



## HI Global Registry

We are pleased to announce the launch of the HI (congenital hyperinsulinism) Global Registry, a collaborative effort between Congenital Hyperinsulinism International and the National Organization for Rare Disorders (NORD) to study hyperinsulinism (HI). Congenital Hyperinsulinism International supports research on rare diseases and how they progress over time - natural history studies.

### OVERVIEW OF RESEARCH STUDY

The HI Global Registry is more than a versatile online system that securely collects and stores data for medical research; it is a dynamic participant-driven resource that can empower and unite the HI community through shared knowledge. Registry participants not only can complete surveys about their own disease experiences, but also can learn about other participants' experiences by viewing aggregated survey data. As the registry sponsor, Congenital Hyperinsulinism International will ensure that data privacy and confidentiality are strictly maintained. Participation in the HI Global Registry is free and voluntary, and participants may withdraw at any time.

### COMMUNITY INVOLVEMENT

The HI Global Registry is a powerful opportunity for individuals with HI and their family members to contribute directly to research that will enhance our understanding of HI, thus facilitating the development of new diagnostic and treatment options. Participation is especially vital given the rarity of HI - every patient experience is a unique and invaluable part of the natural history of HI.

For further information or to join, please contact: (973) 842-7559  
[www.congenitalhi.org/higlobalregistry](http://www.congenitalhi.org/higlobalregistry) [info@higlobalregistry.org](mailto:info@higlobalregistry.org)



#### About CHI

*Congenital Hyperinsulinism International (CHI) was founded in 2005 by an international group of concerned parents of children born with (congenital hyperinsulinism) HI. CHI's mission is to improve lives of all patients born with HI. CHI partners with leading international HI physicians, researchers and patient advocates to raise awareness of the condition to prevent brain damage and death, search for better treatments and a cure, and improve the quality of life for all HI patients. CHI is the only US-based non-profit working globally to support patients born with the condition.*

#### About NORD

*NORD, a 501(c)(3) organization, is a patient advocacy organization dedicated to individuals with rare diseases and the organizations that serve them. NORD, along with its more than 250 patient organization members, is committed to the identification, treatment, and cure of rare disorders through programs of education, advocacy, research, and patient services.*

