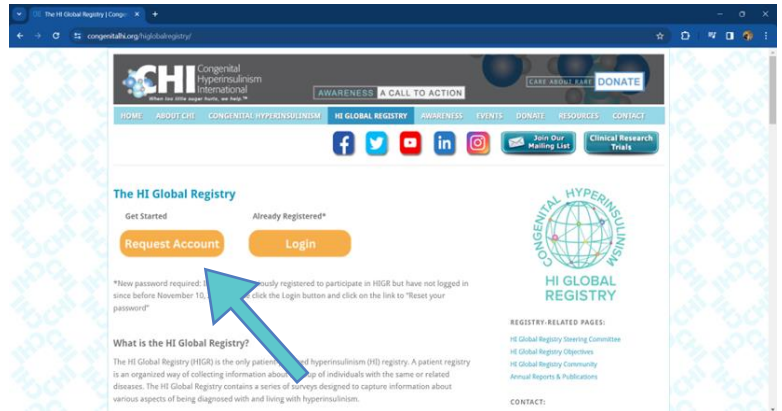


# How to Join the HI Global Registry

## A Guide for People with HI (Participants)

### 1 Request an account

- Request an account at: <https://accountrequest.higlobalregistry.org/en-US/#/user-request>
- Or, visit [higlobalregistry.org](https://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 on the HI Global Registry website. The form is titled 'Request Access' and includes the HI Global Registry logo. Below the title, it says 'Join us and get connected today!'. The form is divided into sections: 'Your Information:' and 'In order to proceed with your account creation, please acknowledge the following:'. The 'Your Information:' section includes fields for 'Your First Name \*', 'Your Last Name \*', and 'Email \*'. The 'In order to proceed...' 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.' Arrows from the text on the left point to the 'Your Information:' section and the radio button options.



HI GLOBAL  
REGISTRY





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

Select the Account type:

- Select **Patient** if you have or had HI. This includes:
  - Any HI or HI-related condition
  - Suspected/unconfirmed HI
  - Resolved/cured HI

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

- Then, click **Sign Up**. You will see a page that says your request was successfully submitted




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

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.

**3**

**Create a password**

- Check your email for an Account Creation Notice from [info@higlobalregistry.org](mailto: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: 

### 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

**Continue**

**Cancel**



## 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](https://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



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

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CONGENITAL HYPERINSULINISM  
HI GLOBAL REGISTRY

Sign in with your email address

Email Address

Forgot your password?

Password

Sign in Not Registered?

PRIVACY POLICY TERMS OF USE

## 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

English

Holly Ivy  
Terms of Use

You must first read, agree to, and accept the following Terms of Use in order to gain access to this software application.

**Matrix**  
Terms of Use  
Last Updated: March 08, 2023

These Terms of Use constitute a legally binding agreement made between you, whether personally or on behalf of an entity ("you") and Access Matrix, Inc. ("Matrix," "we," "us," or "our"), concerning the use of the software application.

PREVIOUS NEXT

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## 6 Informed Consent

- Select the button to confirm that you are an adult with HI and you want to provide consent to participate in the HI Global Registry
- Scroll down to click on the green **Next** button to proceed.

English

Holly Ivy  
Please complete our Informed Consent below.

Please indicate the option below that applies to you. \*

I am an adult Participant (age 18+) who has/had HI or an HI-related condition and I am providing consent for myself to participate in this study.

Next

Page 1 of 3

PREVIOUS NEXT

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# 7

## 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](mailto:info@higlobalregistry.org).

- 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.

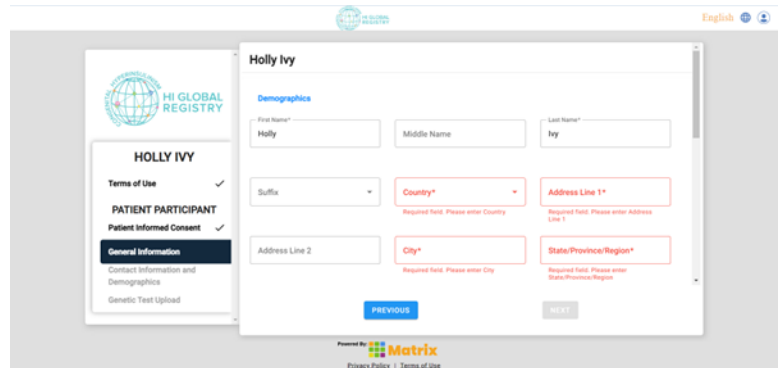
- For those who choose to join the registry, additional questions will appear after you select “Yes”. Please provide your answers to these questions. All questions require a response, but you can select “Yes” or “No” to all questions and still join the registry.

- Enter your name to consent to join the HI Global Registry. 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



