How to Join the HI Global Registry

A Guide for Caregivers







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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

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 themself 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 HIrelated 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	<u>GO TO LOGIN</u>

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

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 Please review each type of account below and select the one (or multiple, if applicable) that describes YOU, the person creating the account Please review and the 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 Ceargiver 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 or ones for themself OR The person you care for is an adult with their own HIGR account and you only want to complete the caregiver survers.



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- 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

Create Password A password must be between 8 and 64 characters; A password must

Matrix

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 <u>https://login.higlobalregistry.org/</u> or by visiting <u>higlobalregistry.org</u> 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 <u>https://login.higlobalregistry.org/</u> or by visiting <u>higlobalregistry.org</u> and clicking Log In

Sign in with your email address	HI GLOBAL REGISTRY
Email Address	
Forgot your password?	
Password	
Password Sign in	Not Registered?





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



- en Stra	Harry Indigo	- 82
HI GLOBAL	Please complete our Informed Consent below.	- 11
REGISTRY		
HARRY INDIGO	Please indicate the option below that applies to you. *	
Terms of Use 🗸	 I am a parent/guardian providing parental permission on behalf of my child (age 0-17) to participate in this study, and for myself to complete caregiver surveys. 	14
CAREGIVER PARTICIPANT Caregiver Informed Consent	 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 aurwys. 	
General Information	I am a caregiver of an adult who is participating in the registry. I am joining the registry to complete caregiver surveys.	
	PREVIOUS	

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.





fields



Caregiver Information (continued)

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



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





- 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.









Specify your relationship to the person with HI

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

and a second	Male		Man (or boy)	*	
HI GLOBAL REGISTRY	Britslaw Courty* United States		Definition: Same Province Surger	or Britghan City City	
HARRY INDIGO	Associated Pat	ent information			
Terms of Use	Name of Patient	What is YOUR rela enrolling?	tionship TO the person you are	Are you biologically related to th enrolling?	e person you are
Caregiver Informed Consent 🧹	Indigo, Helen	Relationships	(Select all that ap. *	Biological Relationship*	•
HELEN INDIGO		Reported Nation Pr	olean artist stor Relationship	Recursed faild. Please orbit mut	CANCEL SAVE
Patient Informed Consent		PRI	wous	6011	



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





• 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.

	(C) acros	English 🕕
HI GLOBAL REGISTRY	Helen Indigo As Caregiver for the patient above, please complete our Informed Consent below:	
HARRY INDIGO	Consent Form to Participate in the HI Global Registry	
Terms of Use 🗸	TITLE: HI Global Registry	
CAREGIVER PARTICIPANT	Principal Investigator: Tai Pasquini, MPA, PhD	
Caregiver Informed Consent 🗸	Contact Information: Email: info@higkchalxepistev.org; Phone: +1-973-842-7559	
General Information 🗸	Definitions	
HELEN INDIGO	For the purpose of this Consent form, the "Participant" refers to the person diagnosed with or	
Patient Informed Consent	PREVIOUS	
	Matrix	





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



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



	A COURT	English 🌐
HIGLOBAL	Statement of Consent: I have had resulp, time to read the consent form and think about agreeing to participate in this study for mysel or on behalf of someone diagnosed with III or an II restated condition. I understand the risks and possible benefits and other important things about the study. I have had the opportunity to ask questions. I understand the information given to me. I give up on video by spiring this form.	
HARRY INDIGO	I give my consent to participate in this study which requires completing online surveys. *	!
CAREGIVER PARTICIPANT Caregiver Informed Consent ✓ General Information ✓	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. *	
HELEN INDIGO		
Patient informed Consent	Prevel of Matrix	_







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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

-SRINSU(Helen Indigo	
HI GLOBAL	GLOSSARY	
REGISTRY	Contact Information and Demographics	
HARRY INDIGO		- 1
Terms of Use 🗸	This survey is meant to identify the participant's country of residence as well as general contact information allowing for HI Global Registry research staff to contact the participant WHEN AND ONLY WHEN the	
CAREGIVER PARTICIPANT	participant has consented to it. The information from this survey also establishes the relationship of the	
Caregiver informed Consent ✓	respondent (person providing the answers to the survey questions) to the participant (individual with HI). Please feel free to leave blank any questions that do not apply to the participant's HI experience or the	
General Information	respondent would prefer not to answer.	
	This survey also aims to document basic information about the participant, such as date of birth, country of	
HELEN INDIGO	birth and of residence and type of insurance coverage the participant may have. This information, when	
	partuolie view	



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

Upload	Genetic	Tes
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

	-	Document Opioad	
HARRY INDIGO		Please upload any Genetic Test document by selecting the button below:	
Terms of Use	~		
		No documents to show	
CAREGIVER PARTICIP	ANT		
Caregiver informed Conser	€ ✓		
General Information	~		
HELEN INDIGO			
		UPLOAD +	
Patient informed Consent	× I	I do NOT have any Genetic Test documents available to upload	
General Information	~		
Contact Information and Demographics	~	Complete	
Genetic Test Upload		PREVIOUS	

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

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

