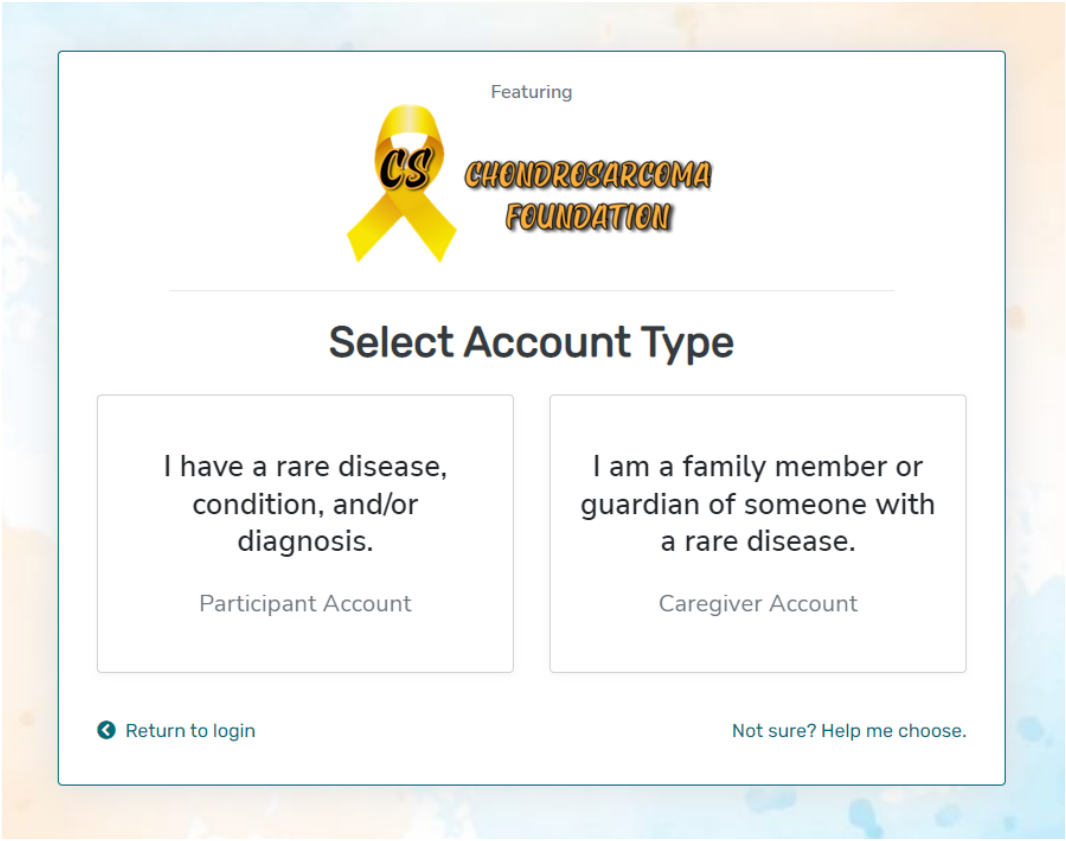
Chondrosarcoma Patient Registry User Guide

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 chondrosarcoma, select **Participant Account**.
    - If you are entering information for someone else who has chondrosarcoma, select **Caregiver Account**.
    - If you are entering information for a chondrosarcoma patient who has passed away, select **Caregiver Account**.



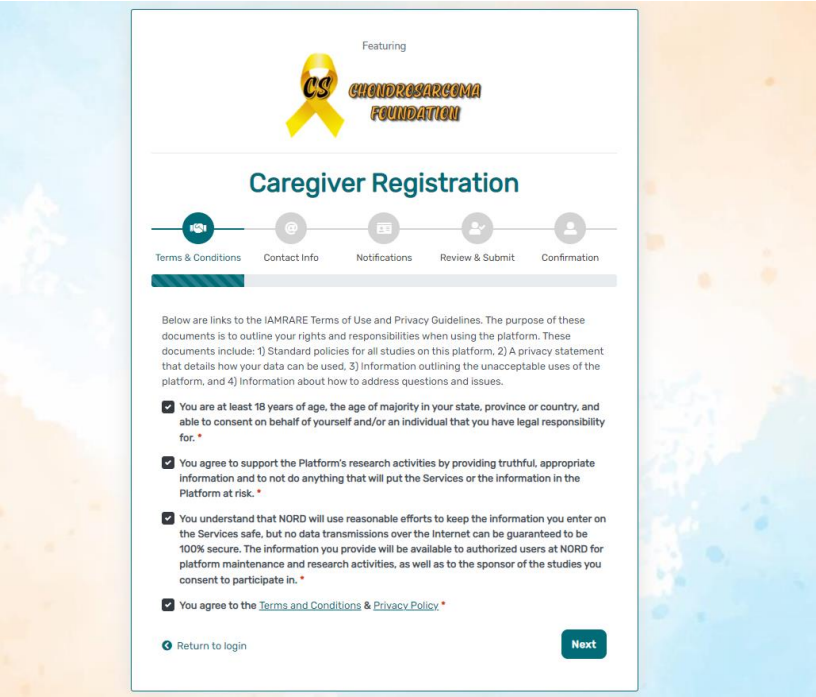
1779 MASSACHUSETTS AVENUE NW, SUITE 500
WASHINGTON, DC 20036
T 202-588-5700 ▪ F 202-588-5701

