




## EHE Global 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 Epithelioid Hemangioendothelioma (EHE), select **Participant Account**.
  - If you are entering information for someone else who has EHE, select **Caregiver Account**.
  - If you are entering information for a EHE patient who has passed away, select **Caregiver Account**.

Featuring



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### 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

[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”.

The screenshot shows the 'Caregiver Registration' page for The HEME Foundation. At the top, the logo for 'THE HEME FOUNDATION' is displayed. Below the logo, the title 'Caregiver Registration' is centered. A progress bar below the title shows five steps: 'Terms & Conditions' (active), 'Contact Info', 'Notifications', 'Review & Submit', and 'Confirmation'. Below the progress bar, there is a paragraph of text explaining the purpose of the Terms and Conditions and Privacy Guidelines. Below this text are four checkboxes, all of which are checked, indicating agreement to the terms. The checkboxes are: 'You are at least 18 years of age...', 'You agree to support the Platform's research activities...', 'You understand that NORD will use reasonable efforts to keep the information you enter on the Services safe...', and 'You agree to the Terms and Conditions & Privacy Policy'. At the bottom left, there is a 'Return to login' link, and at the bottom right, there is a 'Next' button.

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

The screenshot shows the 'Caregiver Registration' page for The HEME Foundation, Step 3: Personal Information. At the top, the logo for 'THE HEME FOUNDATION' is displayed. Below the logo, the title 'Caregiver Registration' is centered. A progress bar below the title shows five steps: 'Terms & Conditions', 'Contact Info' (active), 'Notifications', 'Review & Submit', and 'Confirmation'. Below the progress bar, there are several input fields: a dropdown menu for 'Country of Residence', two text input fields for 'First Name' and 'Last Name', and a text input field for 'E-mail'. At the bottom left, there is a 'Return to login' link, and at the bottom right, there are 'Previous' and 'Next' buttons.

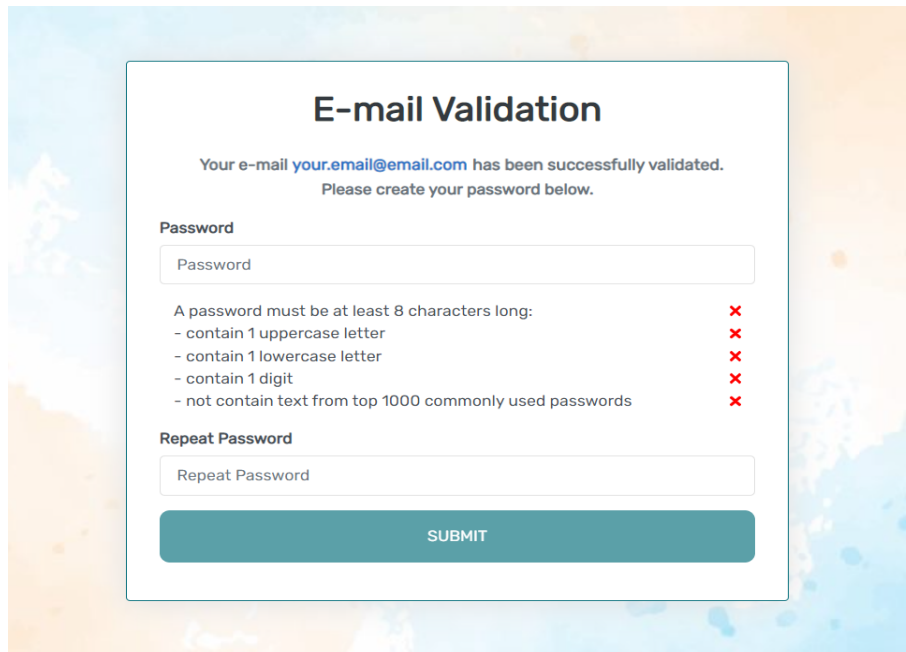
- Step 4: Select whether you are interested in being contacted by NORD regarding available studies. When you are finished with this page, click “Next”.

The screenshot shows the 'Caregiver Registration' form for The HFE Foundation. At the top is the logo. Below it is a progress bar with five steps: 'Terms & Conditions', 'Contact Info', 'Notifications', 'Review & Submit', and 'Confirmation'. The 'Review & Submit' step is currently active. The main text asks, 'I am interested in NORD contacting me regarding available studies. \*'. There are two radio buttons: 'Yes' (which is selected) and 'No'. At the bottom left is a 'Return to login' link with a left arrow. At the bottom right are two buttons: 'Previous' and 'Next'.

