



## 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 ocular melanoma, select **Participant Account**.
  - If you are entering information for someone else who has ocular melanoma or you have ocular melanoma and are also entering information for yourself, select **Caregiver Account**.
  - If you are entering information for an ocular melanoma patient who has passed away, select **Caregiver Account**.



### Select Account Type

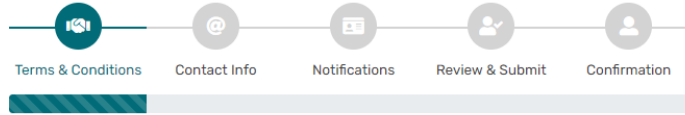
I have a rare disease, condition, and/or diagnosis. Participant Account	I am a family member or guardian of someone with a rare disease. Caregiver Account
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[Return to login](#)

[Not sure? Help me choose.](#)

- 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”.

## Participant Registration



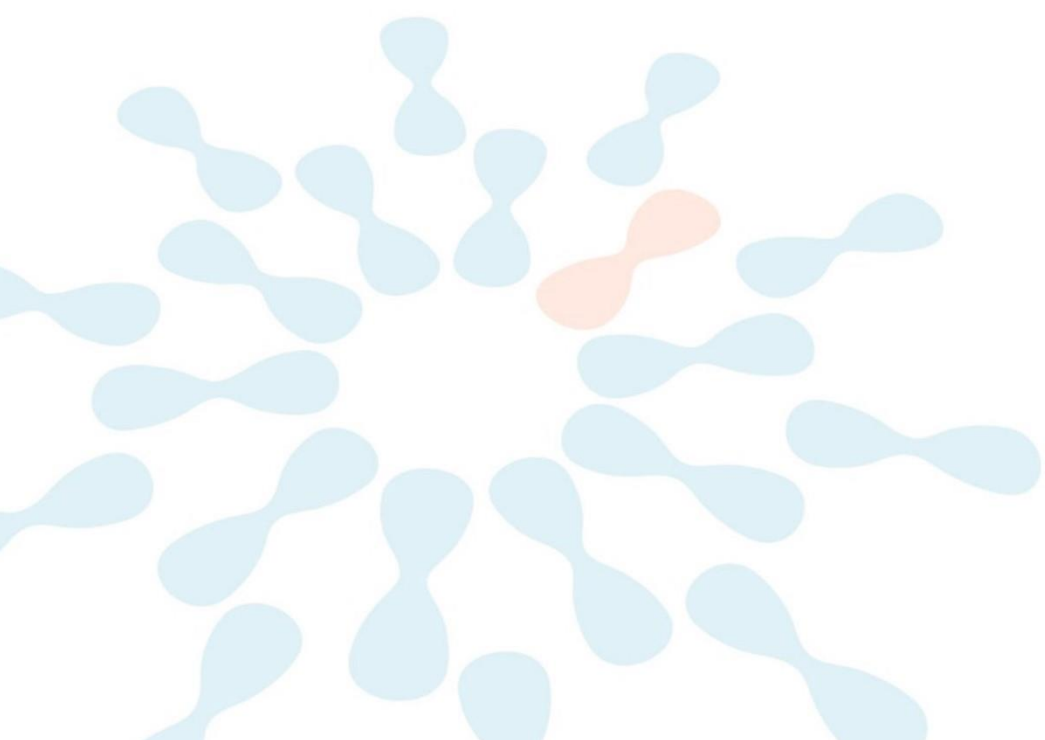
Below are links to the IAMRARE Terms of Use and Privacy Guidelines. The purpose of these documents is to outline your rights and responsibilities when using the platform. These documents include: 1) Standard policies for all studies on this platform, 2) A privacy statement that details how your data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

**Acknowledgements:**

- 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. \*
- 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. \*
- 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. \*
- You agree to the [Terms and Conditions](#) & [Privacy Policy](#). \*

[Return to login](#)

