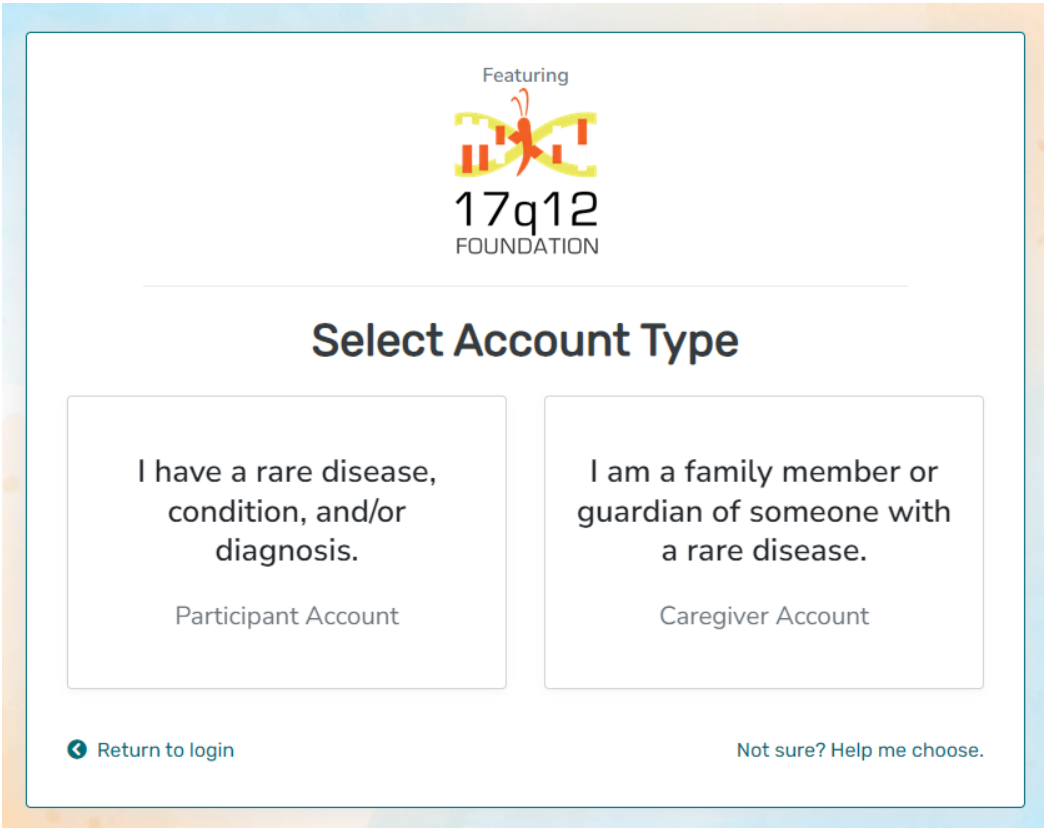
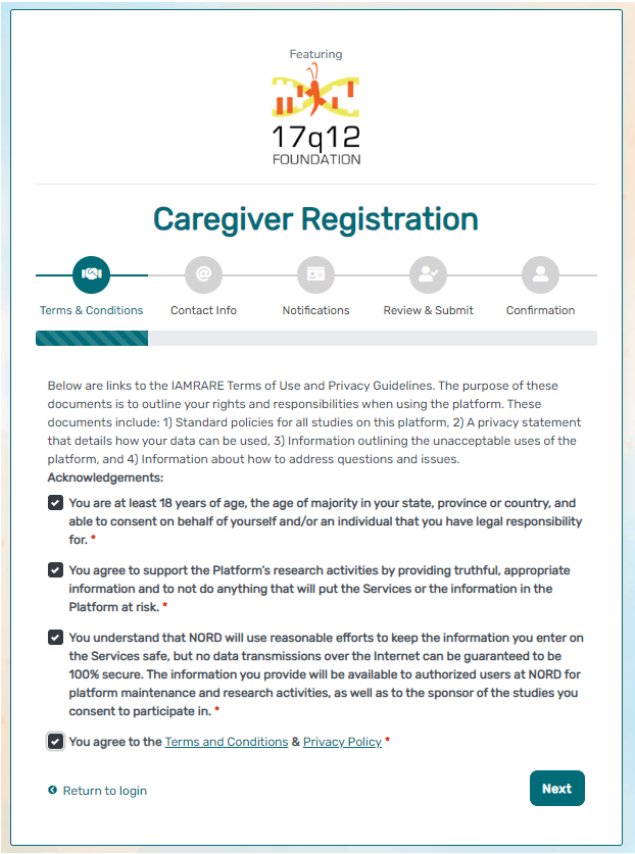
Chromosome 17q12 Deletion & Duplication Syndromes Patient Registry (17q12 Patient Registry) Participant User Guide

