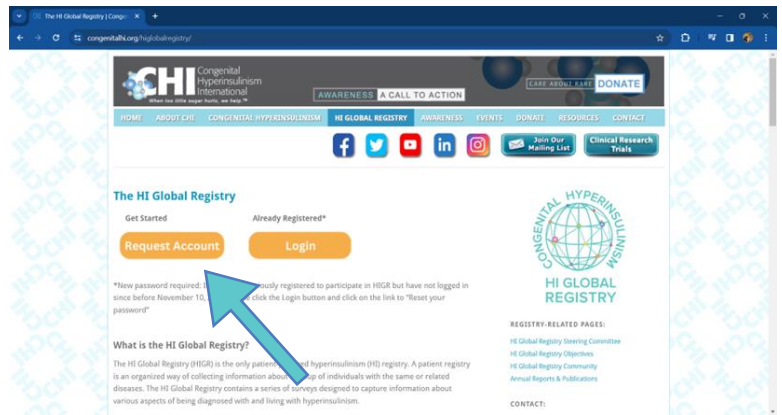


How to Join the HI Global Registry

A Guide for Caregivers

1 Request an account

- Request an account at: <https://accountrequest.higlobalregistry.org/en-US/#/user-request>
- Or, visit higlobalregistry.org and click **Request account**



2 Complete the form



You must enter **YOUR** name and email address. If you are a caregiver for someone with HI, you will add their information later.

- Enter your full name and a valid email address
- You must be at least 18 years of age to create an account. If you are under the age of 18, your parent or guardian must create an account for you.
- You must acknowledge that you are in the US, or that you are outside of the US and understand that information will be transmitted to the US

The screenshot shows the 'Request Access' form. The form title is 'Request Access' with the subtitle 'Join us and get connected today!'. The form is divided into sections: 'Your Information:', 'Your Information:' (with a note about data usage), and a section for acknowledging terms. The 'Your Information:' section includes fields for 'Your First Name *' and 'Your Last Name *' (with a note 'Enter Letters Only') and an 'Email *' field. The acknowledgment section includes three radio button options: 'I am at least 18 years of age (or at least the Age of Majority in my State/Country)', 'I acknowledge that I am located in the United States; OR', and 'I acknowledge that I am located outside of the United States, and that the information I am providing will be transmitted to the United States for account creation.' Orange arrows point from the text on the left to the name and email fields, and the acknowledgment section.



Note that this guide will walk through the registration process for **Caregivers**. If you are a person with HI, please check out our guide for **Participants** (the sign-up process is a little different!)

Select the Account type:

- Select **Caregiver** if you care for someone with HI. This includes:
 - **You care for a child under the age of 18 if you are their parent or guardian.** You will complete surveys on behalf of the child, and you will also complete your own caregiver surveys.
 - **You care for an adult with HI who does not have the legal capacity to consent to research,** as long as you are their Legally Authorized Representative (LAR). You will complete surveys on behalf of the adult with HI, and you will also complete your own caregiver surveys.
 - **You care for an adult with HI who has already created their own registry account.** You will only complete your own caregiver surveys. You will not complete participant surveys on behalf of the adult with HI.
- Select **Person who has lost a loved one** if you are registering on behalf of someone who has passed away.
- Then, click **Sign Up**. You will see a page that says your request was successfully submitted

Please review each type of account below and select the one (or multiple, if applicable) that describes **YOU**, the **person creating the account**:

Patient

Select this option if you:

- Have been diagnosed with HI or an HI-related condition
- Have suspected or unconfirmed HI or an HI-related condition
- Were previously diagnosed with HI or treated for HI but your disease is now resolved/cured

Caregiver

Select this option if you are the caregiver of a person with HI or an HI-related condition (diagnosed, suspected, or resolved) and:

- You want to provide information on behalf of a child with HI or an adult who does not have the capacity to consent for themselves
OR
- The person you care for is an adult with their own HIGR account and you only want to complete the caregiver surveys

Please **create an account in your own name**, and once logged in, you will be able to add information about the person with HI or an HI-related condition.

Providing data on behalf of someone who has passed away

Select this option if you are the parent or legally authorized representative of a person with HI or an HI-related condition who is now deceased.

Please **create an account in your own name**, and once logged in, you will be able to add information about the deceased person. Please note: Within the application you will be referred to as a "Caregiver", as this role allows you to enter information on behalf of someone else.

[SIGN UP](#)

[PRIVACY POLICY](#) [TERMS OF USE](#) [GO TO LOGIN](#)



Only ONE ACCOUNT is needed if you would like to register multiple people with HI.

If you are a caregiver for multiple people with HI, create a **Caregiver** account in your own name. You will be able to add one or more people with HI as registry participants at a later stage.

If you have HI and you care for someone with HI, select both **Patient** and **Caregiver**. This will allow you to answer your own registry surveys, and you will be able to add the person you provide care for and answer surveys on their behalf.

