

What is the HI Global Registry?



Your involvement is key to the success of the HI Global Registry!

How will the information I provide be used?



The purpose of the HI Global Registry is to advance the understanding of congenital hyperinsulinism (HI) by studying the experience of those who live with it. The Registry will also support clinical trials and other research studies in the field of HI.

The HI Global Registry is a research study that consists of online surveys that collect information about HI.



The power of a patient registry is dependent on individuals sharing their knowledge and experience.

How do I Participate?



If you have HI, or if you are a parent or legally authorized representative of a person with HI, we invite you to participate in the HI Global Registry. The Registry is open to all individuals with HI and surveys can be completed by the person with HI or a parent or guardian.

The HI Global Registry includes a series of surveys with questions about health, treatment, development, and quality of life. You will have the choice to share your information for research purposes with healthcare professionals and academics. Participants will also be able to compare their responses with the greater HI global community.

The information you provide will be made anonymous by removing any details that can identify you. Your information will be combined with the data from other HI Global Registry participants to improve knowledge of HI.

Reports will be compiled from this information and shared with the patient community and HI experts and researchers. The project is governed by a group of internationally recognized HI patient advocates and experts, known as the HI Global Registry Steering Committee.

The HI Global Registry will be an important resource for researchers or institutions running clinical trials to develop additional treatments or drugs for patients. The Registry staff will inform participants of clinical trial opportunities and give them the choice to contact clinical trial sponsors.

The HI Global Registry will actively support HI research to advance science and help the patient community.

Link and contact information for questions and concerns:

(973)-842-7559
info@higlobalregistry.org



Hummingbird IRB
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The HI Global Registry is hosted by the National Organization for Rare Disorders – a nonprofit organization that has served the rare disease community for more than thirty years. Their Registry Platform adheres to high standards of encryption to ensure the participant's privacy and confidentiality is protected.



Go to
www.congenitalhi.org/higlobalregistry
to get started!

The HI Global Registry is sponsored by Congenital Hyperinsulinism International (CHI), a nonprofit advocacy organization dedicated to improving the lives of children and adults living with HI.



Why is the HI Global Registry important?

The HI Global Registry is important because individual patients are key to understanding HI and advancing better treatments, a potential cure, care, and more timely and accurate diagnosis. The Registry will:



Generate new insights into HI



Drive new research for treatments and cures



Support the success of HI clinical trials



Study and guide standards of care



Improve the lives of all those affected by HI

The HI Global Registry will:

Provide a patient-friendly online platform for participants to share information about HI.

Document the natural history of the disorder that tracks the individual patients' experience over their lifetime. Understanding the natural history of HI will lead to potential new treatments and improved quality of life.

Improve knowledge of how often HI and other health issues associated with it occur.

Clarify the role of timely diagnosis of HI on patient developmental outcomes.

Provide a better understanding of patient health outcomes relative to different HI treatment options, settings and provider types.

Identify both positive and negative effects related to different HI treatment options.

Support the evolving standards of care of HI patients using natural history and outcome information from a global perspective.

CONGENITAL HYPERINSULINISM
HI GLOBAL
REGISTRY

*Congenital Hyperinsulinism
Patient-Powered Research
for a Brighter Future*

The HI Global Registry has many global partners and is sponsored by www.congenitalhi.org

CHI Congenital Hyperinsulinism International