Register for an Account

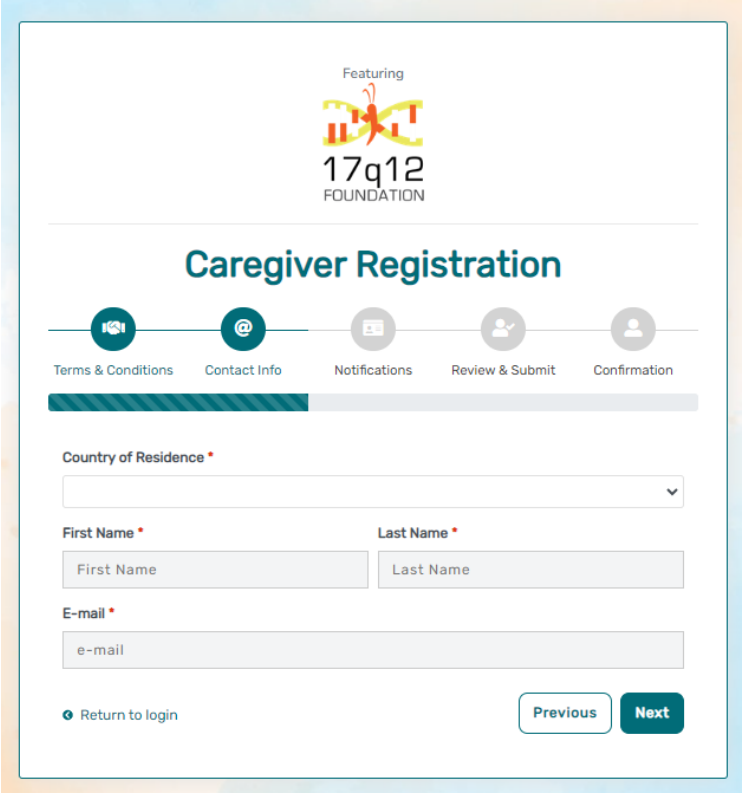
- Step 1: Select the appropriate Account Type. If you need more information to help you choose, click “Not sure? Help me choose”.
    - If **you** have a diagnosis of 17q12 Deletion of Duplication Syndrome, select **Participant Account**.
    - If you are entering information for **someone else** who has 17q12 Deletion of Duplication Syndrome, select **Caregiver Account**.
    - If you are entering information for a 17q12 Deletion of Duplication Syndrome **patient who has passed away**, select **Caregiver Account**.



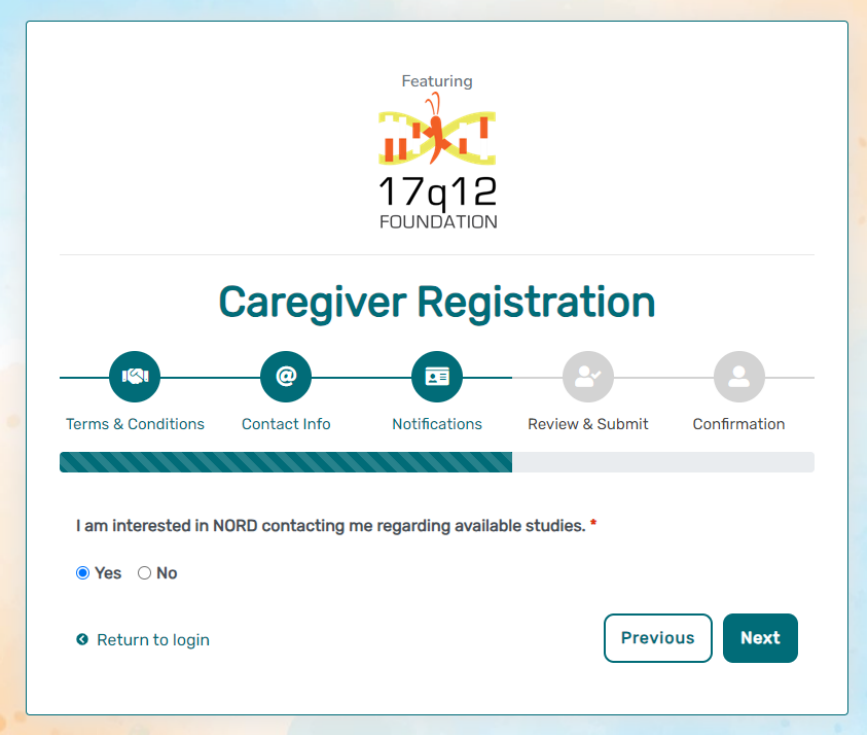
- Step 2: Read the Terms and Conditions and Privacy Policy and attest to the statements provided. When you are finished with this page, click “Next”.



