

Gorlin Syndrome Alliance Patient Registry (GSAPR)

Procedure for Registering, Consenting and Completing Surveys

1. Go to the **Gorlin Syndrome Alliance Patient Registry** website at:
gorlinsyndrome.iamrare.org.

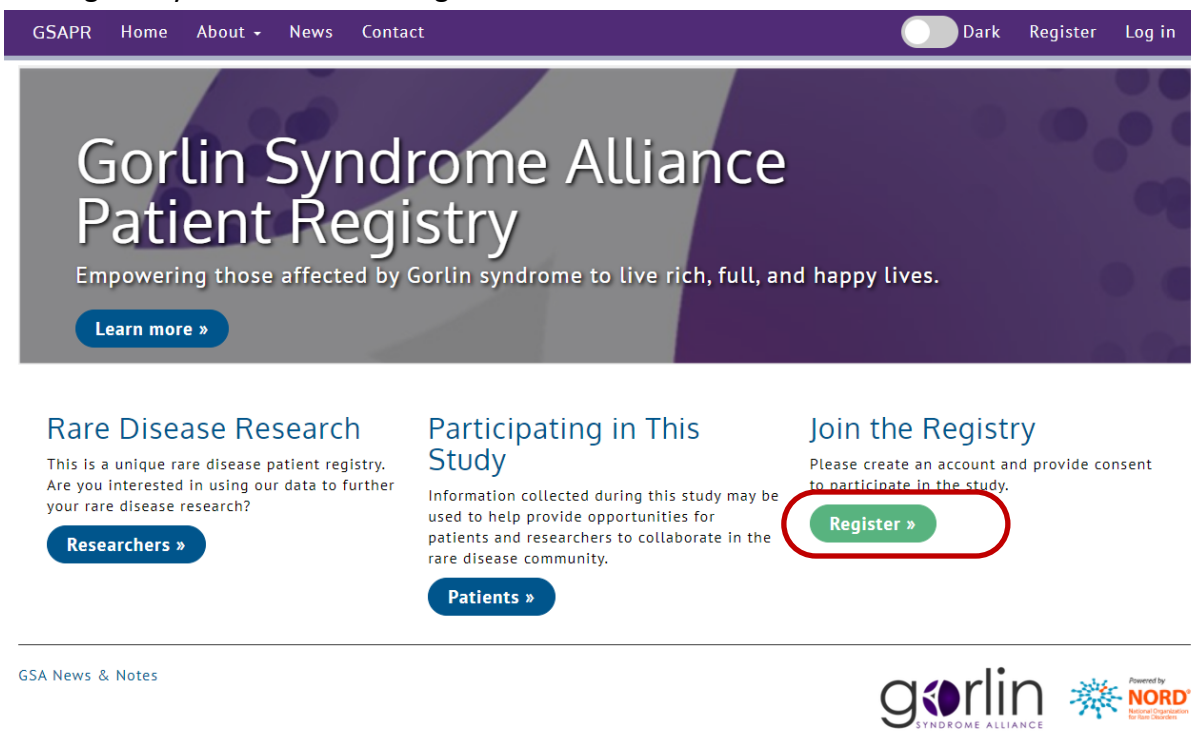


Figure 1. Landing Page

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

The screenshot shows the 'Register' page. At the top, a blue header contains 'NORDUAT', navigation links, and 'Register' / 'Log in'. Below the header, a message states 'You must be at least 18 years old to register.' A breadcrumb trail shows 'Home / Register'. A form instruction says 'Please fill out the form until all red symbols turn into a green symbol.' The first question is 'Before we begin, are you 18 years of age or older? *' with radio buttons for 'No' and 'Yes' (selected). Below the question is a 'Terms and Conditions' section with links to 'View Terms and Conditions' and 'Download as PDF'.

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 registrant's 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.

