HI GLOBAL REGISTRY

**RESEARCH**
- 2010 - 2013
- Rare disease patient registry review
- Rare disease registry assessment
- Adoption of natural history study (NHS) model
- Rare disease NHS registry commitment

**CONCEPT DESIGN**
- 2013 - 2015
- Project blueprint
- Expert Steering Committee review & recruitment
- Registry provider analysis
- CHI seed funding
- Community engagement
- Registry provider selection & contract

**SET UP**
- 2015 - 2017
- Secure NHS registry funding
- Patient community engagement & recruitment
- Clinician engagement & promotion
- Researcher engagement & promotion
- Other collaborating parties engagement & promotion
- Multi-country recruitment

**LAUNCH**
- 2017 - 2018
- Protocol development NHS registry data set
- Data management plan
- Communication plan & deliverables
- Registry design & configuration
- IRB approval
- Registry testing & training
- Funding analysis
- Partnership development
- Community engagement

**POST-LAUNCH**
- 2017 -
- Multi-country recruitment
- Data management
- Data reports, analysis & dissemination
- Clinical trial support services
- Research collaboration requests
- Governance board
- Registry committees
- Protocol amendments
- IRB submissions
- Fundraising & securing funding
- Community engagement & retention
- Resource management

**LONG TERM**

The HI Global Registry has many Global partners and is sponsored by Congenital Hyperinsulinism International.