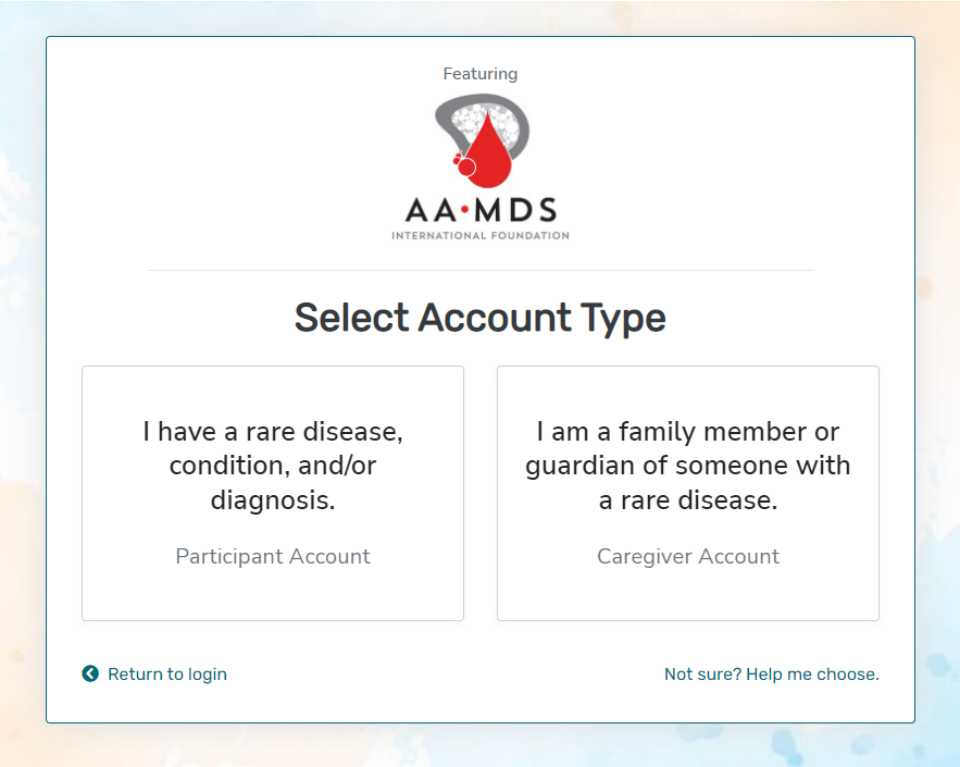
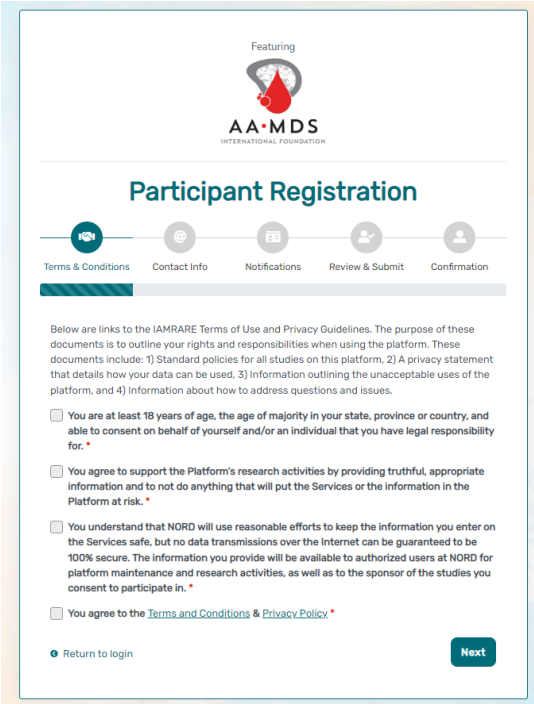
Participant User Guide

