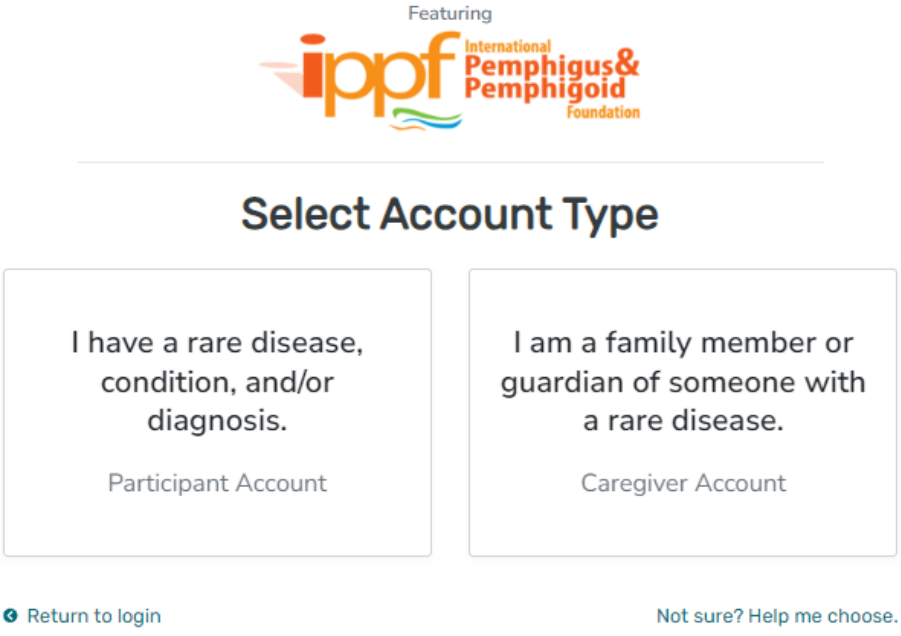
Participant User Guide

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 Pemphigus or Pemphigoid, select **Participant Account**.
    - If you are entering information for someone else who has Pemphigus or Pemphigoid or you have Pemphigus or Pemphigoid and are also entering information for yourself), select **Caregiver Account**.
    - If you are entering information for a Pemphigus or Pemphigoid patient who has passed away, 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”.

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Featuring

Participant Registration

Terms & Conditions | Contact Info | Notifications | Review & Submit | Confirmation

Below are links to the IAMRARE Terms of Use and Privacy Guidelines. The purpose of these documents is to outline your rights and responsibilities when using the platform. These documents include: 1) Standard policies for all studies on this platform, 2) A privacy statement that details how your data can be used, 3) Information outlining the unacceptable uses of the platform, and 4) Information about how to address questions and issues.

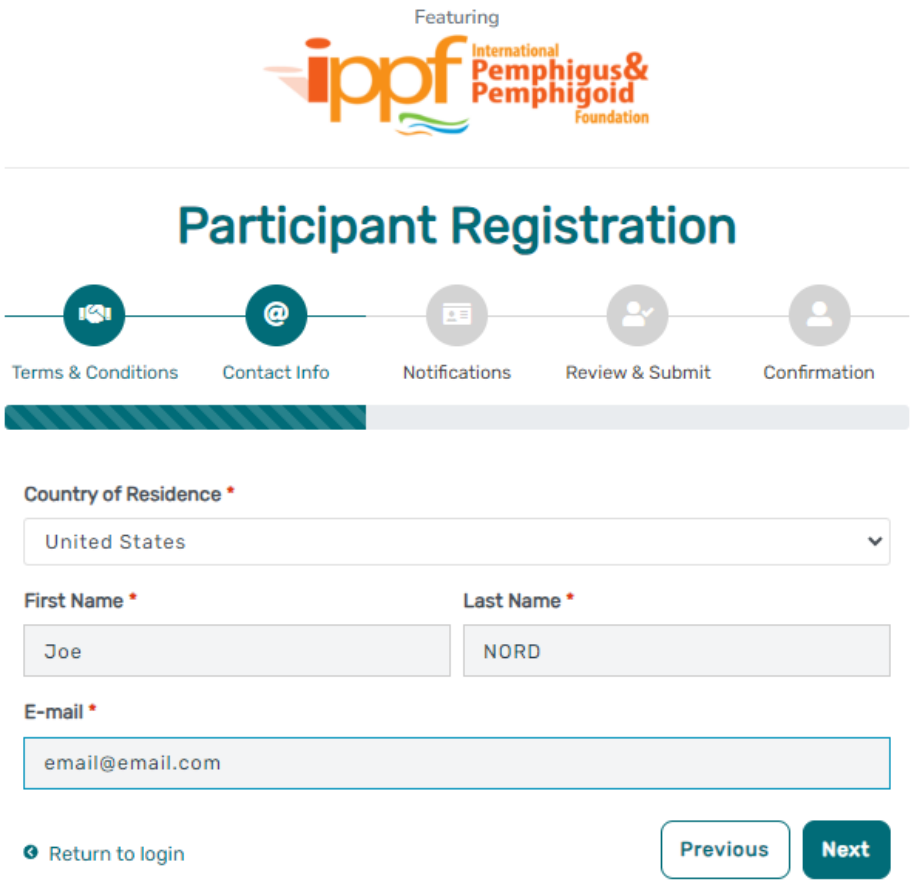
Acknowledgements:

- [x] **You are at least 18 years of age, the age of majority in your state, province or country, and able to consent on behalf of yourself and/or an individual that you have legal responsibility for. ***
- [x] **You agree to support the Platform's research activities by providing truthful, appropriate information and to not do anything that will put the Services or the information in the Platform at risk. ***
- [x] **You understand that NORD will use reasonable efforts to keep the information you enter on the Services safe, but no data transmissions over the Internet can be guaranteed to be 100% secure. The information you provide will be available to authorized users at NORD for platform maintenance and research activities, as well as to the sponsor of the studies you consent to participate in. ***
- [x] **You agree to the Terms and Conditions & Privacy Policy ***

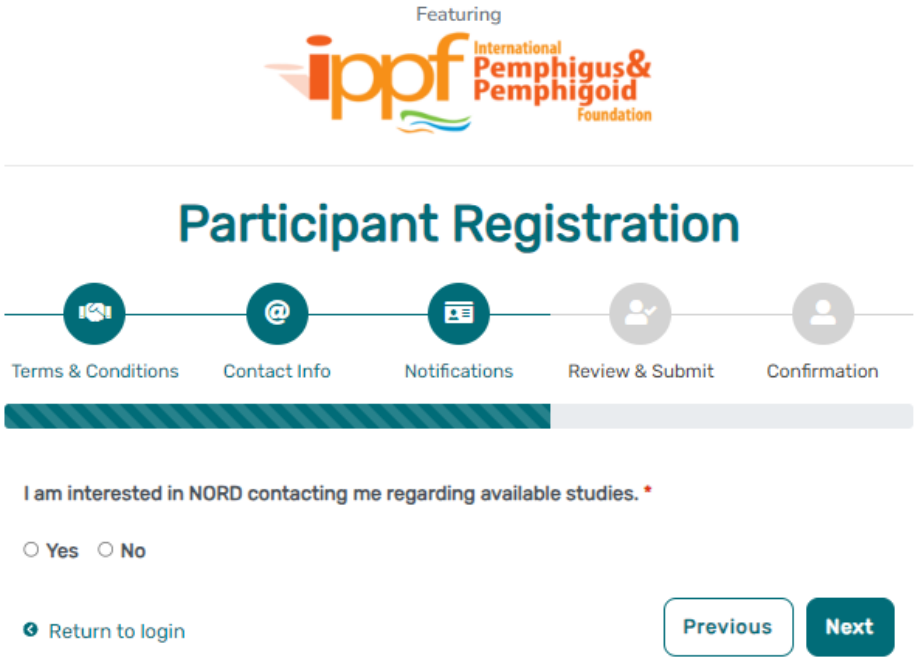
Return to login

Next

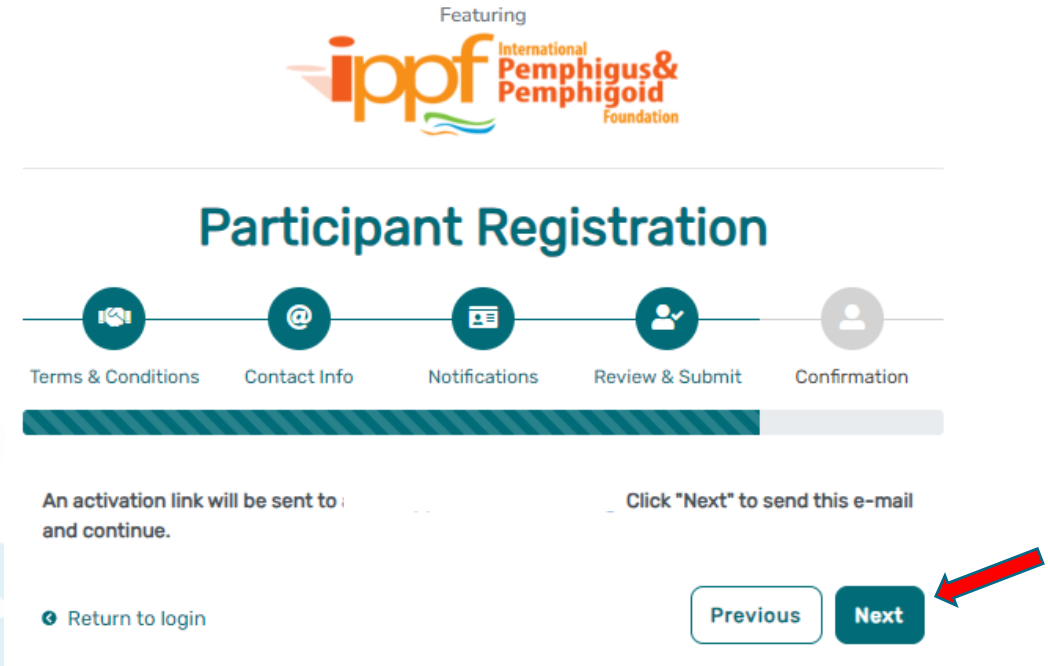
- Step 3: Enter your personal information in the spaces provided. When you are finished with this page, click “Next”.



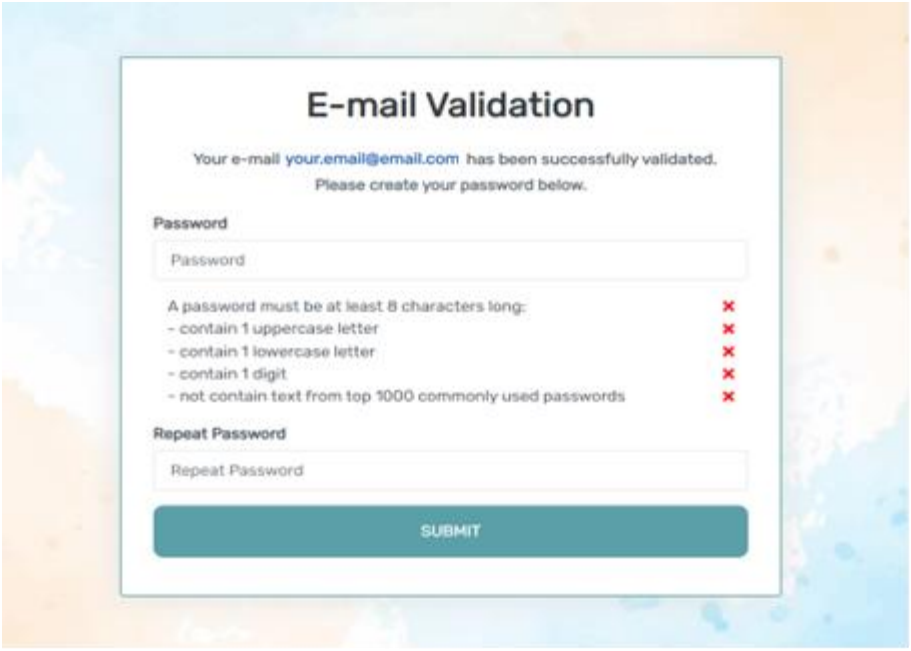
- Step 4: Select whether you are interested in being contacted by NORD regarding available studies. When you are finished with this page, click “Next”.



