



HI GLOBAL REGISTRY

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FOR IMMEDIATE RELEASE
October 8, 2018

THE HI GLOBAL REGISTRY LAUNCHES TODAY

Patient-Powered Research for a Brighter Future

Glen Ridge, NJ, October 8, 2018– The HI Global Registry will generate new insights into congenital hyperinsulinism (HI), drive new research for treatments and cures, and support the success of clinical trials.

“The HI Global Registry is a groundbreaking new global online research study powered by patients and their families, developed by CHI with partners around the world.” – Julie Raskin, CHI Executive Director

Congenital Hyperinsulinism International (CHI) are very excited to announce today’s launch of the HI Global Registry. The HI Global Registry provides a convenient online platform for the HI patient community to share their experiences of living with congenital hyperinsulinism (HI). By participating in this study, the patient community will help themselves and researchers better understand HI to advance better treatments, a potential cure, and more timely and accurate diagnoses.

The HI Global Registry consists of a series of surveys with questions about health, treatment, development, and quality of life. People with HI or their parents or caregivers can participate from anywhere in the world. Participants will be able to view graphic representations of the responses of the greater HI global community to see how their personal experience fits into the greater whole.

“This is an exciting day. The HI Global Registry is the first global patient registry for those affected by HI. The Registry team has brought together patient representatives from around the world to work with international researchers and clinicians on the development of the Registry and today we are live. This patient-powered project will be a vital resource to better understand HI for years to come.”
-- Davelyn Eaves Hood, MD, MBA

The HI Global Registry has been developed and hosted on a platform built by the National Organization for Rare Disorders (NORD), the patient advocacy organization dedicated to individuals with rare diseases and the organizations that serve them.

About HI

HI is a life-threatening genetic disorder that causes severe low blood sugar. In most countries the estimated incidence of HI is approximately 1/25,000 to 1/50,000 births. For those with HI the beta cells of the pancreas secrete too much insulin in an unregulated manner. Excess insulin causes hypoglycemia. Prolonged or severe hypoglycemia can cause seizures, permanent brain damage or death, if left untreated. Due to the dangers of hypoglycemia, HI requires timely diagnosis.

About CHI

CHI, a 501(c)3, is a lifeline to those born with congenital hyperinsulinism (HI) and their families. CHI is the global organization dedicated to supporting children and adults born with HI. CHI is a leading source of funding for research for better treatments and cures, and the foremost advocate for increased awareness and better medical protocols for HI to reduce preventable brain damage and death from prolonged hypoglycemia.

For more information about this topic, please visit www.congenitalhi.org/higlobalregistry or call Jacqueline Kraska, CHI Research and HI Global Registry Program Director, at 973-842-7559 or email at info@higlobalregistry.org. You may also contact Davelyn Hood, HI Global Registry Principal Investigator, at dhood@congenitalhi.org.