Register for an Account

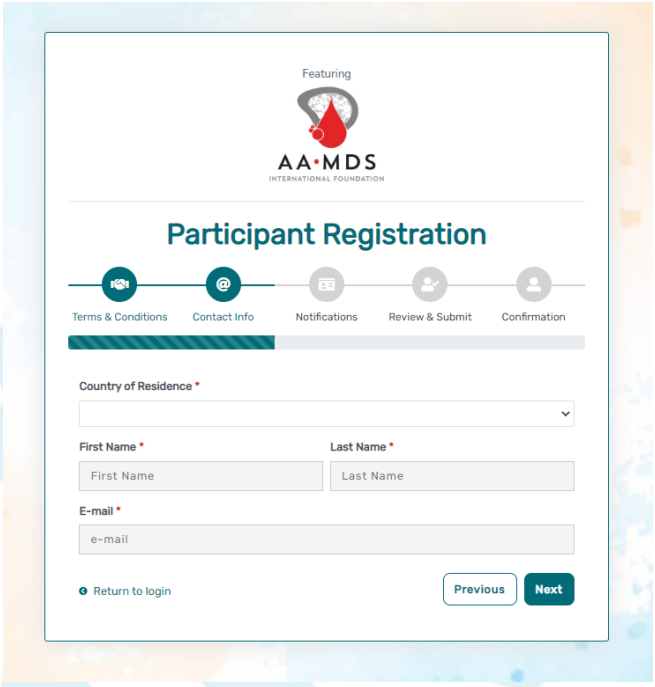
- Step 1: Select the appropriate Account Type. If you need more information to help you choose, click “Not sure? Help me choose”.
    - If you have a diagnosis of Paroxysmal Nocturnal Hemoglobinuria, select **Participant Account**.
    - If you are entering information for someone else who has Paroxysmal Nocturnal Hemoglobinuria (or you have Paroxysmal Nocturnal Hemoglobinuria and are also entering information for yourself), select **Caregiver Account**.



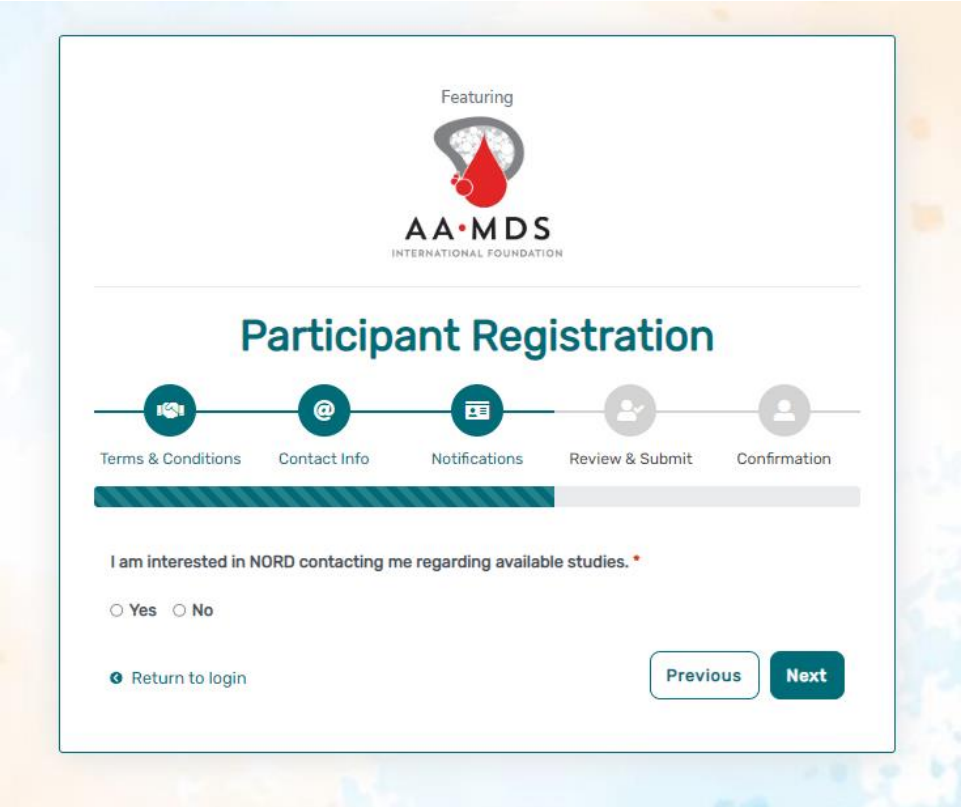
- Step 2: Read the Terms and Conditions and Privacy Policy and attest to the statements provided. When you are finished with this page, click “Next”.