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

This screenshot is identical to the previous one, but the progress bar now shows that the 'Review & Submit' step is completed and the 'Confirmation' step is active. The main text has changed to: 'An activation link will be sent to [your.email@email.com](mailto:your.email@email.com). Click "Next" to send this e-mail and continue.' A red arrow points from the right side of the page towards the 'Next' button.

- 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.

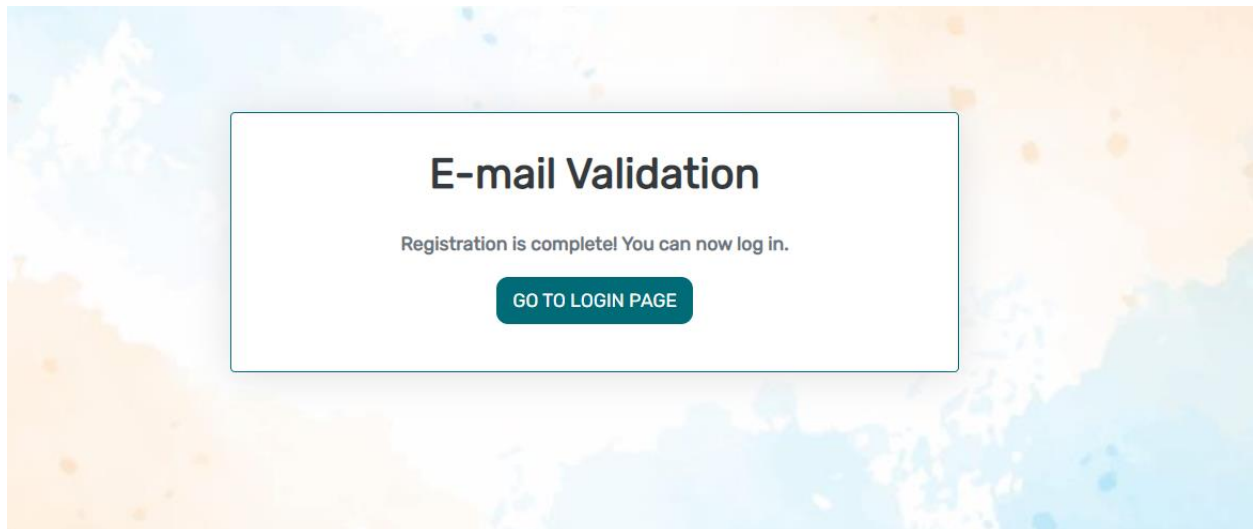
**Password**

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

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](#)

THE EHE FOUNDATION

### Add a Participant

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

×

THE EHE FOUNDATION

Welcome to the IAMRARE program where the EHE Global Patient Registry is located!

Would you like to register a participant to join the EHE Global Patient Registry

Not right now      Yes, register new participant

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

### Add Participant x

**Acknowledgement\***

By checking this box, you acknowledge that information collected on this platform will only be used for research purposes by NORD and in ways that will not reveal who you are. Federal or state laws may require us to show information to university or government officials (or sponsors) who are responsible for monitoring the safety of any studies running on this platform. You will not be identified in any publications.