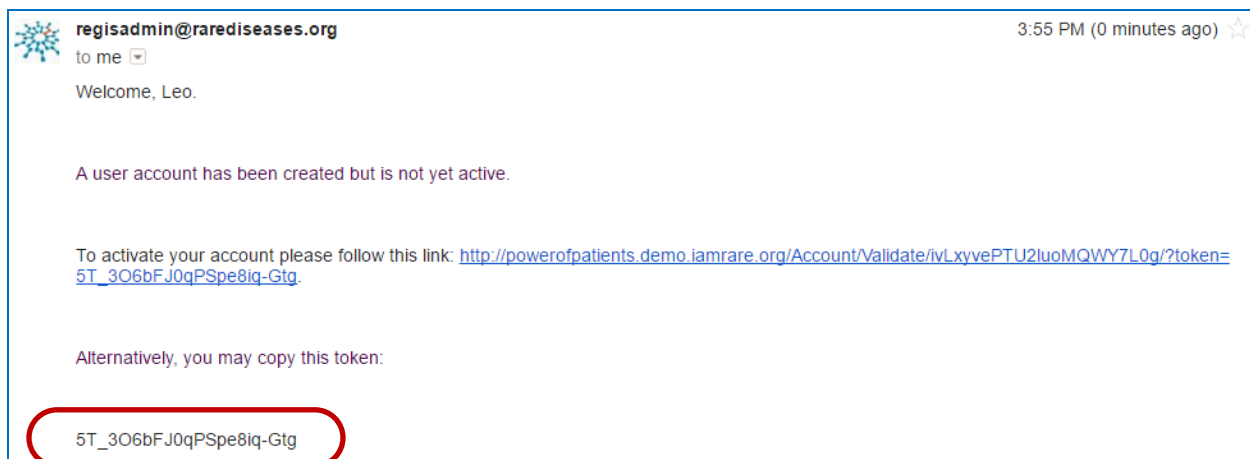


Figure 5. Registration confirmation email

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.

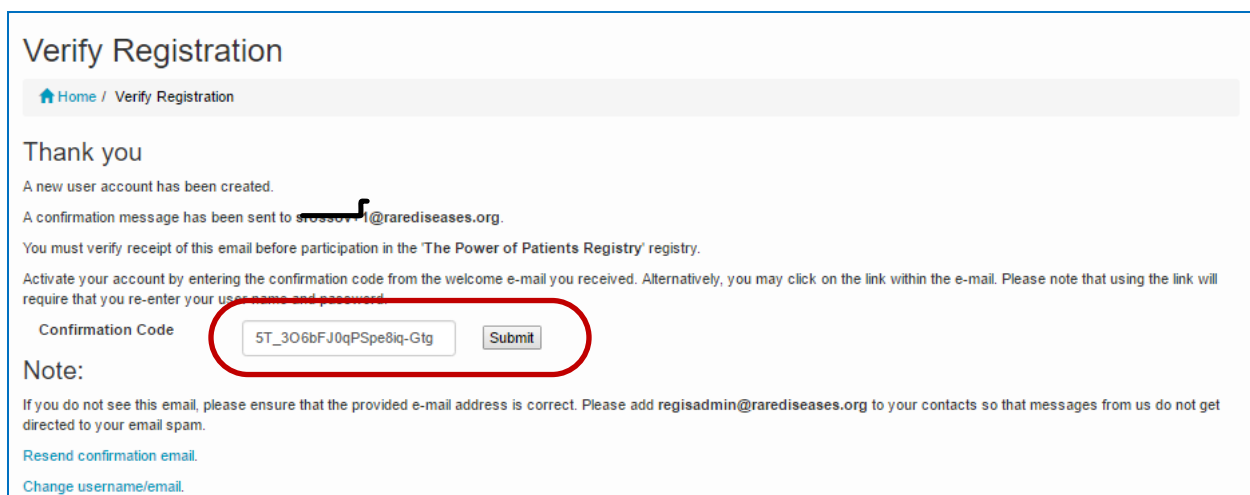


Figure 6. Entering the confirmation code into the study to complete registration.

11. Click on “**Participant Enrollment.**”
12. Select the appropriate **Option** - You can add yourself, or someone else.

Participant Enrollment

Welcome! You are in good company. There are currently 89 Participants in this registry.

[Home](#) / Participant Enrollment

I have a rare disease diagnosis and would like to answer surveys on my experience.

[Add Yourself as a Participant](#)

I am a parent or other legally authorized representative of a person with a rare condition and I would like to answer surveys on their behalf.

[Add Someone Else as a Participant](#)

I would like to start answering surveys for a participant that has already been enrolled by another legally authorized representative.

[Start Participant Transfer](#)

You have no active participant enrollments.