55 KENOSIA AVENUE
DANBURY, CT 06810
T 203-744-0100 ▪ F 203-263-9938

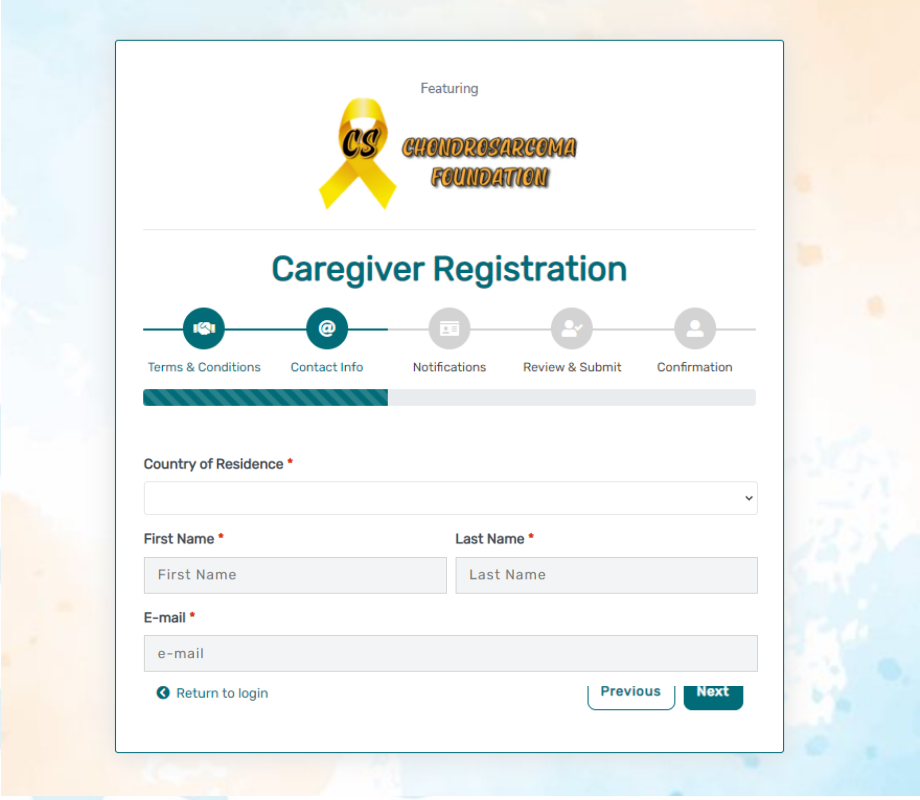
1900 CROWN COLONY DRIVE, SUITE 310
QUINCY, MA 02169
T 617-249-7300 ▪ F 617-249-7301