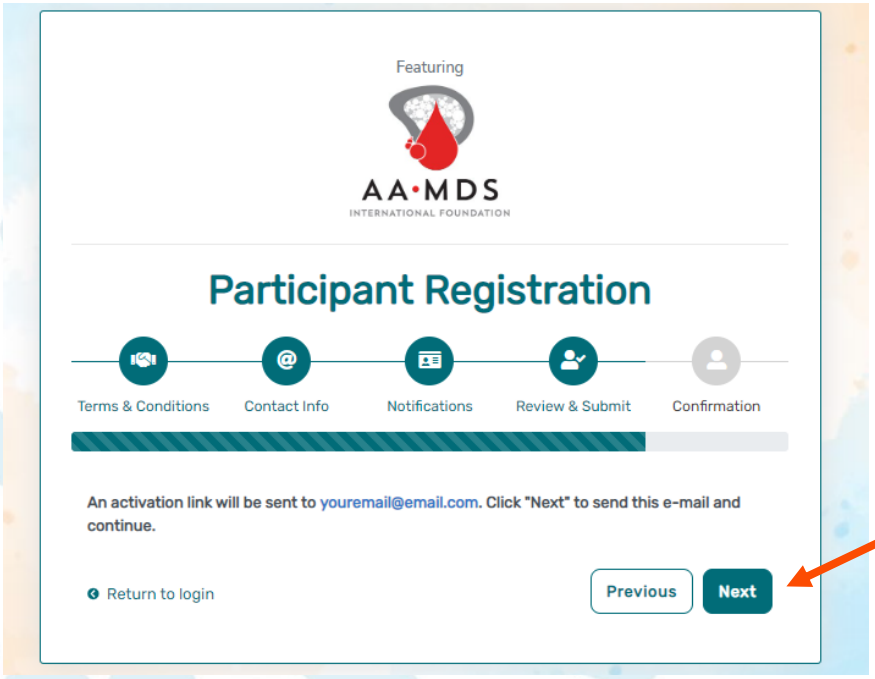
- Step 3: Enter your personal information in the spaces provided. When you are finished with this page, click “Next”.



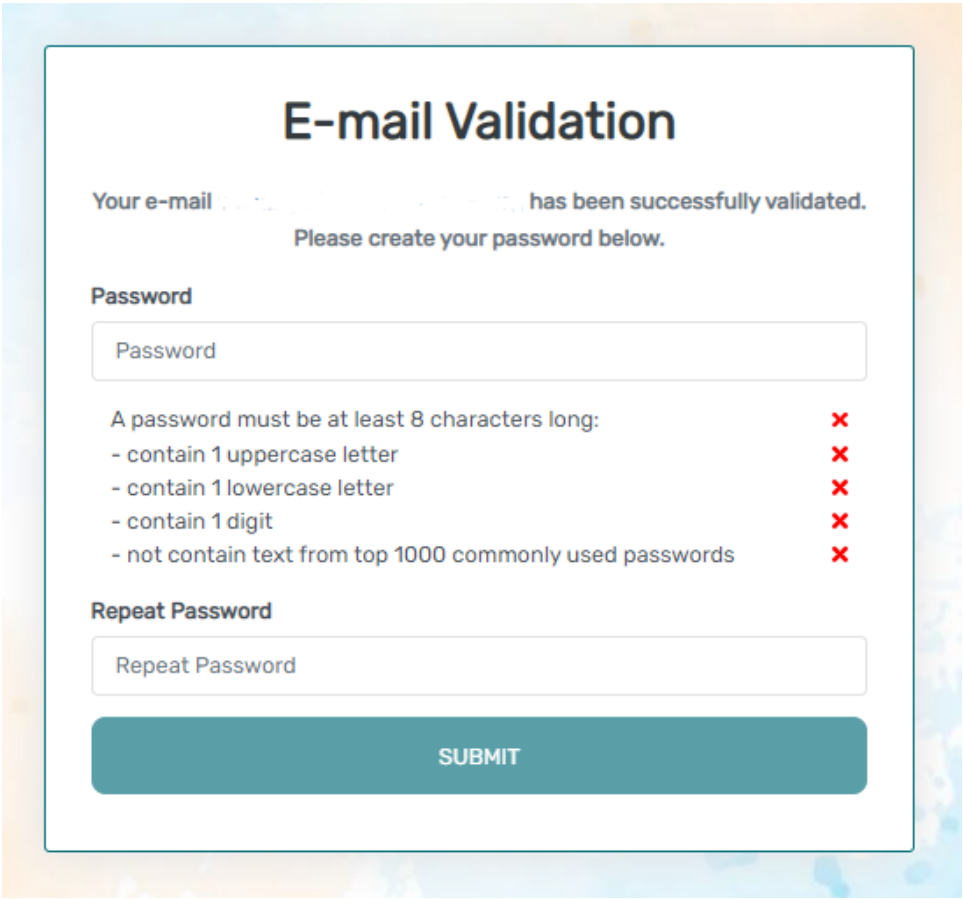
- Step 4: Select whether you are interested in being contacted by NORD regarding available studies. When you are finished with this page, click “Next”.