You haven't added any survey participants yet.

[Newsletter](#)

Figure 7a. Adding a Participant

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

13. To enroll a Participant, fill in the fields as they apply to the **Study Participant**.

Add Yourself as a Survey Participant

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

Before you can add yourself as a survey participant, we need a bit more information about you.

Participant Birthdate (MM/DD/YYYY) * 02/09/1997

Participant Age 22 years old

Country of Residence * United States

Preferred Contact Method ---

Preferred Contact Language ---

Home Phone 202-222-1111

Work Phone

Mobile Phone

Address Line 1

Address Line 2

City

State, Province, or Prefecture

Postal Code

[Add Yourself](#)

[Cancel](#)

Add Yourself as a Participant

Please verify that your birth date is February 9, 1997.

If this is correct, click [Add Yourself](#) to add yourself as a participant.

[Cancel](#) [Add Yourself](#)

Figure 7b. 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 *

Can we contact the participant directly? ☒ Yes ☐ No

Preferred Contact Method

Preferred Contact Language

Email

Home Phone

Figure 7c. Adding participants - Adding another person as a participant.

14. Grant Consent

Participant Enrollment

Welcome! You are in good company. There are currently **45** Participants in this registry.

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

Active Participants

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

Name	Consent Granted	Actions
Charles Brown	No	Grant Consent To Take Surveys Edit Delete
Sally Brown	No	Grant Consent To Take Surveys Edit Delete

Figure 8a. Accessing the Consent

Note: you must agree to all terms outlined in the consent form.

The screenshot shows a consent form with two questions, each with a "Yes" radio button selected and a red arrow pointing to it. The first question is "Do you confirm that you have read the Informed Consent Agreement?" with a checked checkbox and a red arrow. The second question is "I give permission on behalf of the study participant to provide research data to the Power of Patients Registry only for the purposes described above." with a selected "Yes" radio button and a red arrow. Below these questions are two buttons: "I Agree with the Terms of Consent" and "Cancel without Agreeing to the Terms of Consent". At the bottom, a "Grant Consent?" dialog box is open, asking for confirmation to agree to all terms, with "Cancel" and "I Agree with the Terms of Consent" buttons.

Figure 8b. Granting Consent

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

The screenshot shows the "Participant Enrollment" dashboard. It includes a welcome message, a breadcrumb trail "Home / Participant Enrollment", and a section for "Active Participants". Below this section is a table with columns "Name", "Consent Granted", and "Actions". The table contains one row for "Jed Clampett" with "Yes" under "Consent Granted". In the "Actions" column, there are four buttons: "Take Surveys", "Edit", "Delete", and "Manage Consent". The "Take Surveys" button is highlighted with a red box.

Figure 9. Participant Dashboard

16. Complete the **surveys** applicable to the **Study Participant**. Click the **Take** button next to the **Survey Title** to open the 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.

Study Participant

Reporter

POWER OF PATIENTS Home About News Contact Dark Participant Enrollment Bruce Wayne

Surveys for Dick Grayson

Home / Participant Enrollment / Surveys for Dick Grayson

Survey Progress: 1 of 7 Surveys Completed
14%

Initial Surveys (5) Started (1) Results (1)

Surveys Not Taken

Survey Title		Survey Version Date	Prerequisite Surveys
Participant Profile	Take	August 31, 2018	
Diagnosis	Resume	August 31, 2018	
Treatment and Review of Systems	Take	September 13, 2016	
Quality of Life Pediatric	Take	September 13, 2016	
Medical Reports		August 31, 2018	Participant Profile

Figure 10. Completing Surveys

17. Complete the survey. Questions marked with a red * require a response.

In which country was the Participant born, as shown on his/her birth certificate? *

United States

In which state or territory was the Participant born, as shown on his/her birth certificate?

Alaska

What is the name of the city, town or village of the Participant's birth (as it appears on the birth certificate)?

Answering Participant profile for Dick Grayson

Help Cancel Finish Later **I'm Finished**

Figure 11. Completing questions and submitting surveys

18. When each Survey has been completed, click on the **I'm Finished** button. If not completed, Surveys can be saved as drafts by clicking the **Finish Later** button. Or click the **Cancel** button to leave the survey and return later. Note that if you click Cancel, no changes will be saved.