rarediseases.org ▪ orphan@rarediseases.org

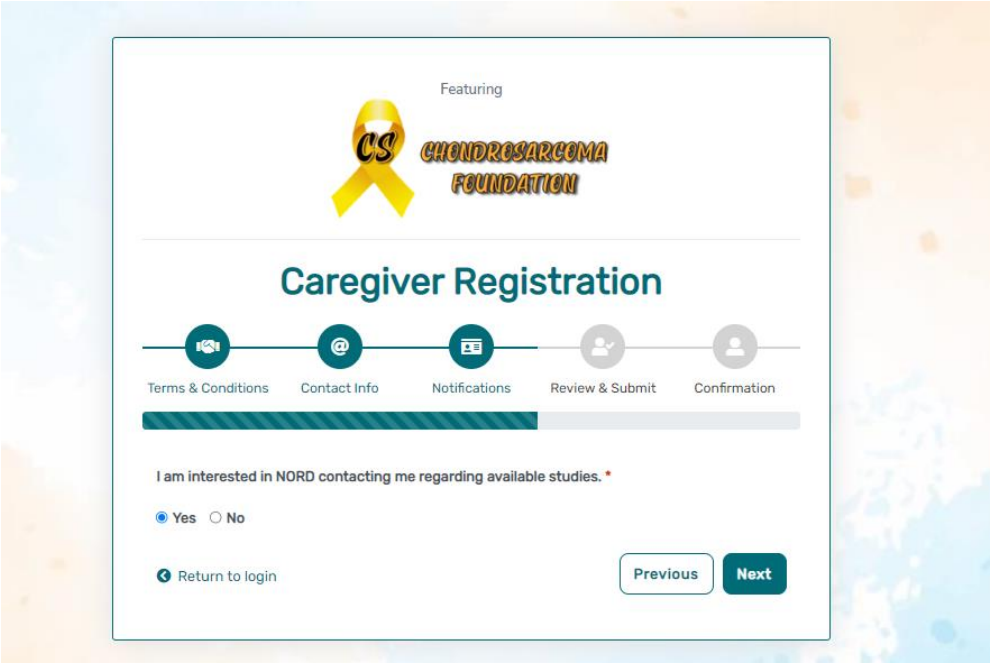
- Step 2: Read the Terms and Conditions and Privacy Policy and attest to the statements provided. When you are finished with this page, click “Next”.



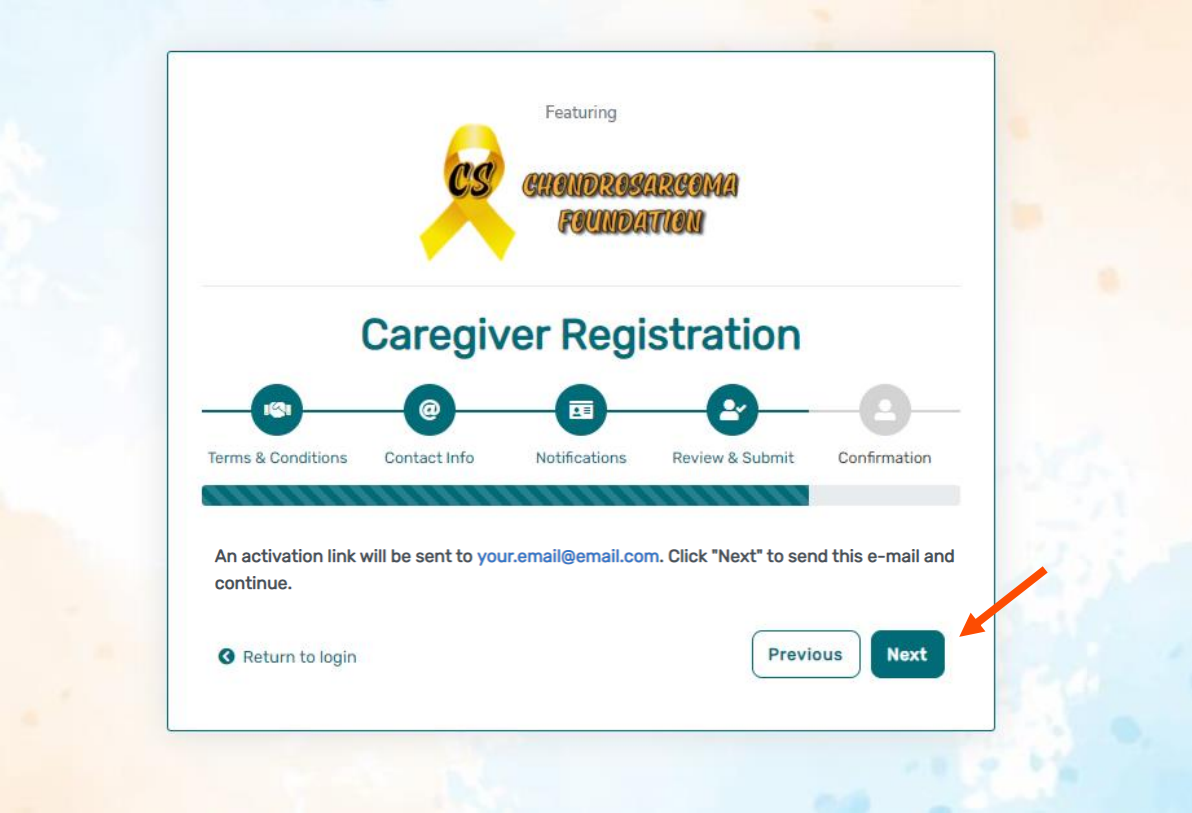
- Step 3: Enter your personal information in the spaces provided. When you are finished with this page, click “Next”.