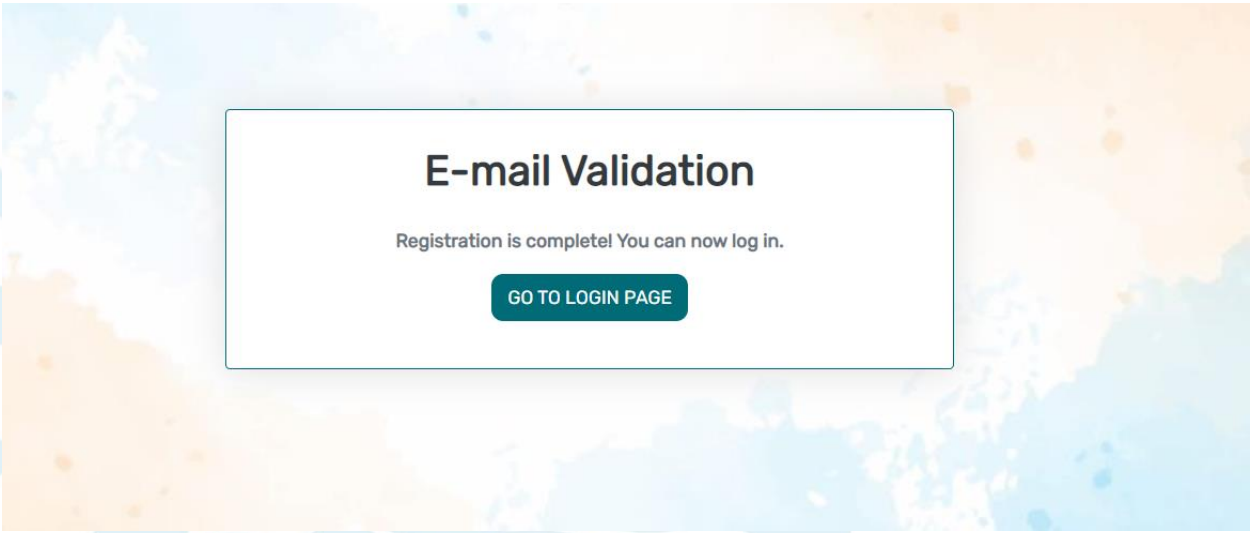
- Step 5: Select “Next” so that an activation link is sent to your e-mail to complete registration.