**Who Is Being Added as a Participant?\***

Self  Other

**Preferred First Name\***


**Current Last Name\***


**First Name on Birth Certificate\***

**Middle Name on Birth Certificate\***

**Last Name on Birth Certificate\***

**Date of Birth\***

**Sex Recorded on Birth Certificate\* **

**Country of Residence\***

**State/Province of Residence\***

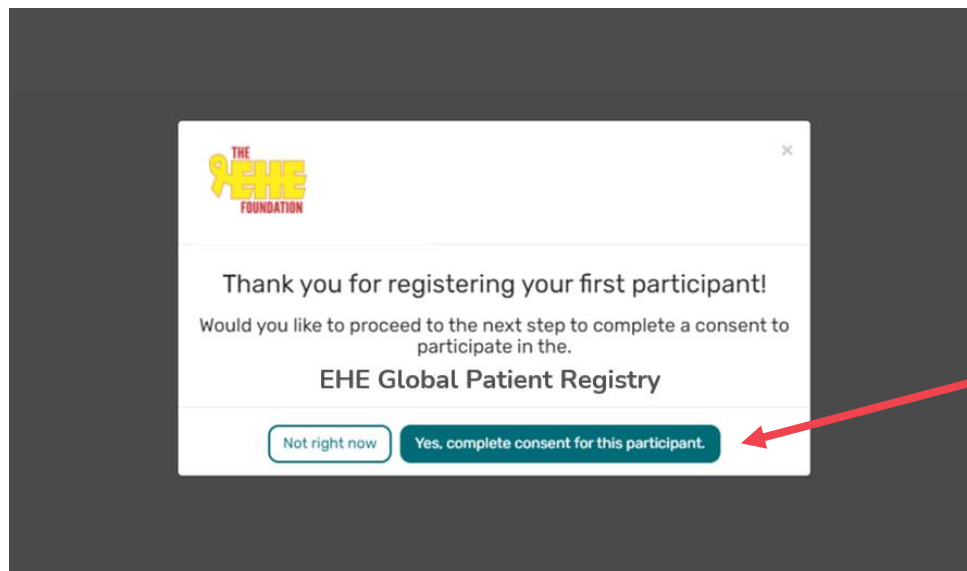
**Country of Birth\***

**City/Municipality of Birth\***

**What Is Your Relationship to?\***

## 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.

Consent to NORD Core

1 / 2

For persons who are residents of the European Union and Switzerland, transfers of your personal information outside of the European Union and/or Switzerland, if any, will be undertaken in compliance with the General Data Protection Regulation under an appropriate transfer mechanism provided for by the General Data Protection Regulation, including the use of standard data protection clauses adopted by the European Commission. Please be aware that, under the General Data Protection Regulation, the European Commission is permitted to issue a decision that the data protection laws of a third country are adequate to the protection of personal information and that, to date, the European Commission has not done so with respect to the United States.

For persons who are residents of the European Union and Switzerland, processing of personal information will also be undertaken in such a manner as to ensure the rights of data subjects provided for by the General Data Protection Regulation. Specifically, Registry participants who are residents of the European Union and Switzerland are entitled to:

- Request to obtain access to and rectification or erasure of personal data;
- To receive personal data in a portable, readily-accessible format;
- To restrict or withdraw permission for the processing of personal information;
- To lodge a complaint with an appropriate supervisory authority.

Please note that the rights to erase personal data or restrict or withdraw permission for the processing of personal information are subject to limitations provided for by Article 17 of the General Data Protection Regulation, namely, that such rights may be limited as necessary to protect the public interest in the area of public health or for archiving purposes in the public and scientific interest.

**Getting Answers to Your Questions about the Registry**

We have used some technical terms in this form and talked about issues in research and data sharing with which you may not have been familiar. Take as long as you need or want to consider what was presented here and whether you want to share your personal and medical information with the Registry. If you have any questions or want anything explained further, please contact the Registry Staff at: [Name and contact information]. It is our responsibility to answer your questions.

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 those 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

**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.

**IMPORTANT: Please do not sign the form on the next page unless you have had all your questions answered.**

[Next](#)

- 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.”

Consent to NORD Core

2 / 2

### Authorization

The following statements are intended to ensure that you have had the time and opportunity to consider whether you want to participate in this Registry, have had your questions answered, and agree to participate in the study as described. You will be asked to acknowledge that you have:

- Read the consent form and have no further questions about the Registry and your participation
- That you wish to provide personal data to the registry for the purposes of the Study
- And that you wish to provide your pseudonymized data for future research

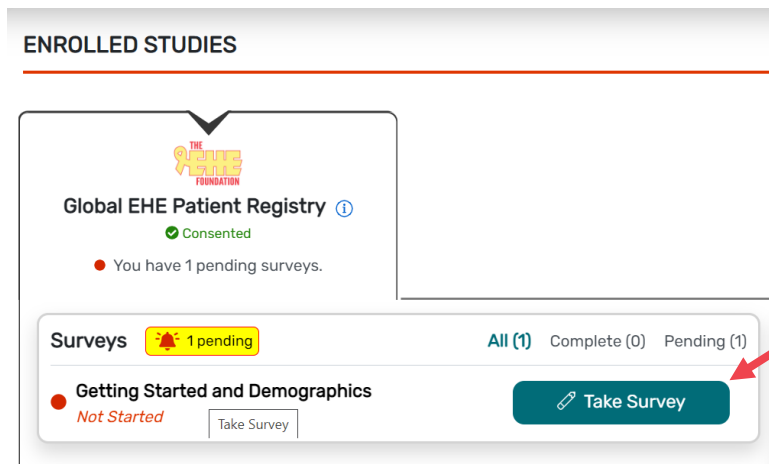
This is a web-based form and by answering Yes to all of the following statements, you are giving your consent to participate in the NORD Core, just as if you had signed your name to a paper document. After signing, a copy of the consent form will be emailed to you.

If you cannot comfortably answer “Yes” to these three statements and you have no further questions, please do not check the boxes below:

- I have read (or someone has read to me) this Consent and Authorization Form to provide my 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 my research data to the NORD Core for the purposes described above under Study Aims.
- I wish to provide my research data that has been pseudonymized to the NORD Core for future research within recognized ethical standards for scientific research, as described under How We Use Your Data.

[Previous](#) [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.