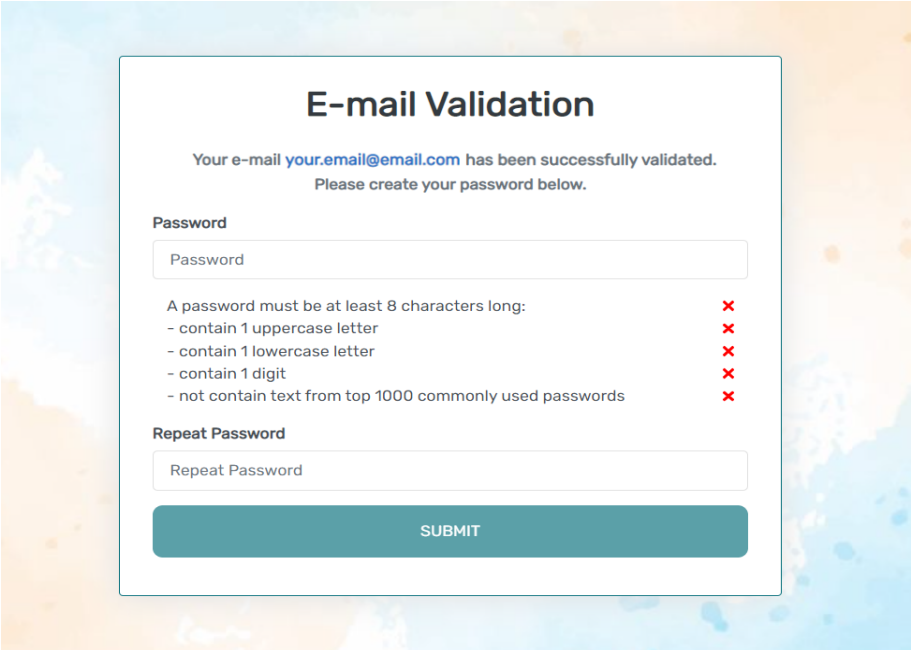
- Step 4: Select whether you are interested in being contacted by NORD regarding available studies. When you are finished with this page, click “Next”.



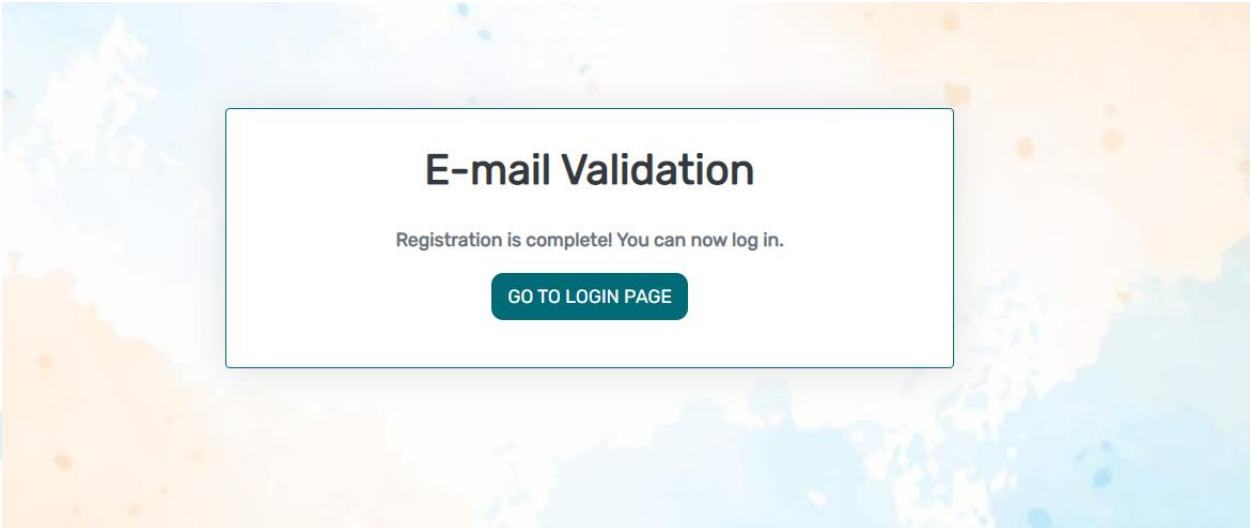
- Step 5: Select “Next” so that an activation link is sent to your e-mail to complete registration.