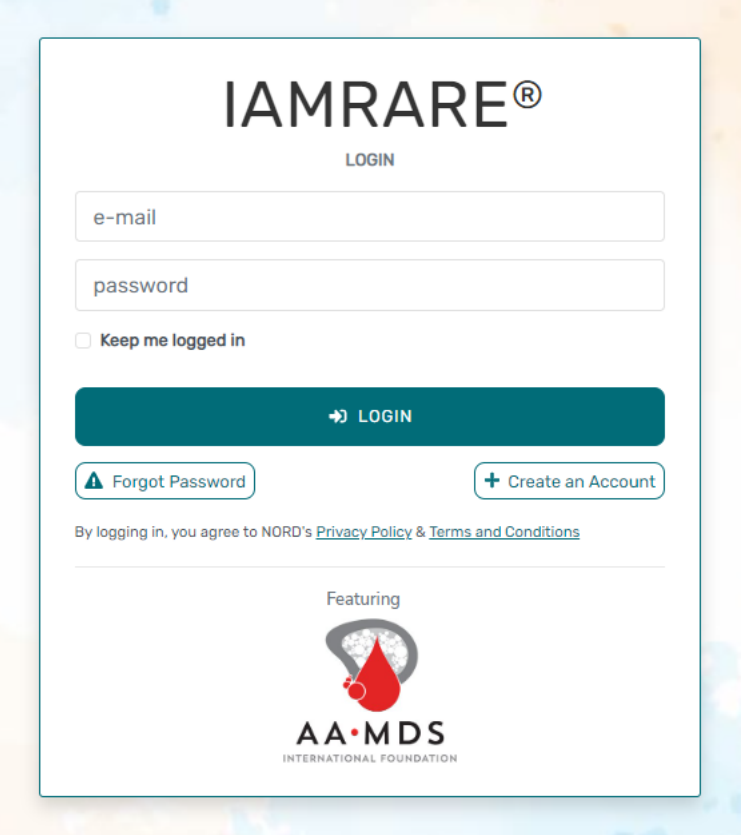
- Step 6: Click the link you are sent via e-mail. Please check your Spam folder if you do not see the e-mail. You will be taken to the following screen in a new tab within your browser. Set your password and click “Submit”.



- Step 7: Your validation is now complete. Select “Go to Login Page”.

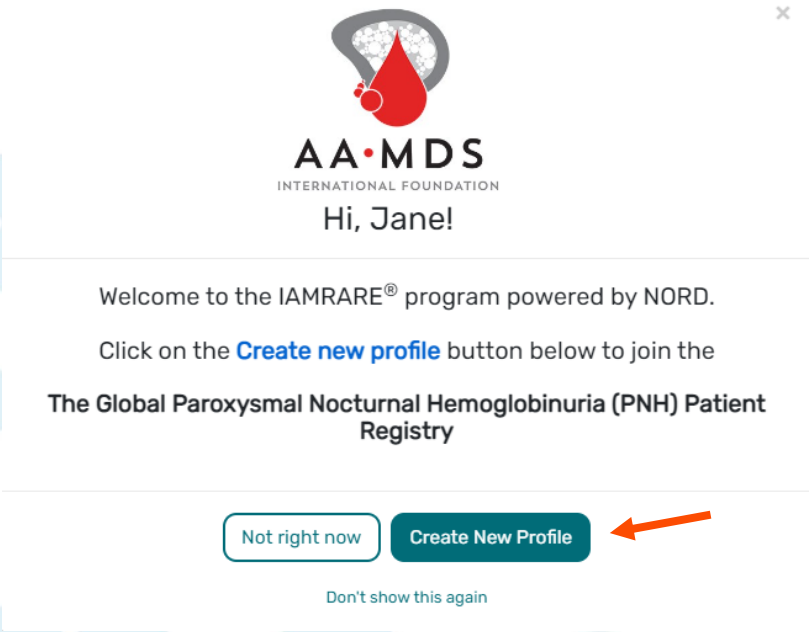


- Step 8: Log in using your new e-mail and password.