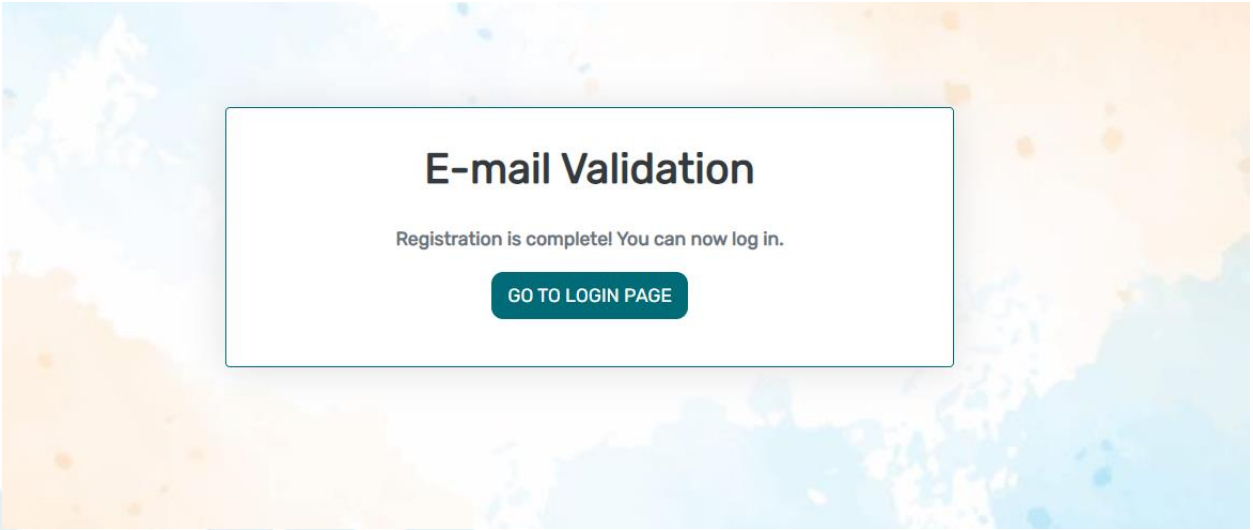
- Step 5: Select “Next” so that an activation link is sent to your e-mail to complete registration.



- 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.