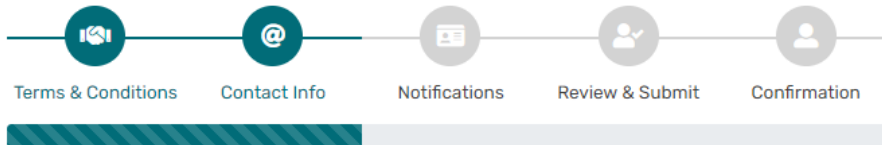
**Next**



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



## Participant Registration



Country of Residence \*

First Name \*

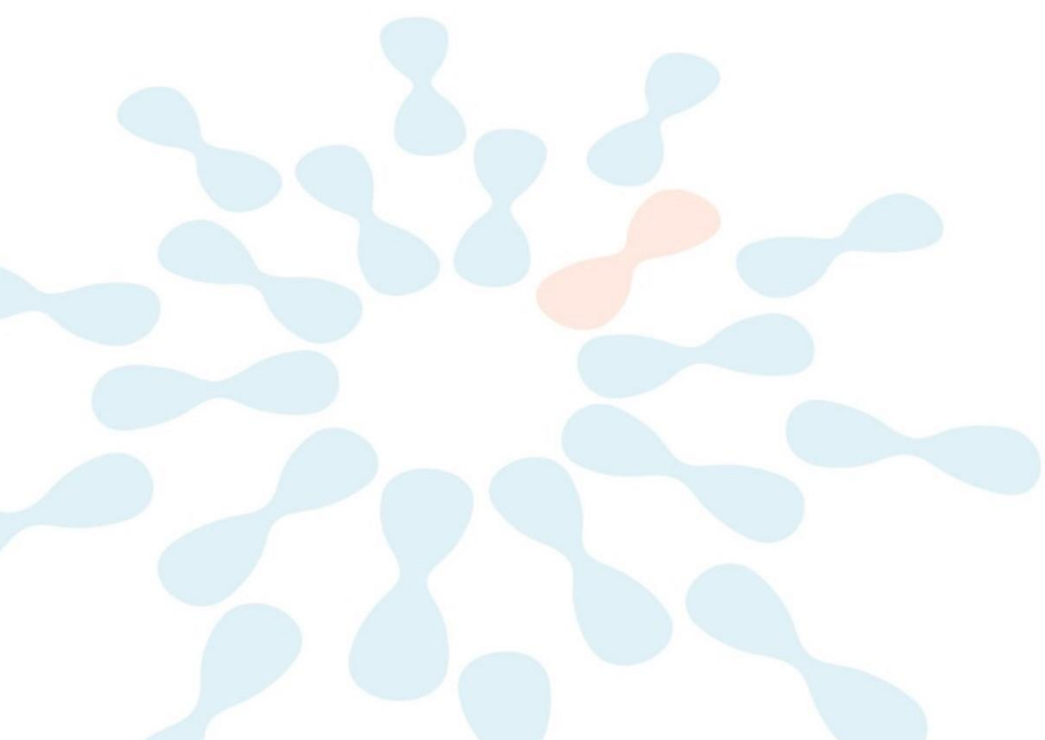
Last Name \*

E-mail \*

[Return to login](#)

[Previous](#)

[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”.

Featuring  
**ACUREINSIGHT**

## Participant Registration

Terms & Conditions   Contact Info   Notifications   Review & Submit   Confirmation

I am interested in NORD contacting me regarding available studies. \*

Yes    No

[Return to login](#)   [Previous](#)   [Next](#)

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

Featuring  
**ACUREINSIGHT**


## Participant Registration

Terms & Conditions   Contact Info   Notifications   Review & Submit   Confirmation

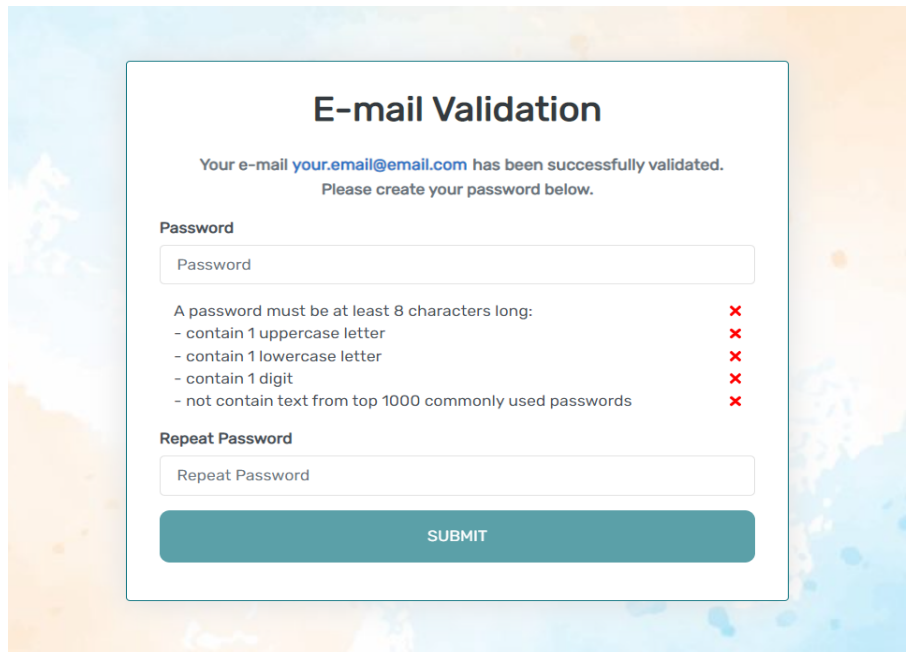
An activation link will be sent to [redacted] and continue.