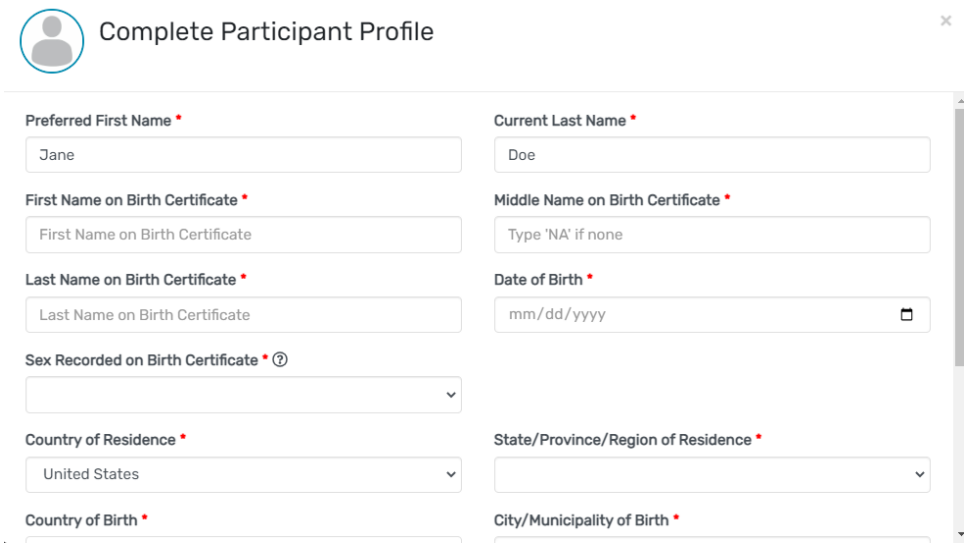


Create Profile

- Step 1: To start, click Create New Profile.