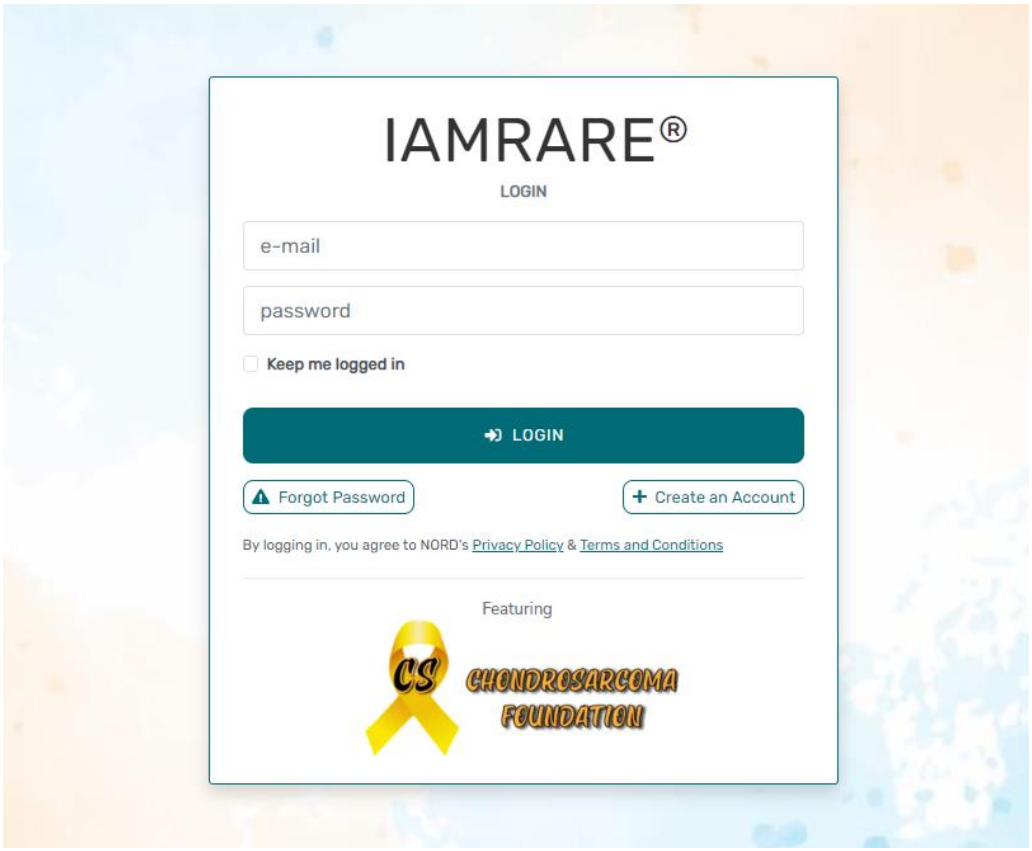
- Step 6: Click the link you are sent via e-mail. Please check your Spam folder if you do not see the e-mail. You will be taken to the following screen in a new tab within your browser. Set your password and click “Submit”.



