Gorlin Syndrome Alliance Patient Registry (GSAPR)

Procedure for Registering, Consenting and Completing Surveys


2. Click on the green Register button.

3. Complete the age attestation

Figure 1. Landing Page

Figure 2. Age attestation
4. Read the "Terms and Conditions" document.

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
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.
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.

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

Figure 7b. Adding Participants – Adding yourself as a participant
14. Grant Consent

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

Figure 8a. Accessing the Consent
Note: you must agree to all terms outlined in the consent form.

![Consent Form Image]

**Figure 8b. Granting Consent**

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

![Participant Dashboard Image]

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

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.