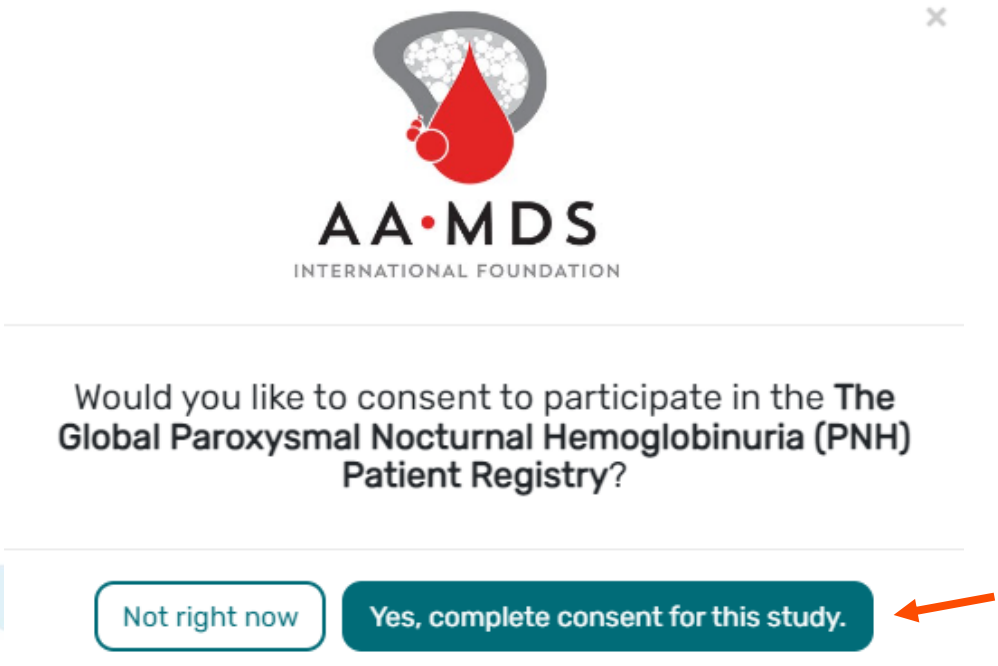


- Step 2: Fill out the Participant Profile

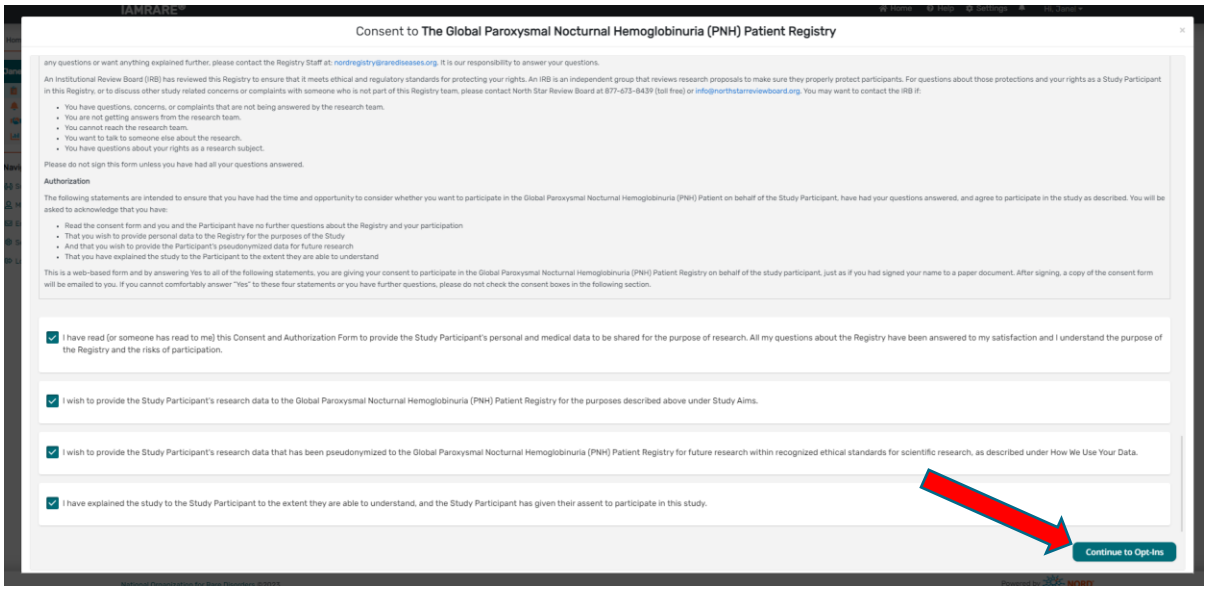


Consent to the Study

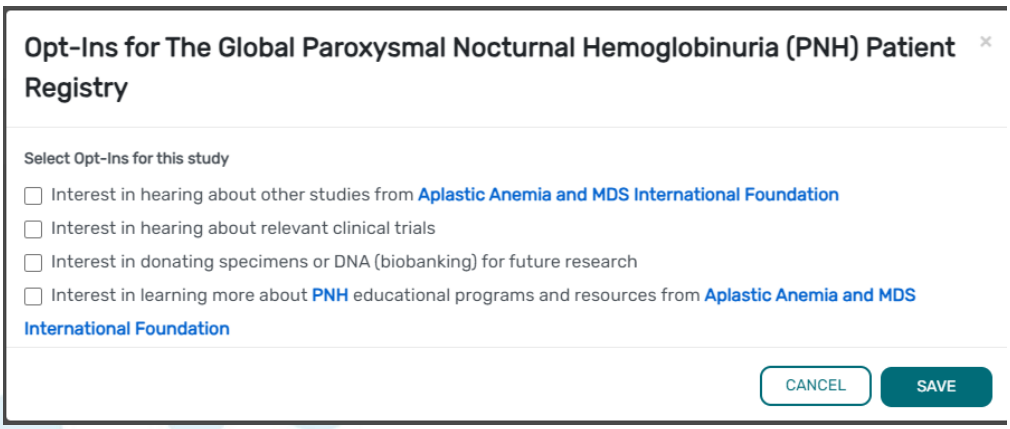
- Step 1: Click on “Yes, complete consent for this study.”