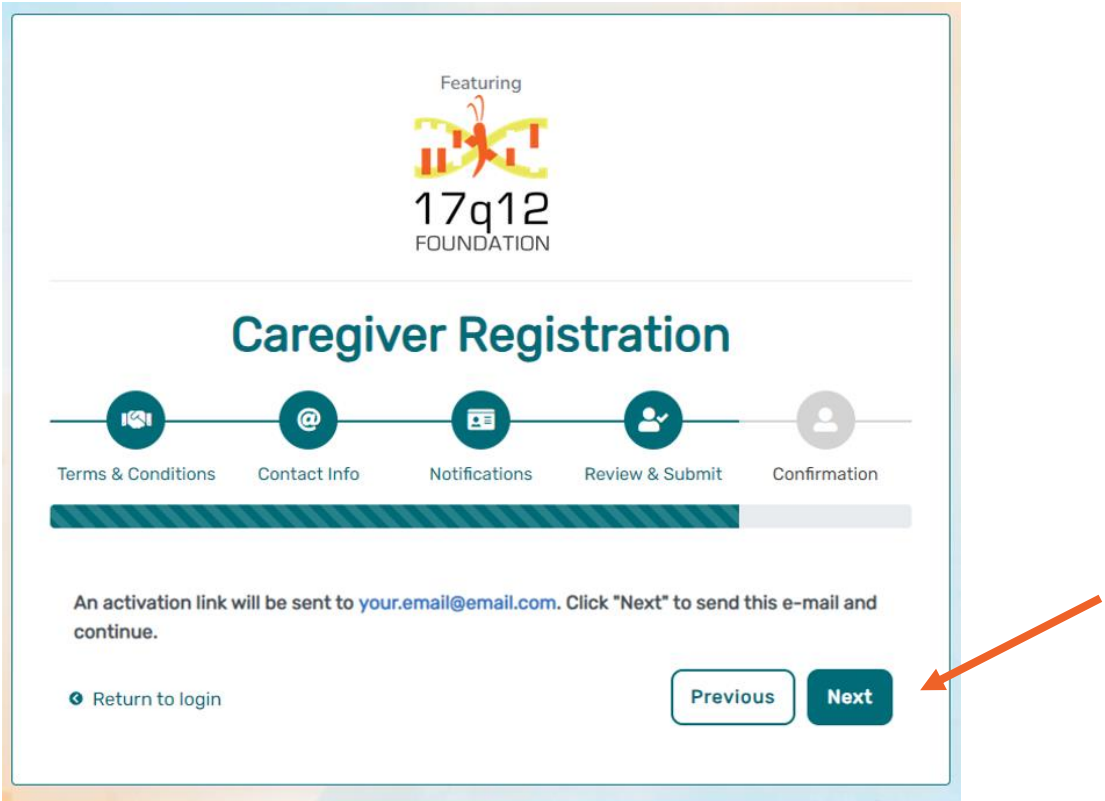
- Step 3: Enter your personal information in the spaces provided. When you are finished with this page, click “Next”.



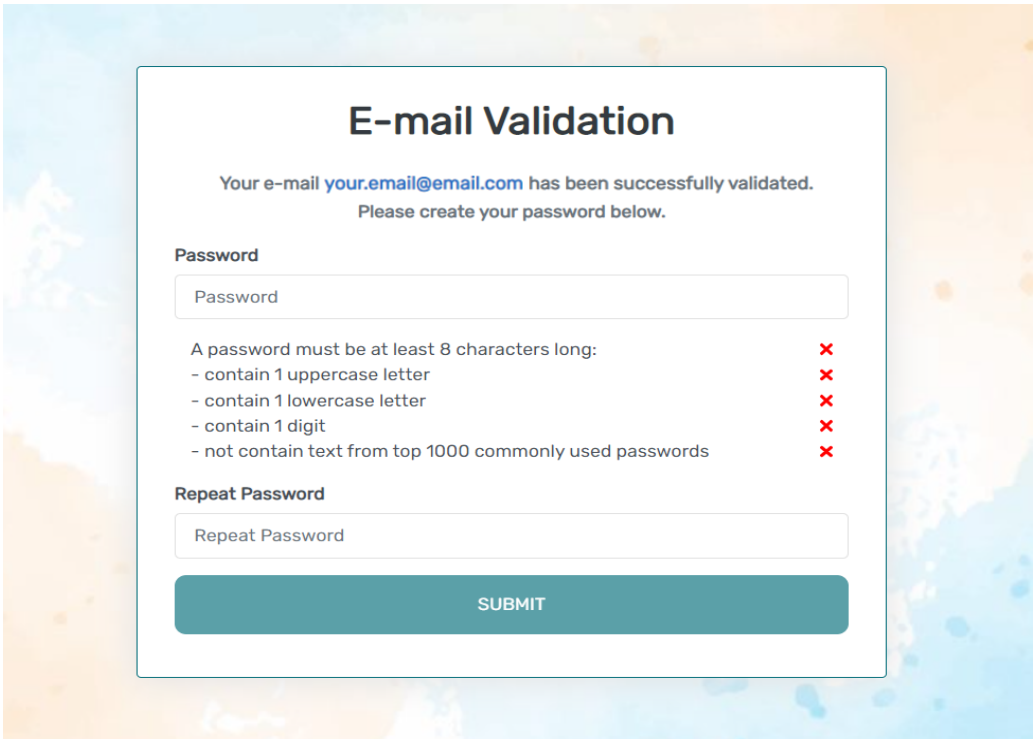
Step 4: Select whether you are interested in being contacted by NORD regarding available studies. When you are finished with this page, click “Next”.