. Click "Next" to send this e-mail

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- 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”.



**E-mail Validation**

Your e-mail [your.email@email.com](#) has been successfully validated.  
Please create your password below.

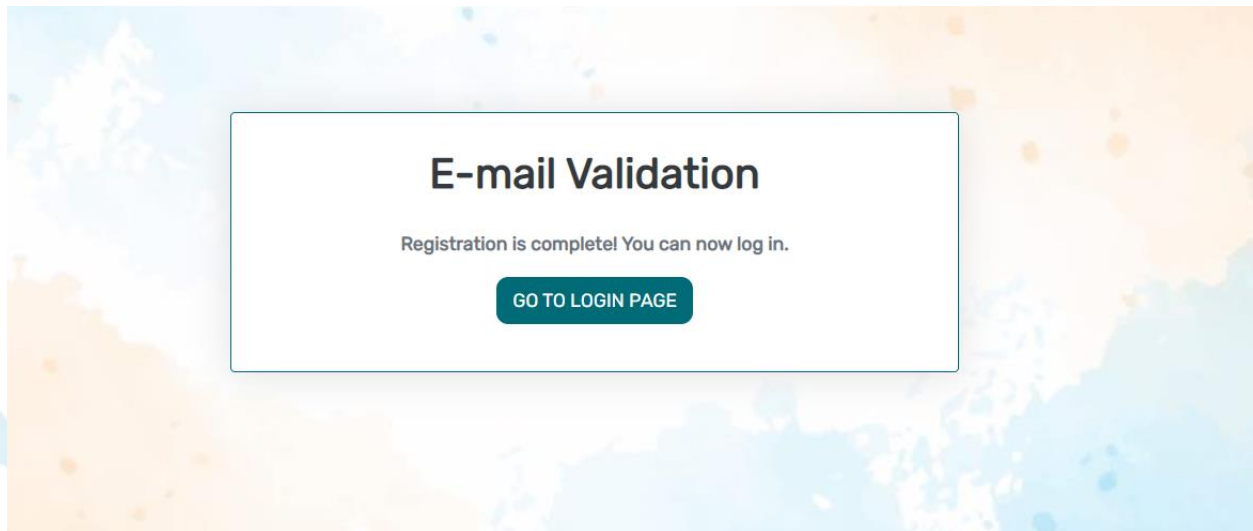
**Password**

A password must be at least 8 characters long: ✘  
- contain 1 uppercase letter ✘  
- contain 1 lowercase letter ✘  
- contain 1 digit ✘  
- not contain text from top 1000 commonly used passwords ✘

**Repeat Password**

**SUBMIT**

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



**E-mail Validation**

Registration is complete! You can now log in.

**GO TO LOGIN PAGE**

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

# IAMRARE®

LOGIN



Keep me logged in

➔ LOGIN

Forgot Password

+ Create an Account

By logging in, you agree to NORD's [Privacy Policy](#) & [Terms and Conditions](#)



## Set Up Profile

- Step 1: To start, click "Create new profile".



Welcome to the IAMRARE® program powered by NORD.

Click on the [Create new profile](#) button below to join the

INSIGHT

Not right now

Create New Profile



Don't show this again

- Step 2: Fill out the Participant Profile.

