**APBD Natural History Study Registry**

***Steps for Navigating the Registry***

1. Go to the **APBD NHS Registry** website at: **apbd-fan.iamrare.org**.



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1. Click on the green **Register** button.
2. Read the **­­­­­­­"Terms and Conditions"** document.



1. Fill in the requested information.
2. Agree to the Terms and Conditions
3. **Opt-in or out** of reasons to be contacted by study personnel
4. Click **Create Account** button



1. 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.



1. Paste the confirmation token into the “**Confirmation Code**” field. Click **Submit**.
	1. 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.



1. Click on **“Participant Enrollment**.**”**
2. Select the appropriate **Option** for granting consent.



1. Fill in the fields as they apply to the **Study Participant**.



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



1. Complete the **surveys** applicable to the **Study Participant**. For example, and adult would not complete the Quality of Life Pediatric survey.
	1. **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.

Reporter

Study Participant



1. 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.



1. 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.