Please review each type of account below and select the one (or multiple, if applicable) that describes **YOU**, the **person creating the account**:

Patient

Select this option if you:

- Have been diagnosed with HI or an HI-related condition
- Have suspected or unconfirmed HI or an HI-related condition
- Were previously diagnosed with HI or treated for HI but your disease is now resolved/cured

Caregiver


Select this option if you are the caregiver of a person with HI or an HI-related condition (diagnosed, suspected, or resolved) and:

- You want to provide information on behalf of a child with HI or an adult who does not have the capacity to consent for themselves
OR
- The person you care for is an adult with their own HIGR account and you only want to complete the caregiver surveys

3

Create a password

- Check your email for an Account Creation Notice from info@higlobalregistry.org
- Click on the link in the email to create a password
- Follow the instructions on screen to create a secure password
- Click **Continue**

Powered By:  Matrix


Create Password


The password must be between 8 and 64 characters.
The password must have at least 3 of the following:
a lowercase letter
an uppercase letter
a digit
a symbol

4

Sign in to HIGR

- You will be redirected to the Sign In page for the HI Global Registry
 - In future, you can access this sign in page at <https://login.higlobalregistry.org/> or by visiting higlobalregistry.org and clicking **Log In**
- Sign in with the email address and password you just created
 - *If you ever forget your password, click "Forgot your password?" to reset it*
- Click on the blue **Sign In** button

Powered By:  Matrix



Sign in with your email address

[Forgot your password?](#)

 [Not Registered?](#)
[PRIVACY POLICY](#) [TERMS OF USE](#)

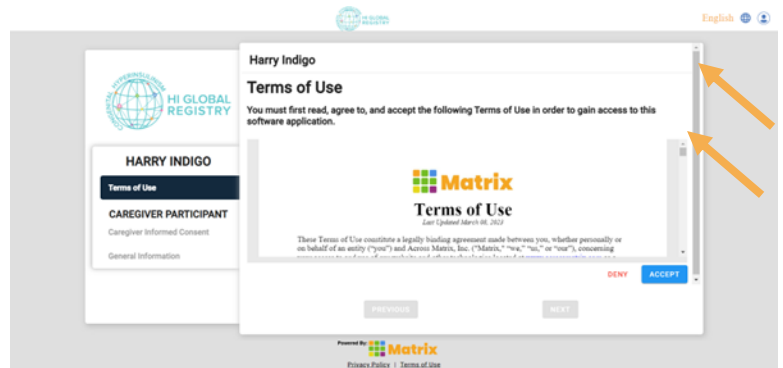
Next time you log in, you can access this sign in page at <https://login.higlobalregistry.org/> or by visiting higlobalregistry.org and clicking **Log In**

5 Terms of Use

- You must read and accept the Terms of Use
- Click on the blue **ACCEPT** button to accept the Terms of Use

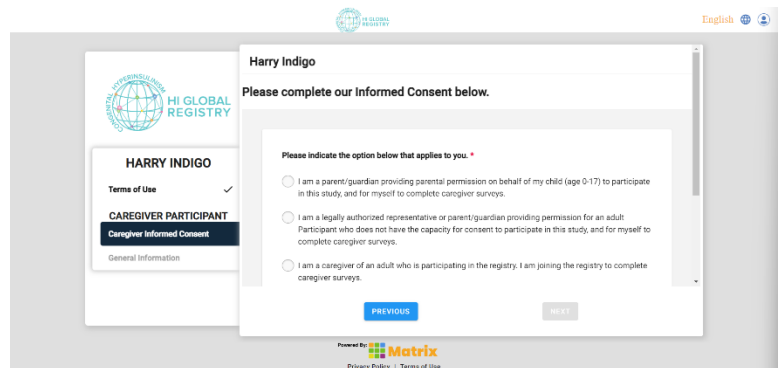


Note that there are two scroll bars. Depending on the size of your screen, you may need to use the outer scroll bar to scroll down to view the blue **ACCEPT** button



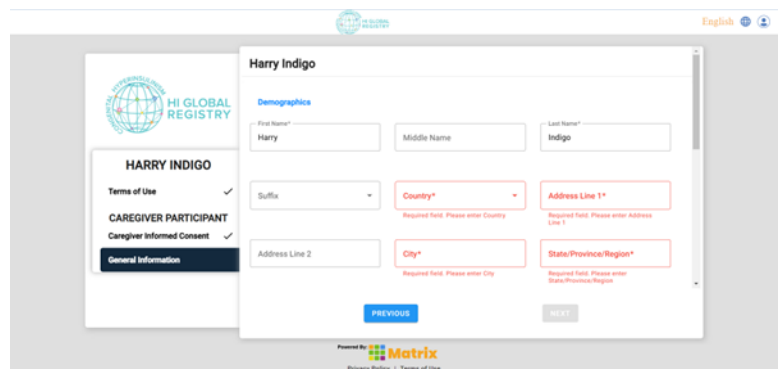
6 Account Type

- Select the option that applies to you
- This step will determine whether you sign the Informed Consent now or at a later step
- Note that individuals who created a Patient account in step 2 (Account Request Form) will only see one option here.
- Scroll down to click on the green **Complete** button to proceed.



