1. Go to The APS Type 1 (APECED) Registry website at: apstype1.iamrare.org.

2. Click on the green Register button.

3. Complete the 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** for granting consent.
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](image)

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

15. 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.
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.

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.