**Complete Participant Profile**

Preferred First Name \*  
Jane

Current Last Name \*  
Doe

First Name on Birth Certificate \*  
First Name on Birth Certificate

Middle Name on Birth Certificate \*  
Type 'NA' if none

Last Name on Birth Certificate \*  
Last Name on Birth Certificate

Date of Birth \*  
mm/dd/yyyy

Sex Recorded on Birth Certificate \* ⓘ  
▼

Country of Residence \*  
United States ▼

State/Province/Region of Residence \*  
▼

Country of Birth \*  
Choose country of birth ▼

City/Municipality of Birth \*  
City/Municipality of Birth

Profile Image  
Choose Avatar OR Upload Your Own Image  
No image selected

CANCEL SUBMIT

### Consent to the Study

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



Would you like to consent to participate in the INSIGHT?

Not right now

Yes, complete consent for this study.

- Step 2: Scroll down and read through the consent form thoroughly. Once you finish reading 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 “Continue to Opt Ins.”

## Consent to INSIGHT

An Institutional Review Board (IRB) has reviewed this registry to ensure that it meets ethical and regulatory standards for protecting your rights. An IRB is an independent group that reviews research proposals to make sure they properly protect participants. For questions about these protections and your rights as a Study Participant in this Registry, or to discuss other study related concerns or complaints with someone who is not part of this Registry team, please contact North Star Review Board at 877-673-8439 (toll free) or [info@northstarreviewboard.org](mailto:info@northstarreviewboard.org). You may want to contact the IRB if:

- You have questions, concerns, or complaints that are not being answered by the research team.
- You are not getting answers from the research team.
- You cannot reach the research team.
- You want to talk to someone else about the research.
- You have questions about your rights as a research subject.

Please do not sign this form unless you have had all your questions answered.

**Authorization**

This is a web-based form, and I understand that, by answering **Yes** to all of the following questions, I will be giving my consent on the Study Participant's behalf to participate in INSIGHT: A Global Ocular Melanoma Registry, just as if I had signed my name to a paper document. I also understand that after signing, a copy of the consent form will be emailed to me and I will be able to download a signed copy.

I have read (or someone has read to me) this Consent and Authorization Form to provide the Study Participant's personal and medical data to be shared for the purpose of research. All my questions about the Registry have been answered to my satisfaction and I understand the purpose of the Registry and the risks of participation.

I wish to provide the Study Participant's research data to the INSIGHT: A Global Ocular Melanoma Registry for the purposes described above under Study Aims.

I wish to provide the Study Participant's research data that has been pseudonymized to the INSIGHT: A Global Ocular Melanoma Registry for future research within recognized ethical standards for scientific research, as described under How We Use Your Data.

I have explained the study to the Study Participant to the extent they are able to understand, and the Study Participant has given their assent to participate in this study.

[Continue to Opt-Ins](#)

- Step 3: Click the boxes to select opt-ins and then click Save and Review.

## Opt-Ins for INSIGHT

### Select Opt-Ins for this study

- Interest in hearing about other studies from [A Cure In Sight](#)
- Interest in hearing about clinical trials you may be eligible for
- Interest in donating specimens or DNA (biobanking) for future research

[Save and Review](#)

- You will now have access to take surveys.

**OCURE IN SIGHT**  
INSIGHT  
Consented

You have 12 pending surveys.

[Search Studies](#)

**Surveys** 🔔 12 pending

All (12) Complete (0) Pending (12)

- Participant Profile**  
Not Started [Take Survey](#)
- Diagnosis**  
Not Started [Take Survey](#)
- Medical History**  
Not Started [Take Survey](#)
- Treatment and Review of Systems**



## View Responses and Reports

- 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.

The screenshot displays the ACURE INSIGHT user interface. At the top left, the logo for ACURE INSIGHT is shown with the text "INSIGHT" and a "Consented" status indicator. Below the logo, a notification states "You have 11 pending surveys." To the right, there is a "Search Studies" button with a magnifying glass icon. Below these elements is a "Surveys" section with a yellow badge indicating "11 pending". On the right side of this section, there are filters for "All (12)", "Complete (1)", and "Pending (11)". A list of surveys is shown, with the first entry being "Participant Profile", which is marked as "Completed on 2-Aug-2023". To the right of this entry, there are two buttons: "View Responses" and "Reports". Two red arrows point from the text in the instructions above to these two buttons.