7 Caregiver Information

- Complete the caregiver information
- Scroll to the bottom of the page to complete all fields



7

Caregiver Information (continued)

- Click the blue **SAVE** button.
- The page will refresh. Click the blue **FINISH** button



You must complete **YOUR** information. If you are a caregiver for someone with HI, you will add their information later.

8

Add a Participant with HI

- Click on the blue **ADD PATIENT** button
- Enter the name of the person with HI
- Click the blue **SAVE** button



Adding a participant with HI will allow you to complete registry surveys on their behalf.

You must be the parent or guardian of a child with HI, or the legally authorized representative (LAR) of an adult with HI who does not have the capacity to consent to research for themselves.

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Specify your relationship to the person with HI

- Specify your relationship to the person with HI
- Click the blue **SAVE** button

10

Select who you are providing consent for

- Select the option that applies to you
- Scroll down to click the green **Next** button

11

Read and sign the Informed Consent

- Scroll down to read the entire document



This document contains important information about participating in the registry.

If you have any questions, please reach out to us at info@higlobalregistry.org.

11

Informed Consent (continued)

- Answer the questions at the bottom of the document to provide consent



Select "Yes" to the first question to give consent to join the registry.

Selecting "No" means you do not give consent and you will not join the registry.

- For those who choose to join the registry, additional questions will appear after you select "Yes". Please provide your answers to these questions. All questions require a response, but you can select "Yes" or "No" to all questions and still join the registry.
- Enter the name of the person with HI who you are consenting on behalf of, and your own name as their caregiver.
- Enter your own name again to consent to completing caregiver surveys. This will serve as your electronic signature.
- If you would like a copy of the signed consent form, check the box that says "I would like an emailed copy of this completed consent".
- Scroll down to click the green **Complete** button

12

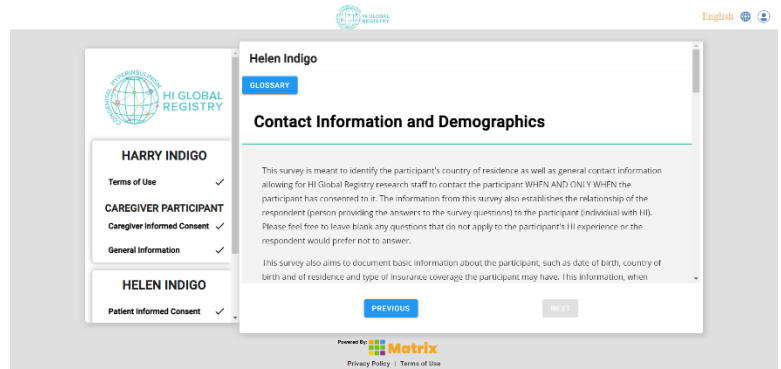
Participant Information

- Complete the participant's information
- Scroll to the bottom of the page to complete all fields
- Click the blue **SAVE** button.

13

Contact Information & Demographics Survey

- Complete the *Contact Information and Demographics* survey
- **Page 1** provides important information to registry staff on the ways we may contact you.
- Click the green **Next** button to go to page 2.
- **Page 2** collects important information on identity and ethnicity to ensure our research is inclusive and considerate of diverse populations.
- Complete the questions on page 2, then click the green **Complete** button

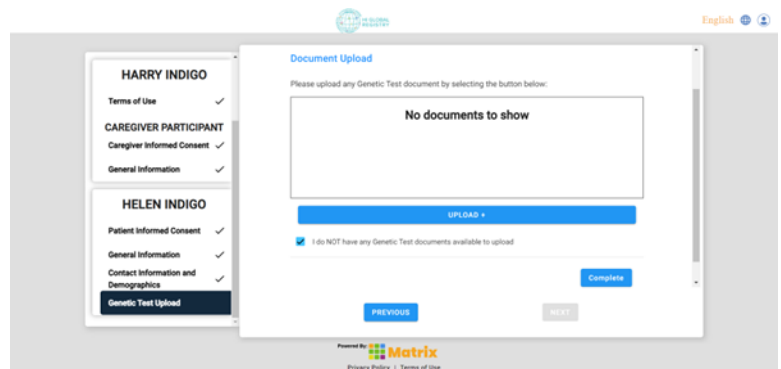


All questions require a response, but you may select “Prefer not to answer” to any questions you do not want to answer.

14

Upload Genetic Test Results

- Click the blue **UPLOAD +** button to upload any genetic test results to the participant’s account
- Or, check the box if you do not have any genetic test results to upload
- Click the blue **Complete** button
- The page will refresh. Then, click the blue **FINISH** button



Congratulations! You have successfully created a HIGR account and added a participant with HI!

Next, complete the surveys to contribute data to HI research!