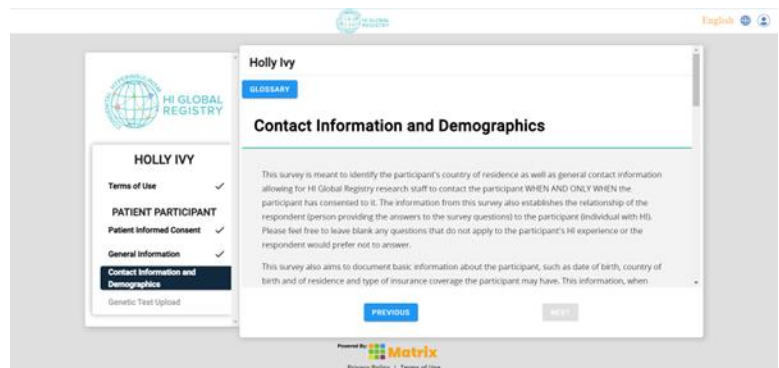
## 12 Participant Information

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



## 13 Contact Information & Demographics Survey

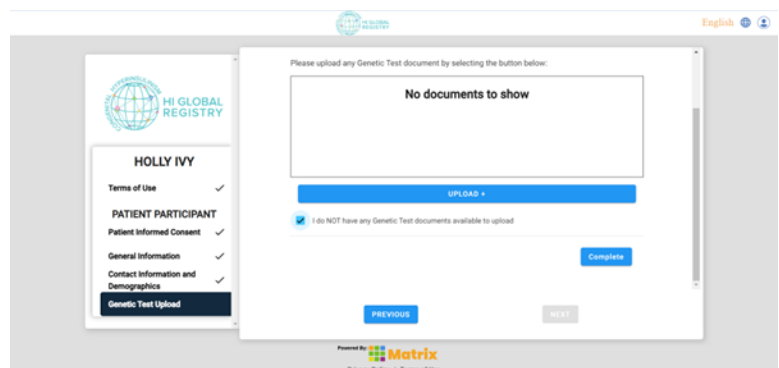
- Complete the *Contact Information and Demographics* survey
- **Page 1** provides important information to registry staff on the ways we may contact you.
- Click the green **Next** button to go to page 2.
- **Page 2** collects important information on identity and ethnicity to ensure our research is 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!**

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

Keep reading if you also care for another person with HI and would like to add them to your account.



HI GLOBAL  
REGISTRY

**CHI** Congenital  
Hyperinsulinism  
International  
When too little sugar hurts,™

# Adding a New Participant to Your Account

## OPTION 1: If you only selected “Patient” when you created your HIGR account.



You are not able to add another Participant to your HIGR account yet.

Email us at [info@higlobalregistry.org](mailto:info@higlobalregistry.org) and we can edit your permissions to add a Participant to your account.

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

## OPTION 2: If you selected both “Patient” and “Caregiver” when you created your HIGR account.

Follow the instructions below to add a Participant to your account.

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

The screenshot shows the HIGR user interface. In the top left corner, the user's role is displayed as "Holly Ivy PATIENT". An orange callout box points to this role with the text: "Click on the person icon and select Change Role". Another orange callout box points to the role with the text: "You can check your current role in the top left corner". The main content area shows a table of "New/In-Progress Surveys/Studies".

Surveys/Studies	Published On	Expiration Date	Time To Complete (minutes)	Questions	Status
MaxHIGR	Nov 13, 2023		1 - 2	0	START
	Nov 13, 2023		5 - 10	0	START
	Nov 13, 2023		10 - 30	0	START
	Nov 13, 2023		2 - 10	0	START
	Nov 13, 2023		10 - 30	0	START
	Nov 13, 2023		5 - 15	0	START
	Nov 13, 2023		5 - 15	0	START

Holly Ivy PATIENT Jan 25, 2024

New/In-Progress Surveys/Studies

Surveys/Studies	Expiration Date	Time To Complete (minutes)	Questions	Status
MaxHIGR				START
Glucose Monitoring		5 - 10	0	START
Diagnosis		10 - 30	0	START
Other Medical Conditions	2023	2 - 10	0	START
Medication Management	Nov 13, 2023	10 - 30	0	START
Diet and Feeding Management	Nov 13, 2023	5 - 15	0	START
Development	Nov 13, 2023	5 - 15	0	START

Change User Role

CAREGIVER ← Select CAREGIVER

PATIENT

CANCEL

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Holly Ivy CAREGIVER

My Patients

ADD PATIENT ← Click ADD PATIENT to add a new person with HI to your account

CONGENITAL HYPERINSULINISM HI GLOBAL REGISTRY

As a Caregiver, you currently have no patients associated with your account.  
To get started, please select the ADD PATIENT button above to begin adding and associating Patients to your Caregiver account.

Items per page: 5 0 of 0

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Holly Ivy CAREGIVER

My Patients

ADD PATIENT

Add New Patient

User Role\* Patient

First Name\* Henry Last Name\* Ivy

Associate to Caregiver\* Holly Ivy

E-mail\*

Enter the name of the person with HI, then click SAVE

CANCEL SAVE

Items per page: 5 0 of 0

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English

HI GLOBAL REGISTRY

Biological Sex at Birth\* Female Gender Identity\* Woman (or

Birthplace: Country\* United States Birthplace: State\* NJ

**HOLLY IVY**

Terms of Use ✓

CAREGIVER PARTICIPANT

Caregiver Informed Consent ✓

**General Information**

PATIENT PARTICIPANT

Patient Informed Consent ✓

General Information ✓

**Associated Patient Information**

Name of Patient	What is YOUR relationship TO the person you are enrolling?	Are you biologically related to the person you are enrolling?
Ivy, Henry	Relationships (Select all that ap...)	Biological Relationship*

Required field. Please enter your Relationship. Required field. Please enter your Relationship.

CANCEL SAVE

PREVIOUS NEXT

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English

HI GLOBAL REGISTRY

**Henry Ivy**

As Caregiver for the patient above, please complete our Informed Consent below:

Please indicate the option below that applies to you. \*

I am a parent/guardian providing parental permission on behalf of my child in this study, and for myself to complete caregiver surveys.

I am a legally authorized representative or parent/guardian providing permission for an adult Participant who does not have the capacity for consent to participate in this study, and for myself to complete caregiver surveys.

PREVIOUS NEXT

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## PATIENT PARTICIPANT

Patient Informed Consent ✓

General Information ✓

Contact Information and Demographics ✓

Genetic Test Upload ✓

Complete the remainder of the forms for the new participant. These are the same as the ones you already completed for yourself.