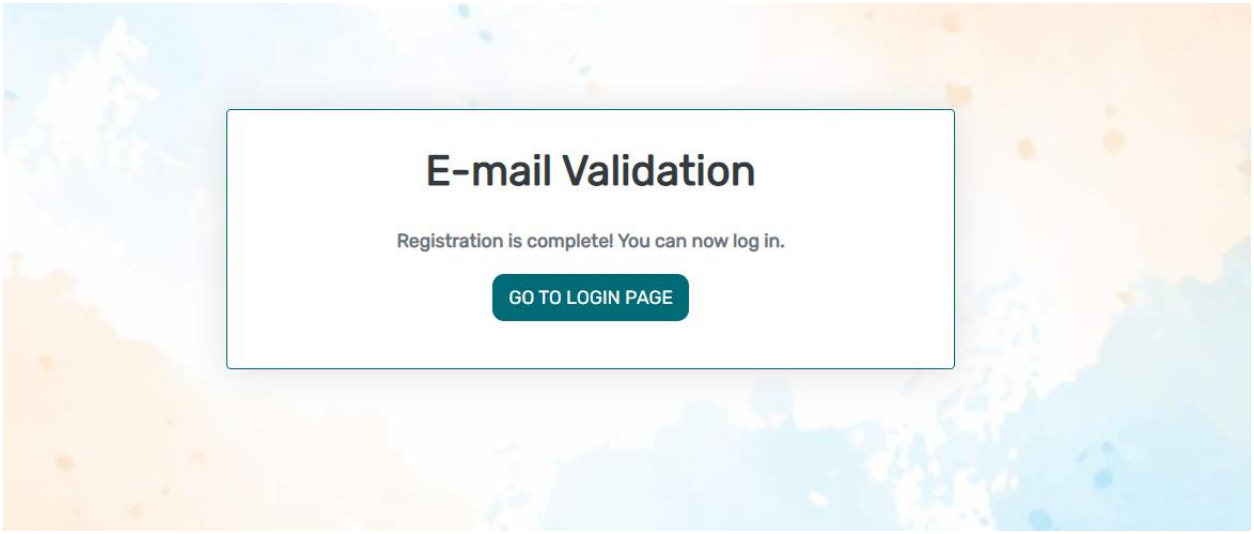
- Step 5: Select “Next” so that an activation link is sent to your e-mail to complete registration.



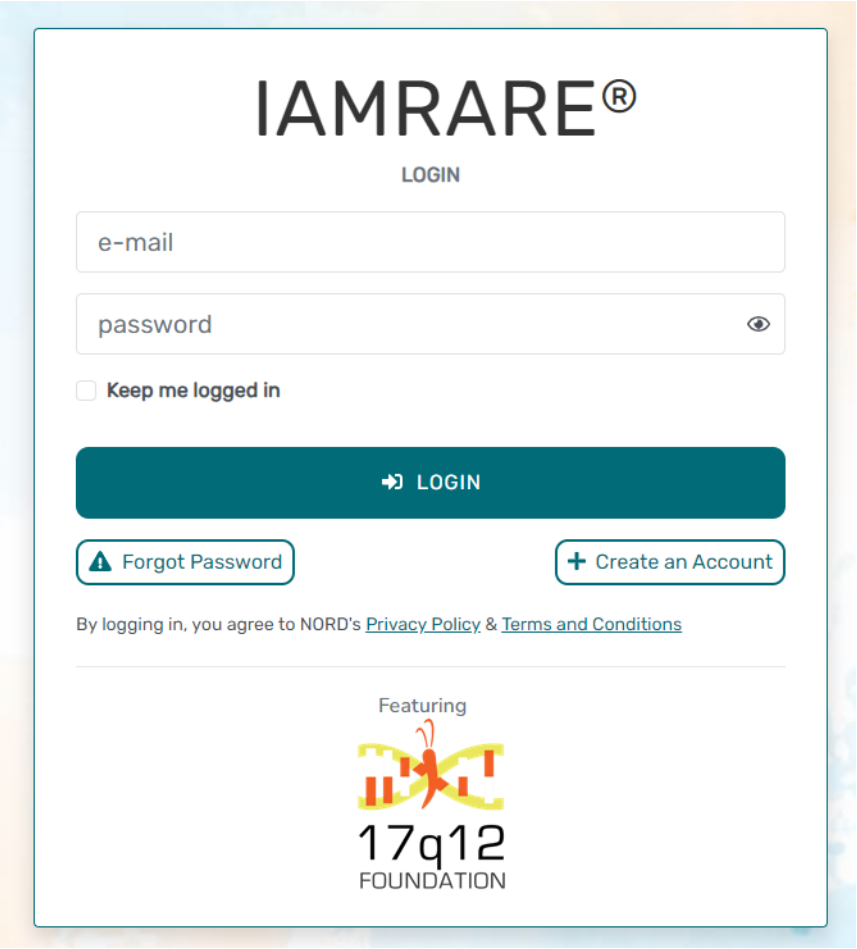
- Step 6: Click the link you are sent via e-mail. Please check your Spam folder if you do not see the e-mail. You will be taken to the following screen in a new tab within your browser. Set your password and click “Submit”.