IAMRARE®

LOGIN

e-mail

password

Keep me logged in

LOGIN

Forgot Password

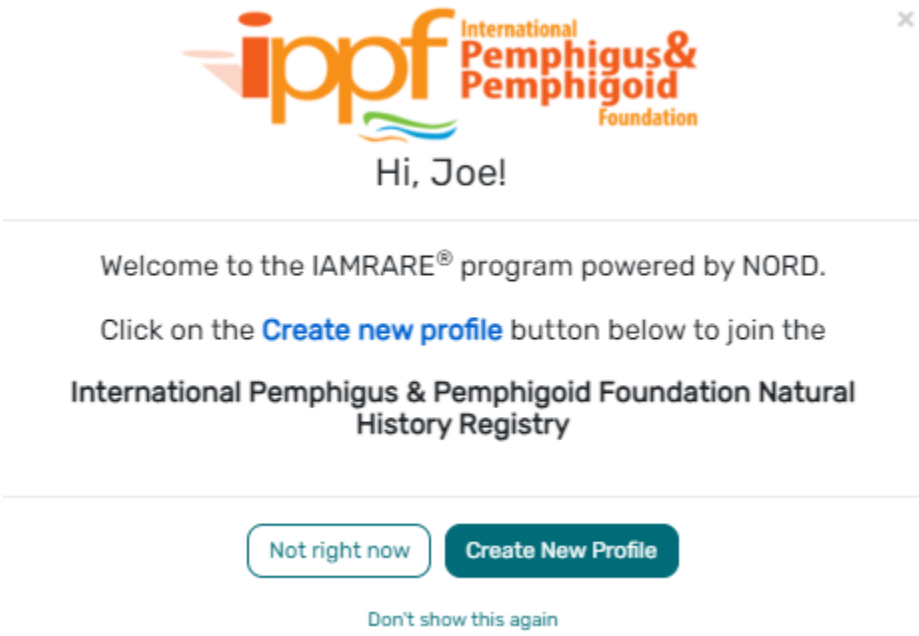
Create an Account

By logging in, you agree to NORD's Privacy Policy & Terms and Conditions

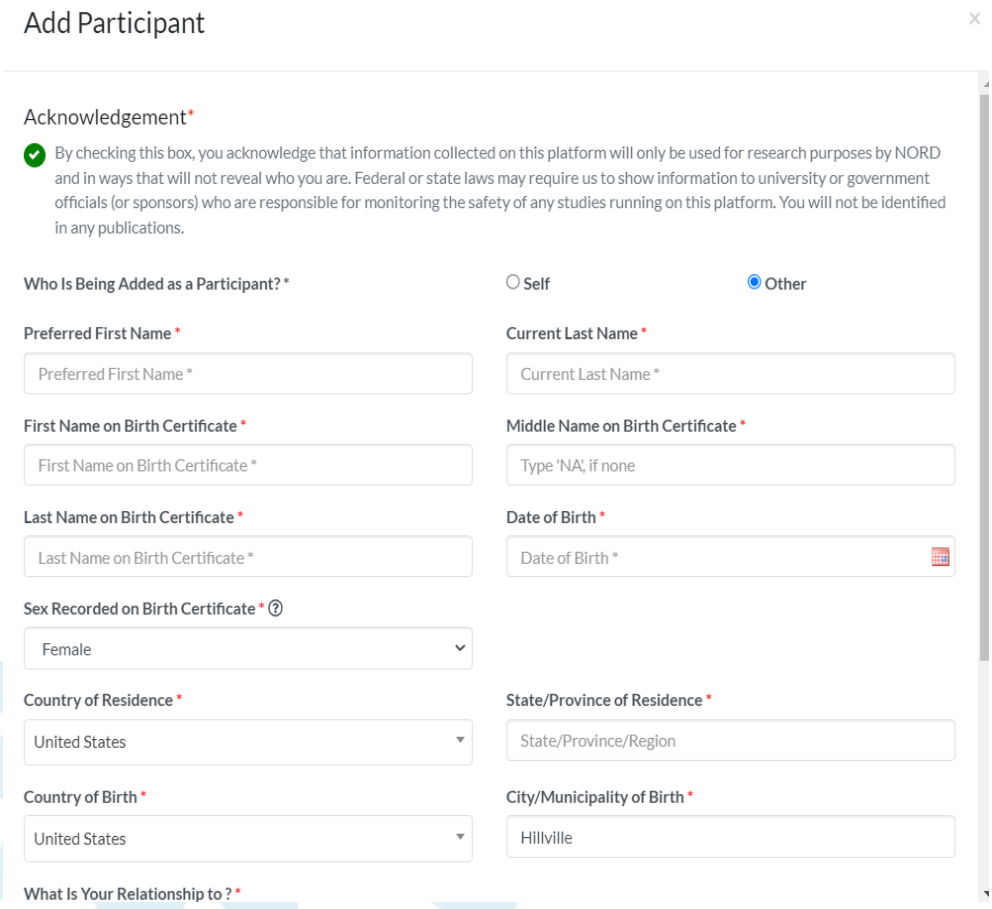
Featuring

Add a Participant

- Step 1: To start, click Yes, register new participant.



