ITP Natural History Study Registry

*Procedure for Registering, Consenting and completing Surveys*

1. Go to the **ITP NHS Registry** website at: [itpstudy.iamrare.org](http://itpstudy.iamrare.org).

2. Click on the green **Register** button.

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

[Image of confirmation email]

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.

10. Click on “Participant Enrollment.”
11. Select the appropriate Option for granting consent.
12. Fill in the fields as they apply to the Study Participant.

13. Grant Consent for participation in Registry by clicking on “Grant Consent.”
14. Select consent option (dependent on whether patient is 18+ or a Legally Authorized Representative “LAR”)

15. Read consent thoroughly. Once you have read the entire agreement, select box that confirms you have read the agreement. Next, answer the three questions below regarding study communication preferences. When finished, select whether you agree with Terms of Consent.

16. You will receive an email with a copy of your consent form. On the registry site, select “Return to Participant Enrollment”

17. Access Surveys by clicking on “Take Surveys.”
18. Complete the **surveys** applicable to the **Study Participant**. For example, an 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.

19. 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.
20. 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.