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

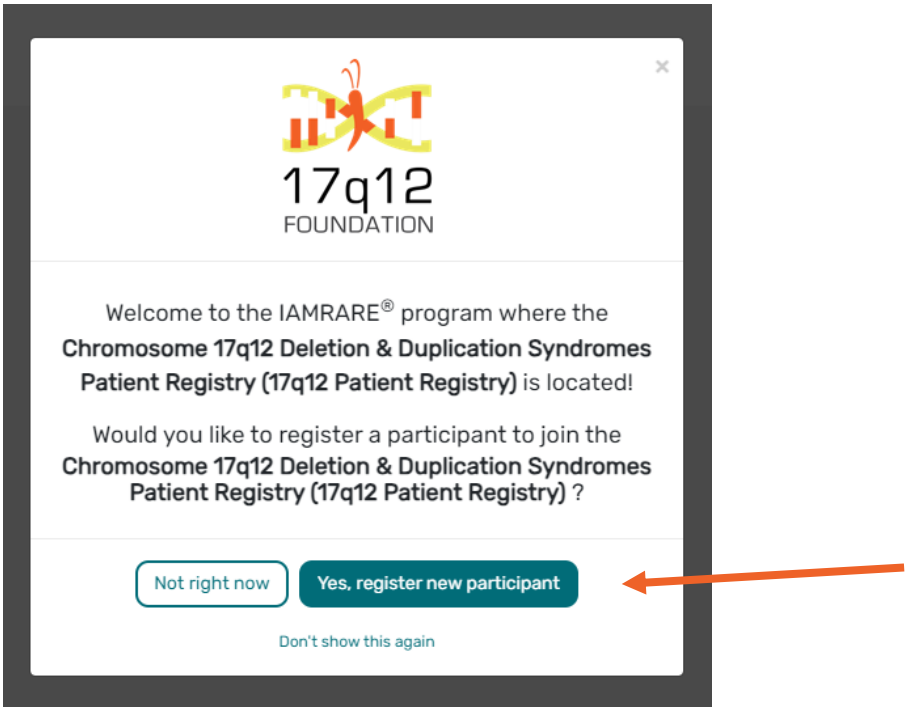


- Step 8: Log in using your new e-mail and password.

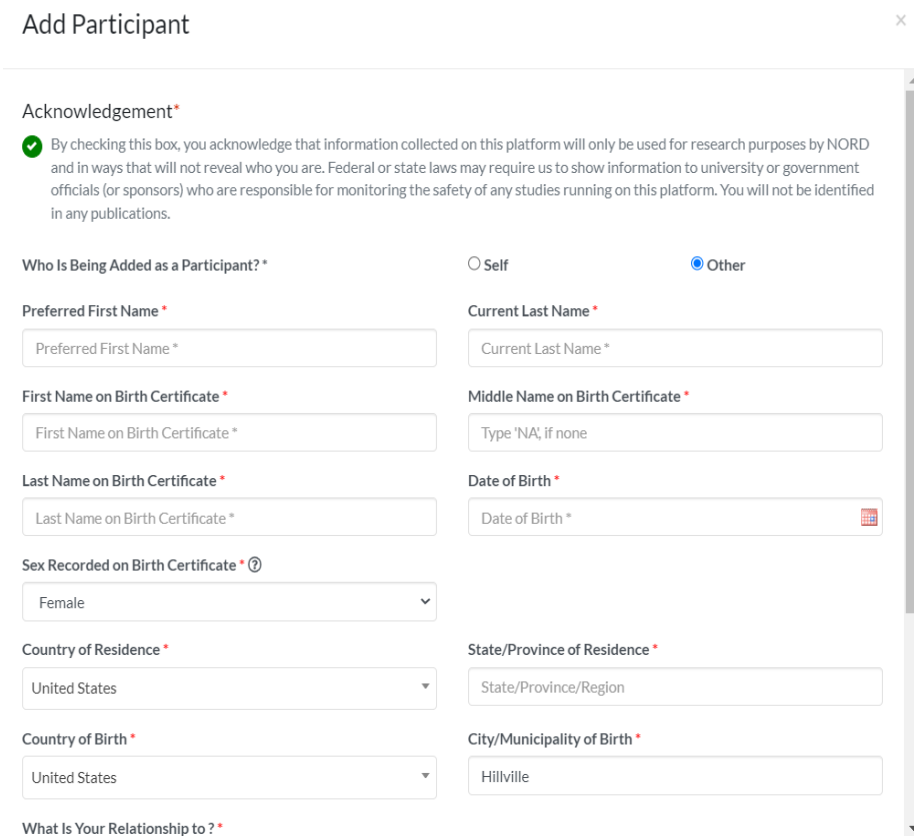


Add a Participant

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

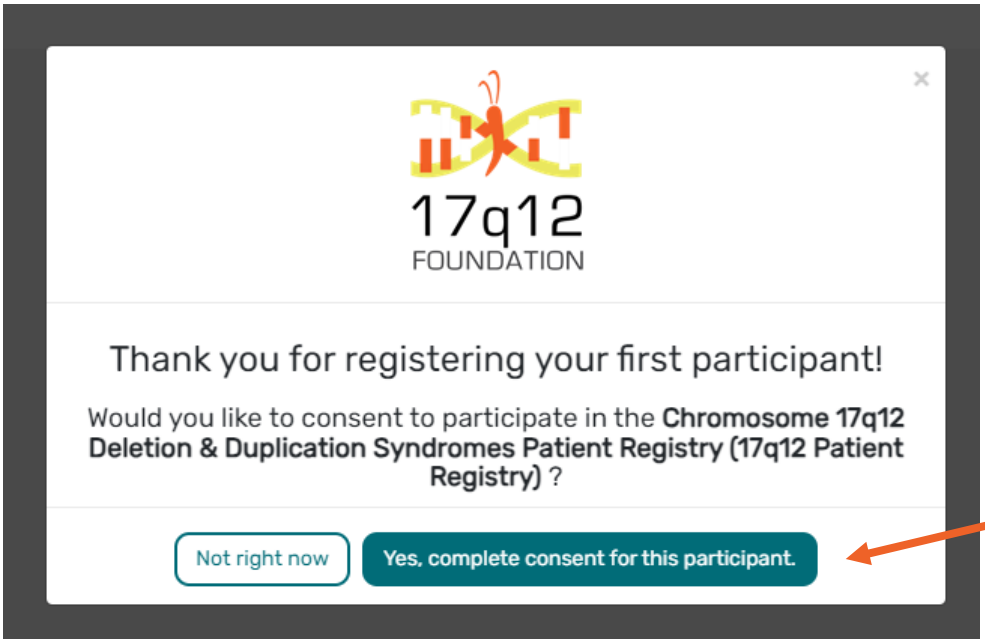


- Step 2: Fill out the Participant's information.