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

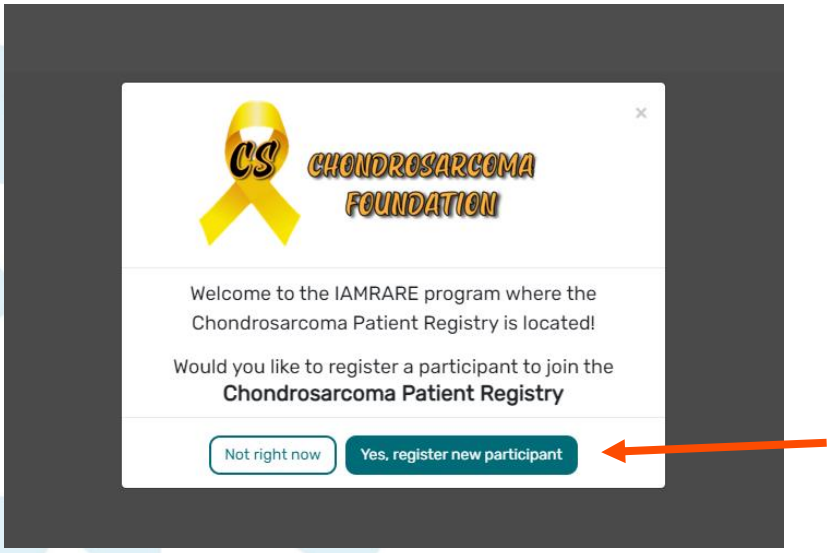


- Step 8: Log in using your new e-mail and password.

