Congenital Hyperinsulinism International

The HI Global Registry

Patient-Powered Research Connecting All HI Stakeholders

CONGENITAL HYPERINSULINISM

HI GLOBAL REGISTRY

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WHO
WHY
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WHERE

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HI GLOBAL REGISTRY

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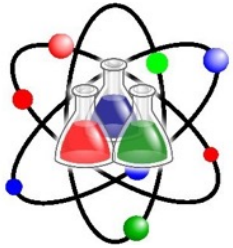

TIMELINE

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 committment

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

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

LAUNCH
2017 - 2018

- Patient community engagement & recruitment
- Clinician engagement & promotion
- Researcher engagement & promotion
- Other collaborating parties engagement & promotion
- Multi-country recruitment

POST-LAUNCH
2018 -

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

LONG TERM
FUTURE

- Further research
- Partner developments
- Regulators & funders relationships
- Boards & committees
- Registry outcomes publications
- Registry developments
- Community engagement & retention
- Resource management
- Strategic planning

The HI Global Registry has many Global partners and is sponsored by

CHI Congenital Hyperinsulinism International

Congenital Hyperinsulinism International

www.higlobalregistry.org

https://www.higlobalregistry.org/

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HI Global Registry

Patient-Powered Research for a Brighter Future!

Learn more »

Rare Disease Research

This is a unique rare disease patient registry. Are you interested in using our data to further your rare disease research?

Researchers »

Participating in This Study

Information collected during this study may be used to help provide opportunities for patients and researchers to collaborate in the rare disaease community.

Patients »

Join the Registry

Please create an account and provide consent to participate in the study.

Register »

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powered by NORD National Organization for Rare Disorders

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YOU

HAVE THE POWER!

HI Global Registry
higlobalregistry.org

Patient-powered research for a brighter future

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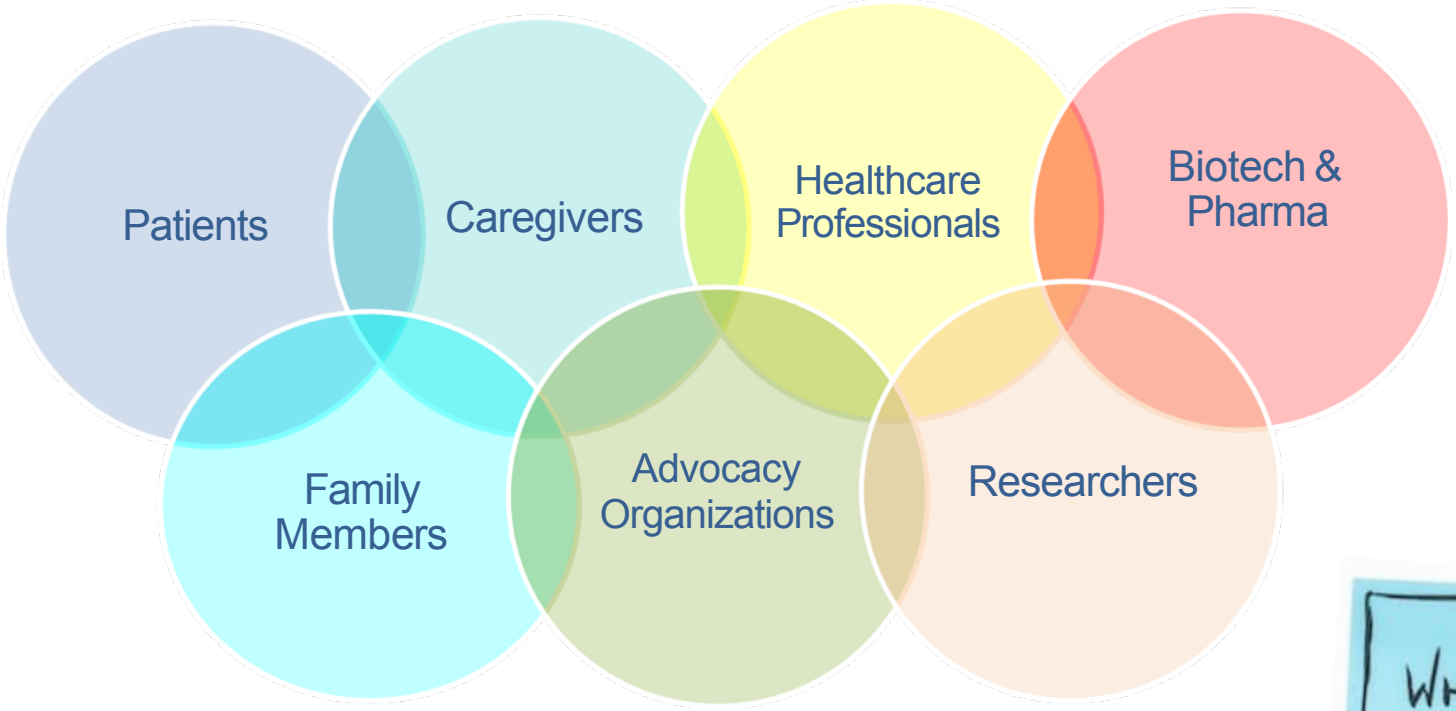
Collaboration of HI Experts