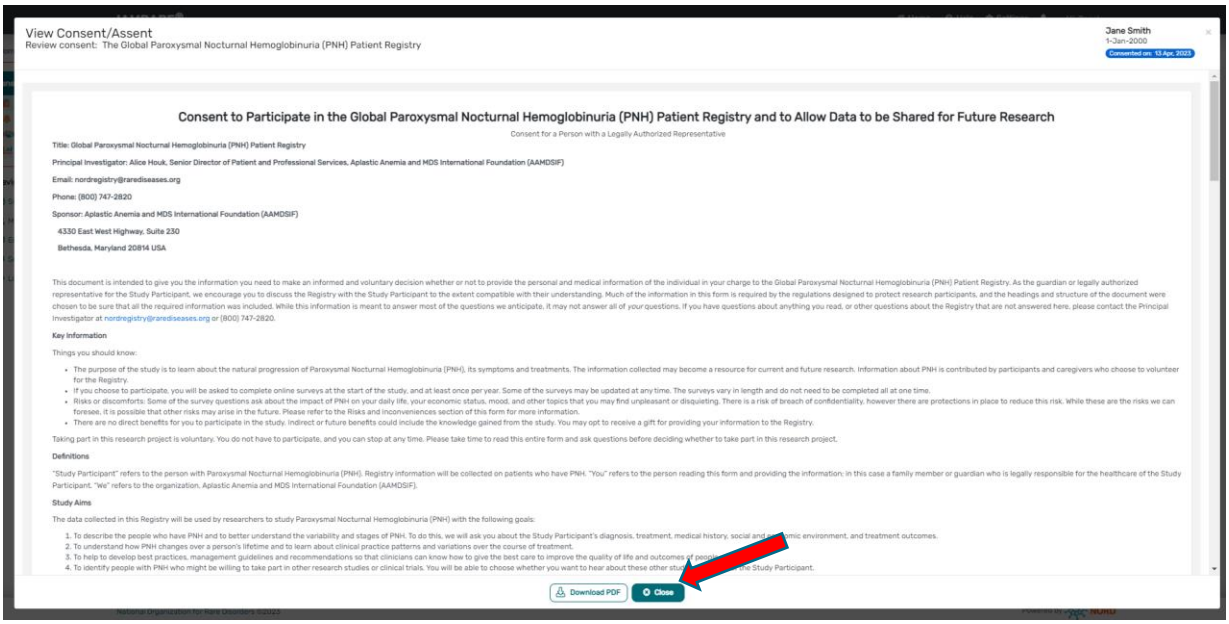
- Step 2: Scroll down and read through the consent form thoroughly. Once you finish reading, read through the statements thoroughly. If you are comfortable consenting to participate in the study, please read each statement and authorize your consent. After checking the boxes, click “Continue to Opt-Ins.”



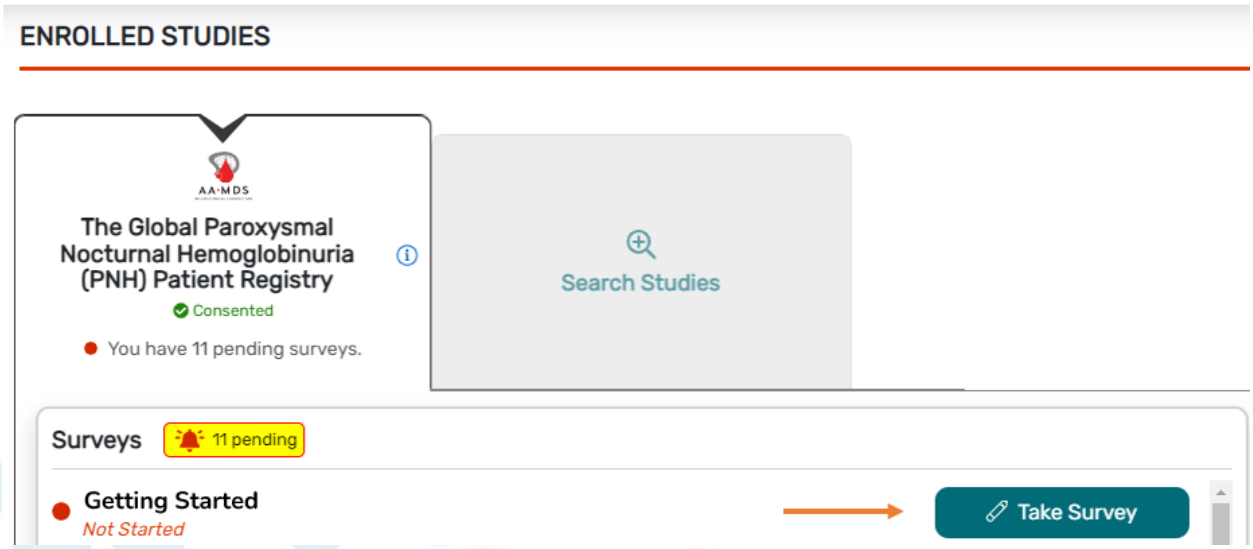
- Step 3: Step 3: Select your opt-ins, then click Save and Review.



- Step 4: Download a copy of your consent or click Close to continue.



- Step 5: You will now have access to start taking surveys.



- Please note, to complete some of the surveys, it may be helpful to gather any PNH treatment notes you have in advance.

View Responses and Reports

- Step 1: Once you have submitted a survey, you are able to view your responses to that survey as well as the graphs for any questions that are programmed to show graphs. Click “View Responses” to see your completed survey. Click “Reports” to see any available graphs.