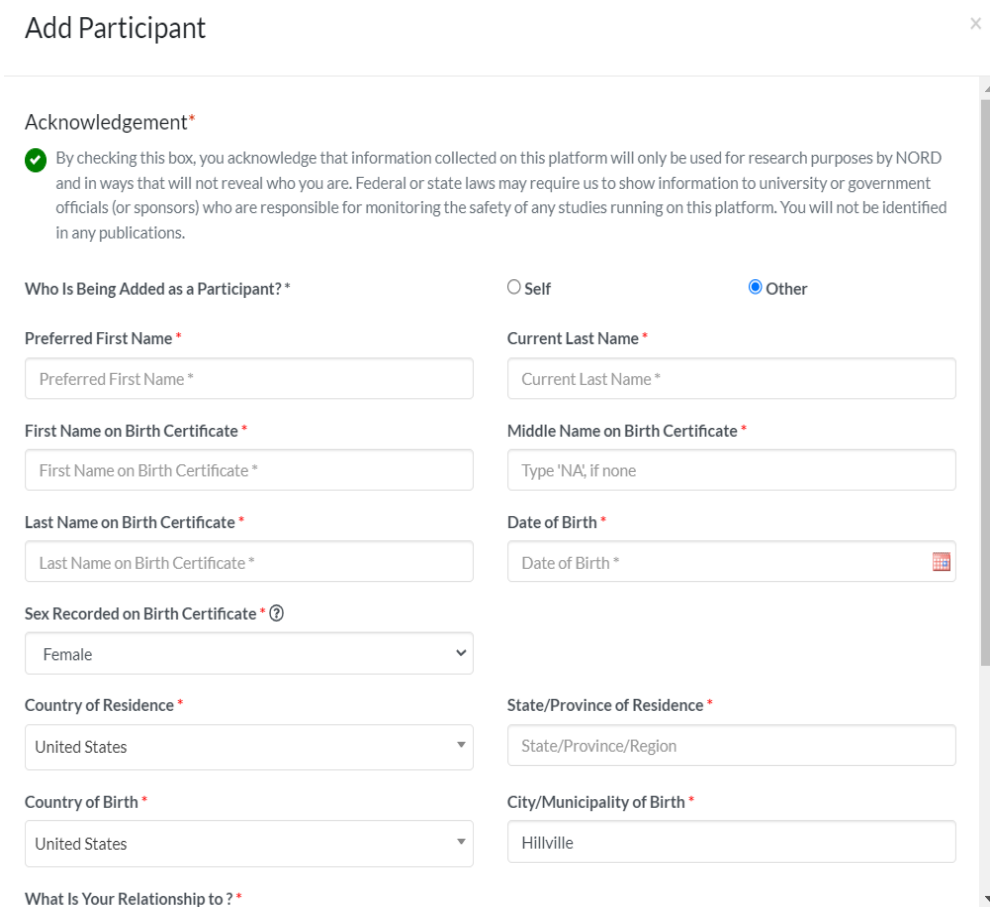


Add a Participant

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

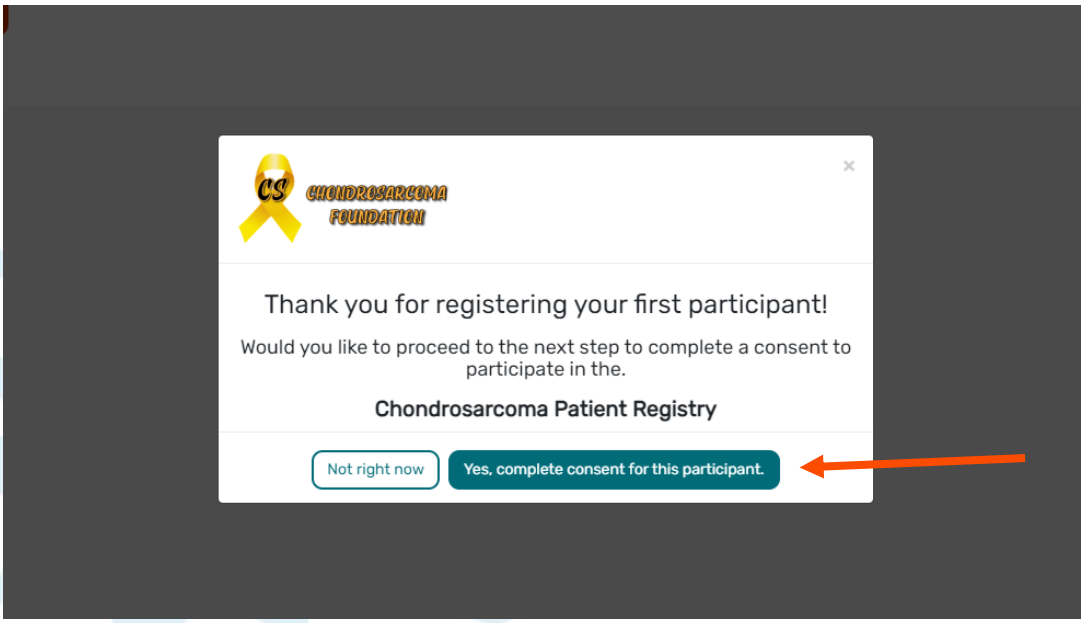


- Step 2: Fill out the Participant's information.