Leads to knowledge, treatments and improved patient care

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HIGR STEERING COMMITTEE

International Patient Advocates

Davelyn Hood, Chair (US)
Isabel Calderón, Vice Chair (Canada)
Julie Raskin (US)
Ulrike Seyfarth (Germany)
Maria Paz Oviedo (Paraguay)
Michelle Walkley (UK)
Sarah Denman (UK)

HI Patient Representative

Rianna Sommers (US)

Scientific Advisors

Jean-Baptiste Arnoux (France)
Indi Banerjee (UK)
Diva De León (US)
Sian Ellard (UK)
Sarah Flanagan (UK)
Klaus Mohnike (Germany)
Pratik Shah (UK)
Charles Stanley (US)
Paul Thornton (US)

Registry Director

Jacqui Kraska (US)

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Sponsors

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Gold

ZEAL&
ZEALAND PHARMA

REZOLUTE
A Metabolic and Orphan Disease Company

Bronze

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How

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BENEFITS TO RESEARCHERS/ CLINICIANS

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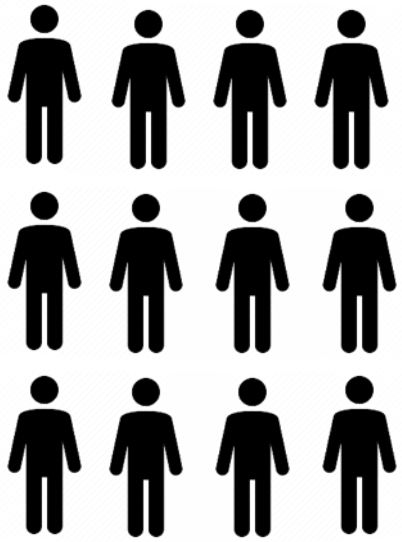
Connection with truly global set of HI patients



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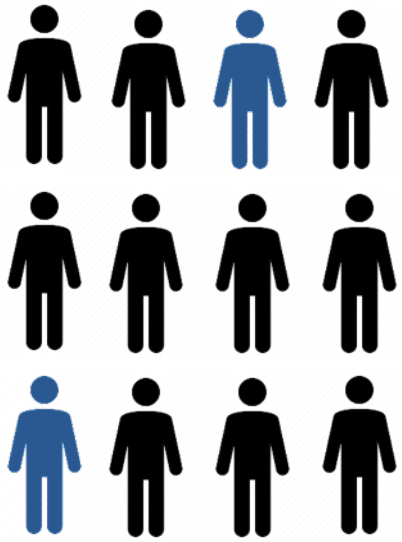
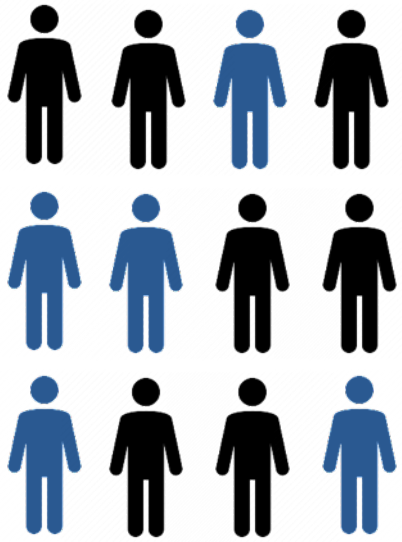


