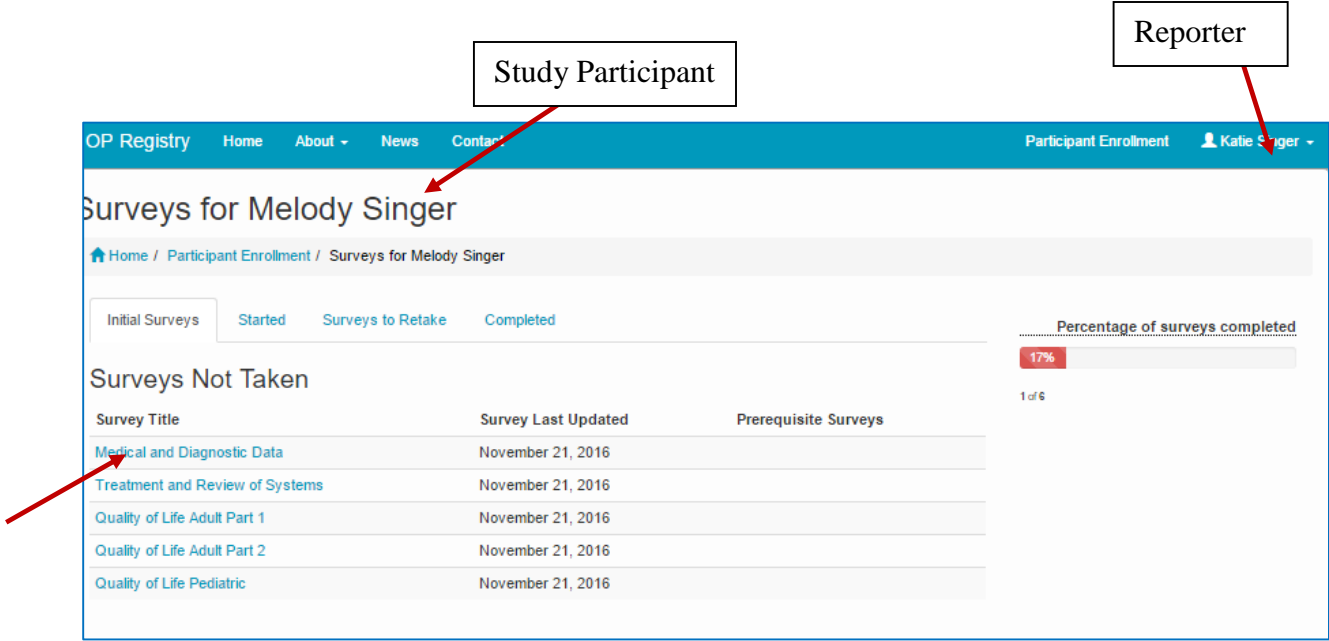


Figure 10. Completing Surveys

16. 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.

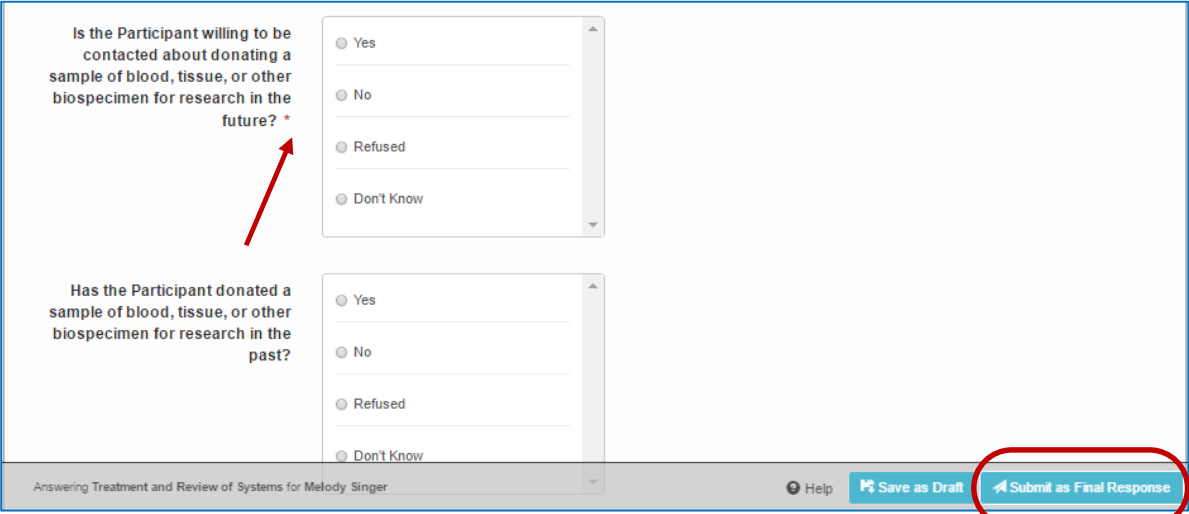


Figure 11. Completing questions and submitting surveys

17. 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.