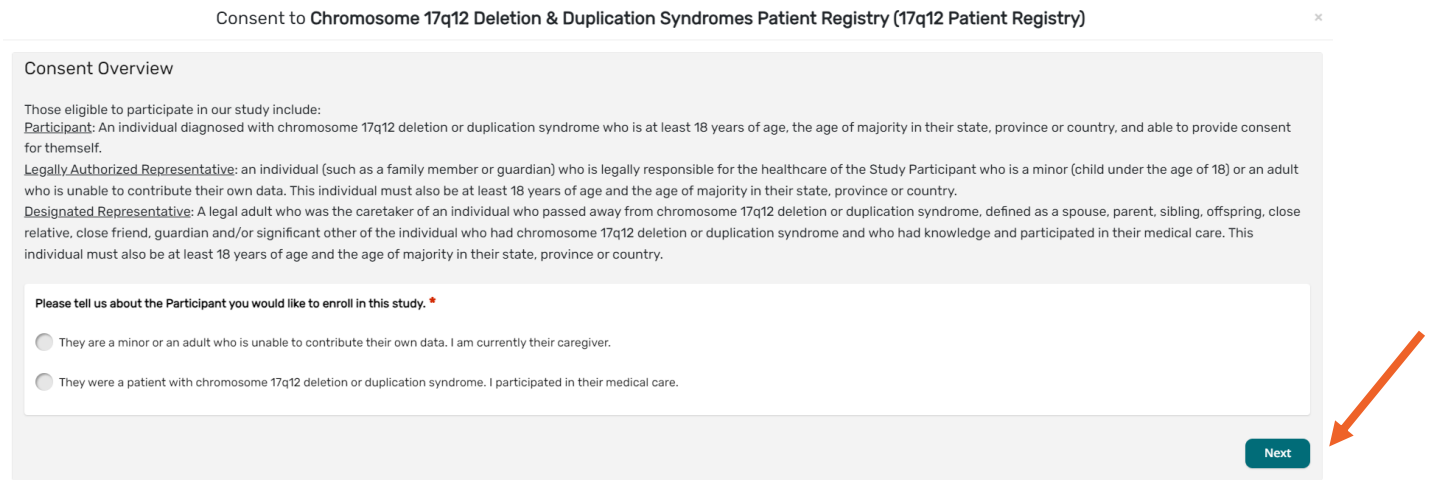


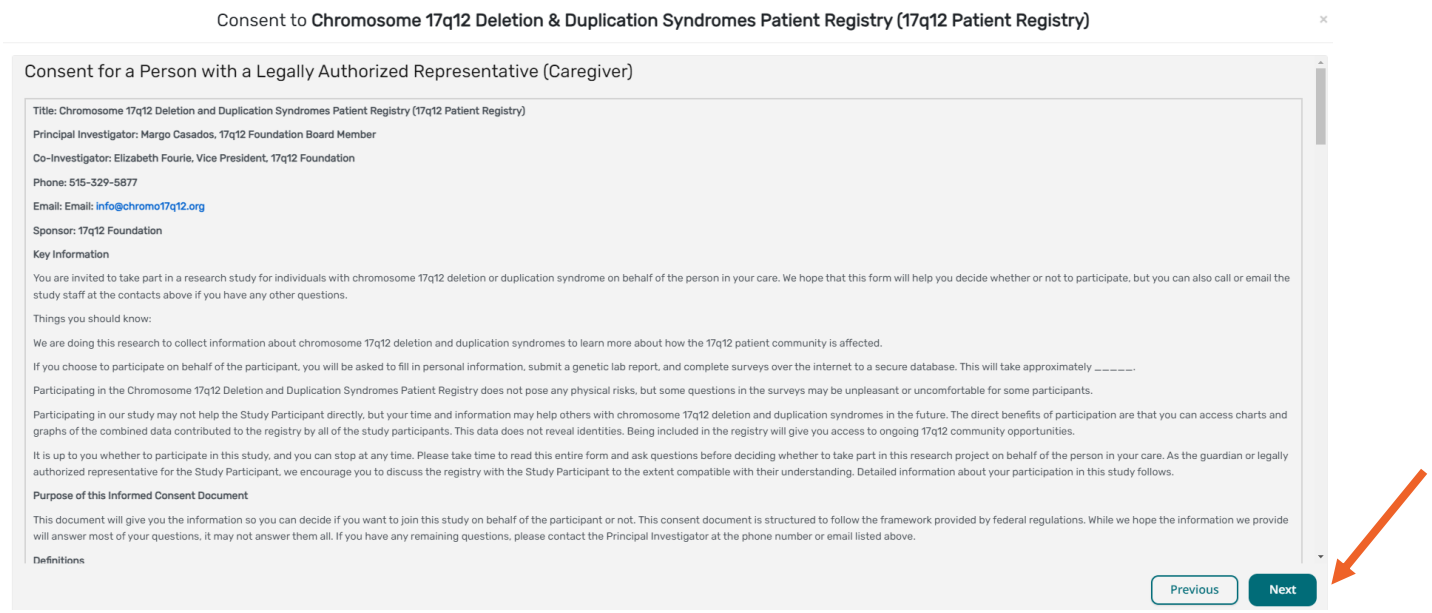
Consent to the Study

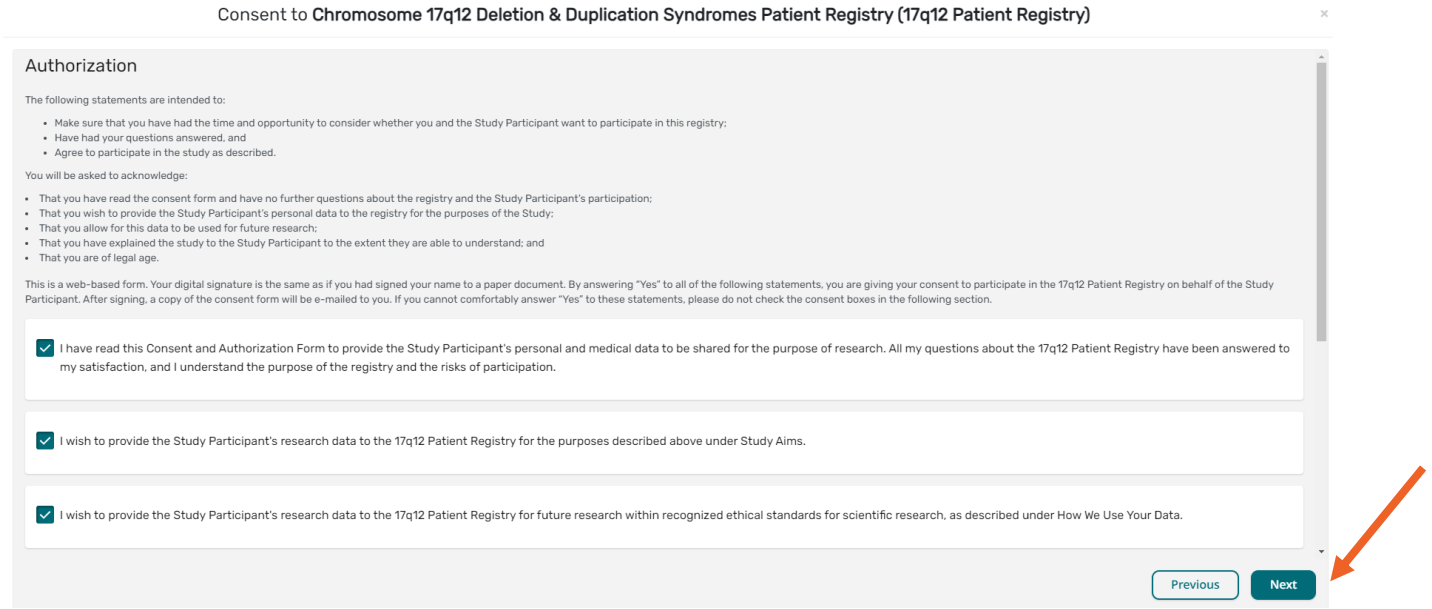
- Step 1: Click on "Yes, complete consent for this participant."



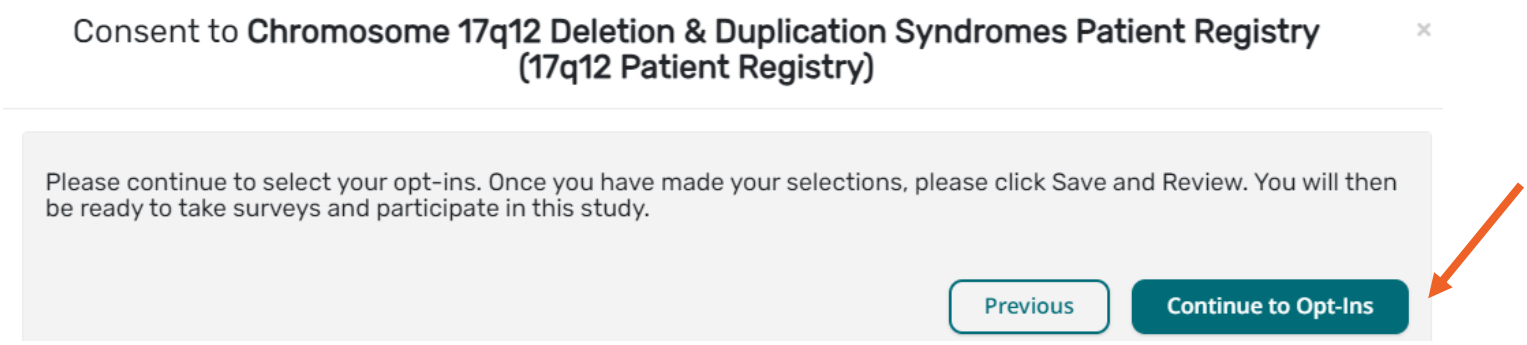
- Step 2: Scroll down and read through the consent form thoroughly. Once you finish each page, click the “Next” button. Once you reach the Authorization form, read through the statements thoroughly. If you are comfortable consenting to participate in the study, please read each statement and authorize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