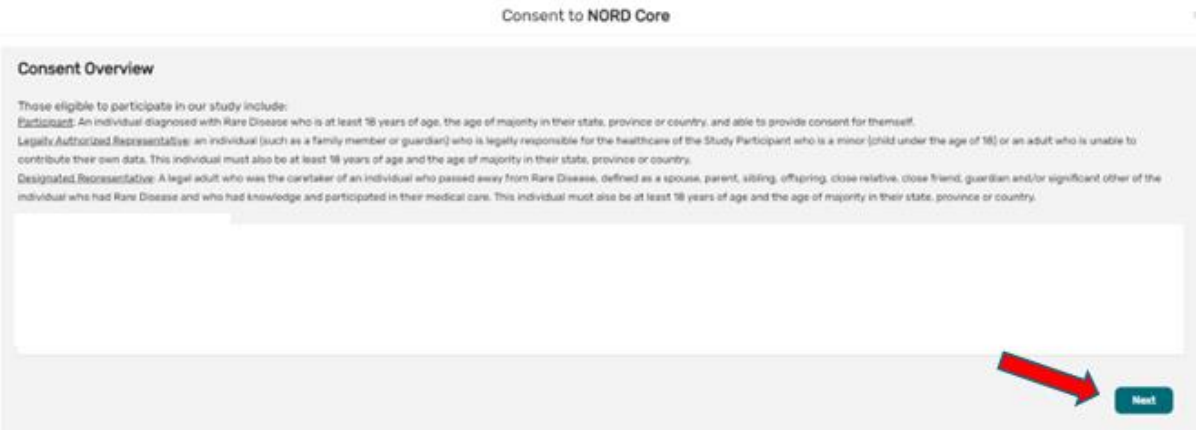
- Step 2: Fill out the Participant's information.



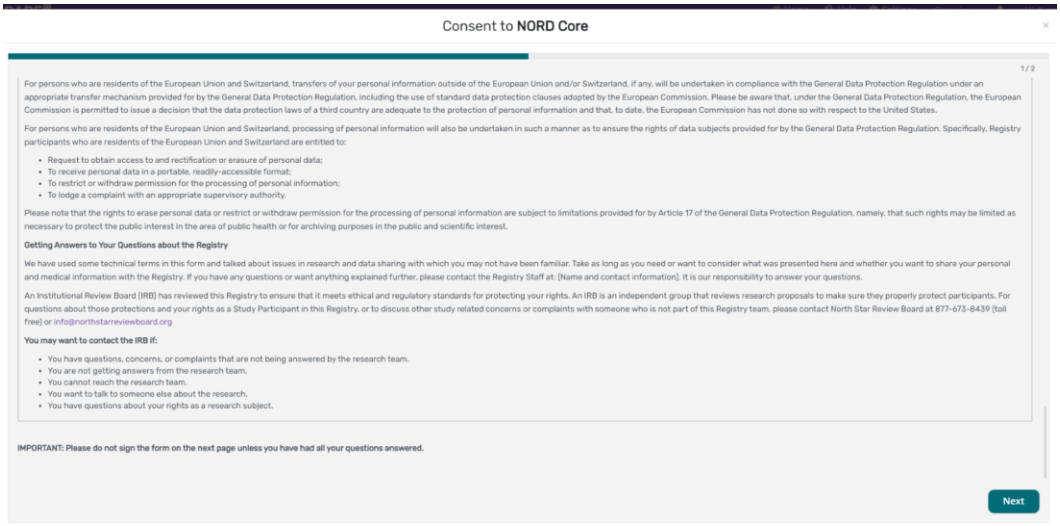
Consent to the Study

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

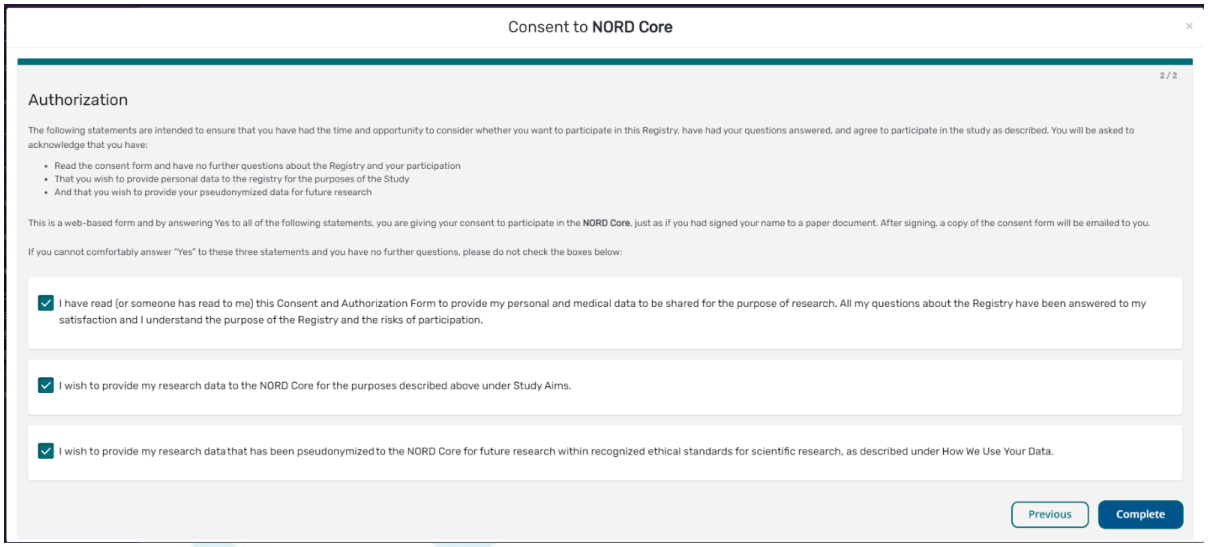
- Step 2: Read through the consent overview and answer any questions.