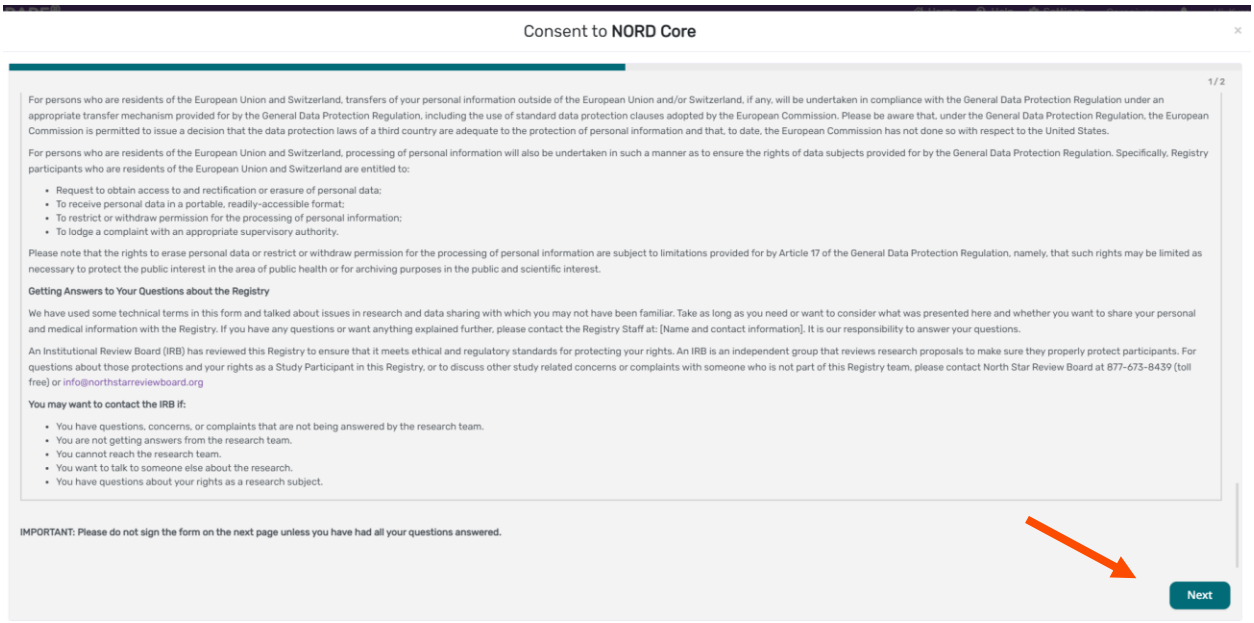


Consent to the Study

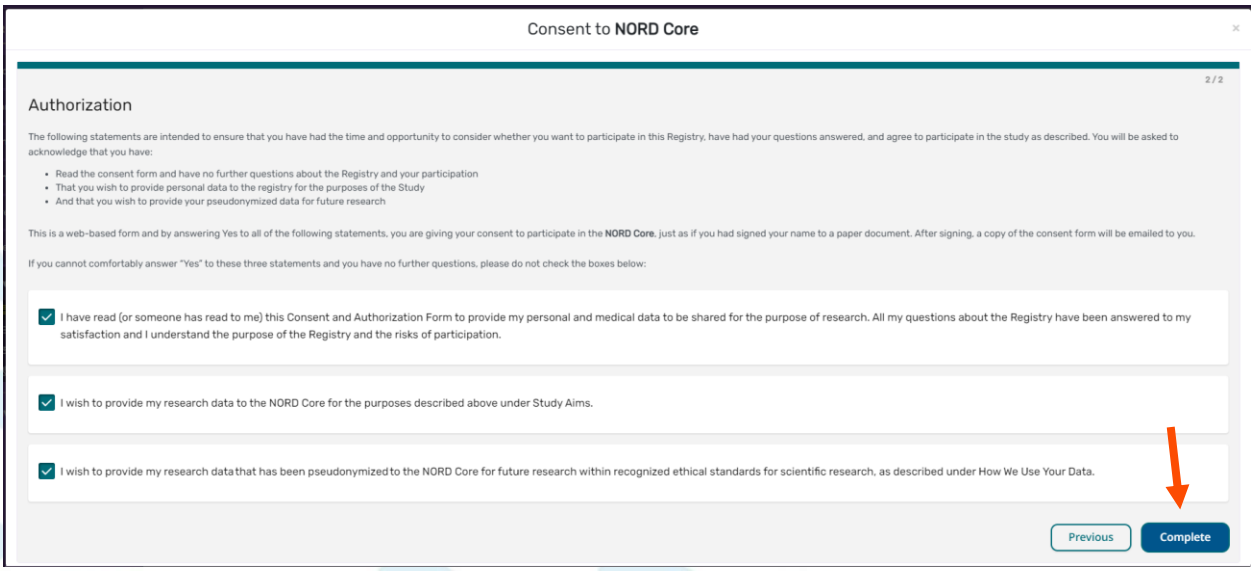
- Step 1: Click on "Yes, complete consent for this participant."



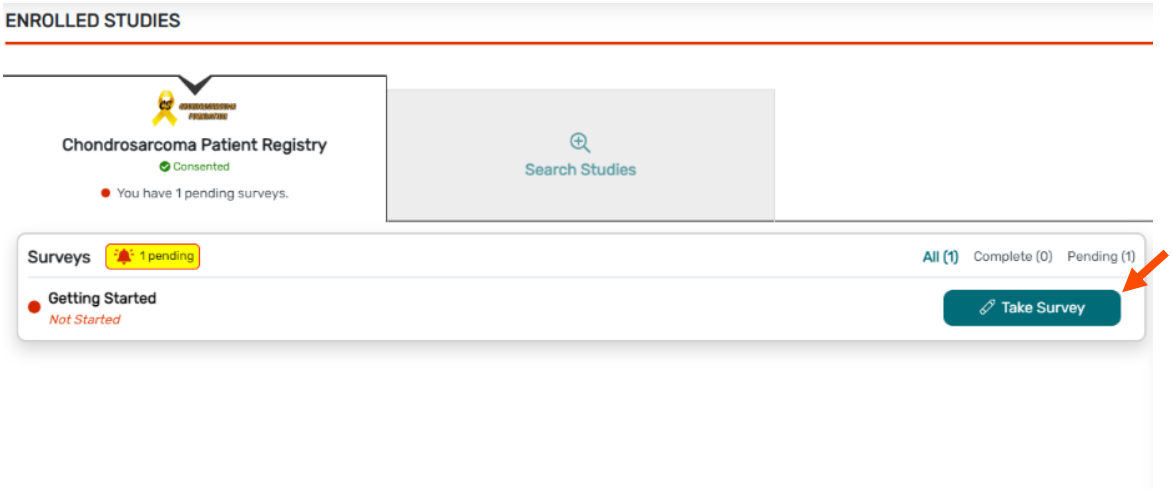
- Step 2: Scroll down and read through the consent form thoroughly. Once you finish reading, click the “Next” button.



- Step 3: 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 4: Once you click “Complete”, you will 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.