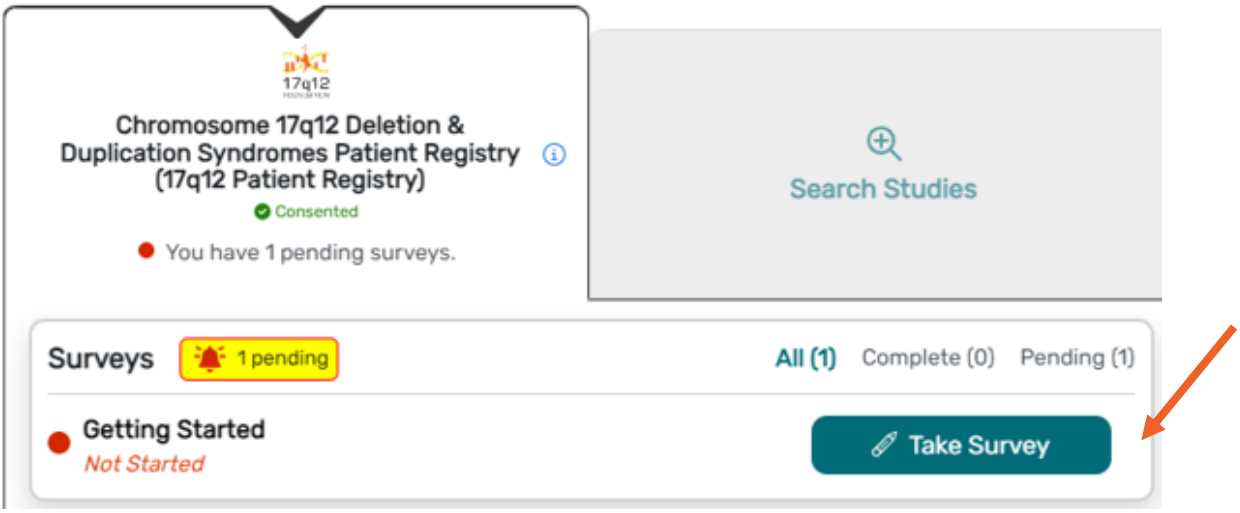


- Step 3: Once you click “Next” and reach the Thank You page, click “Continue to Opt-Ins”.



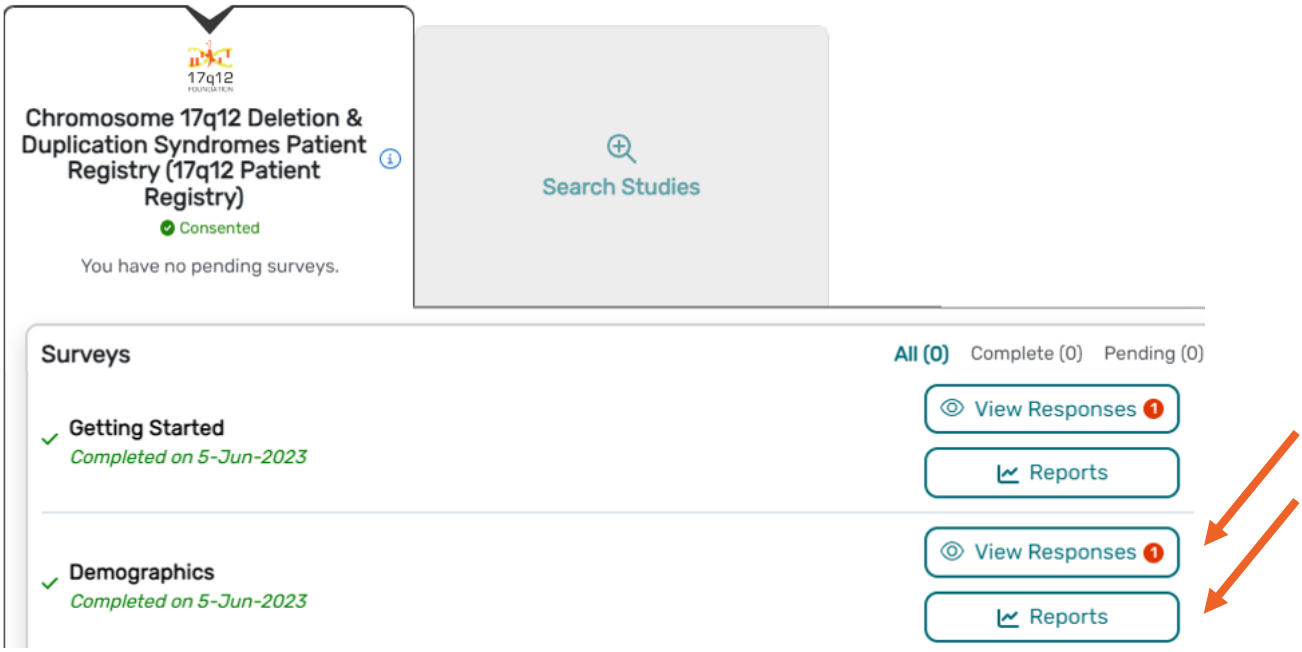
Step 4: Once you click “Continue to Opt-Ins” read through the opt-ins thoroughly. If you would like to receive information about the topic, check the box, and click “Save and Review”.

- Step 5: Once you’ve reviewed your consent, click “Close”. You will then have access to start taking surveys.



View Responses

- 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.



View Consent and Opt-Ins

- Step 1: Once you have consented to the study, you are able to view your consent at any time. Click “Consents/Opt-Ins” to see your consent and opt-ins. You may revoke your consent at any time by clicking “Revoke”. You may also edit your Opt-Ins by clicking “Opt-Ins”.