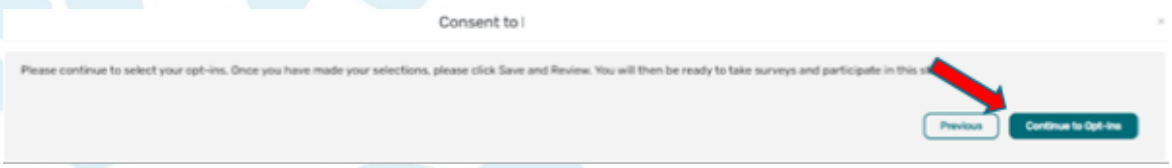
- Step 3: Scroll down and read through the consent form thoroughly. Once you finish reading, click the “Next” button



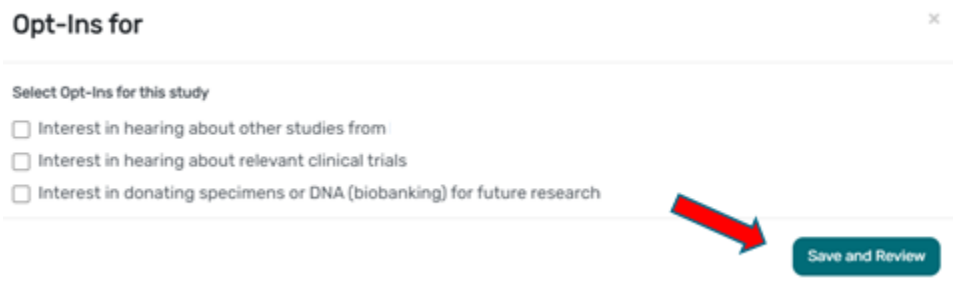
- Step 4: Once you click “Next” and reach the Authorization form, read through the statements thoroughly. If you are comfortable consenting to participate in the study, please read each statement and authorize your consent. After checking the boxes, click “Complete.”



- Step 5: Click Continue to Opt-ins.

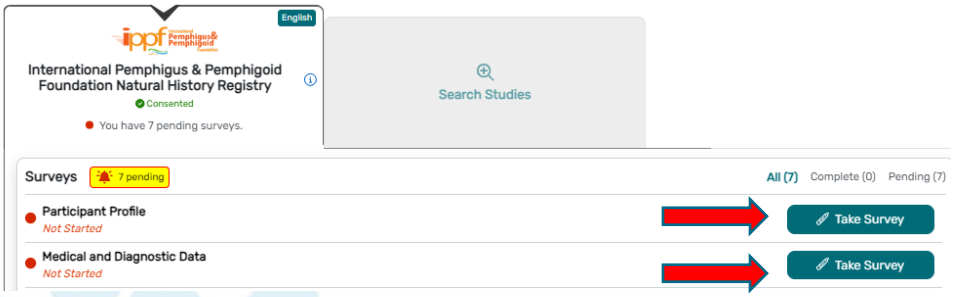


- Step 6: Select your Opt-ins and click Save and Review.



- Step 7: Download a copy of your consent or click Close.

- Step 8: You will now have access to start taking surveys.



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.