BENEFITS TO RESEARCHERS/ CLINICIANS

Better awareness of available clinical trials
to get more participants involved



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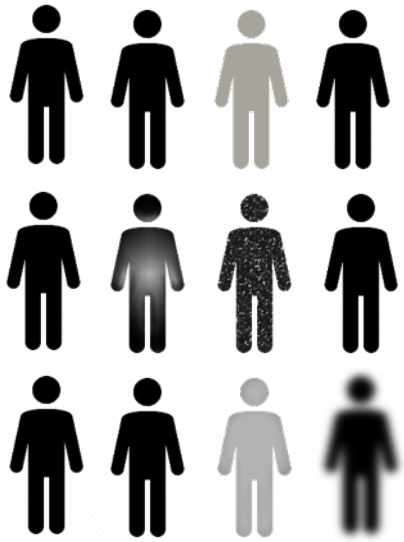
BENEFITS TO RESEARCHERS/ CLINICIANS

Fertile ground for identifying and even performing future research



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BENEFITS TO PATIENTS

- Better understanding of how the whole community of HI patients is affected by the condition
- Individualized comparison of participant to the HI patient community
- Becoming part of the HI community
- Notification of new clinical studies
- Patient community driving change
- De-identified information shared with researchers dedicated to improving treatments and patient outcomes

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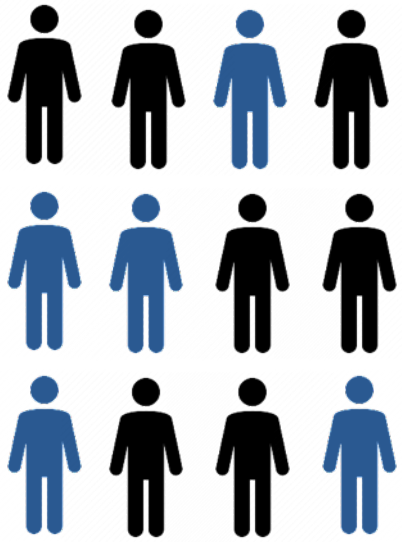
BENEFITS TO PATIENTS



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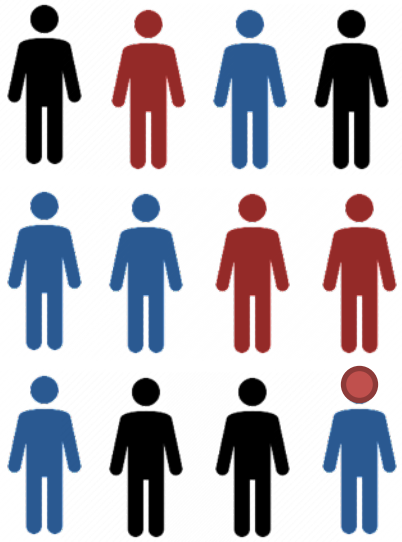

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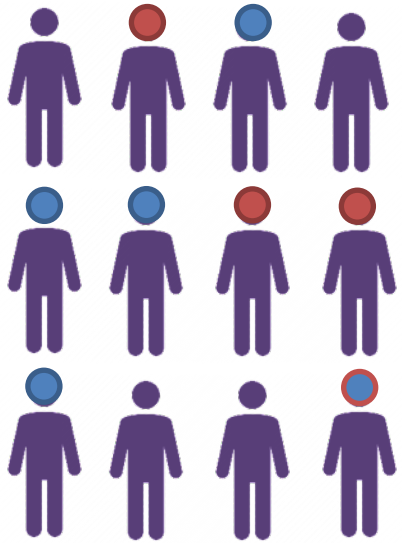
BENEFITS TO PATIENTS

Research to better understand HI that EVERYONE with HI can do!



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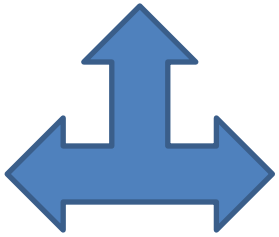
BENEFITS TO PATIENTS

Study Participants

Control Group



Treatment Group

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BENEFITS TO PATIENTS

Study Participants

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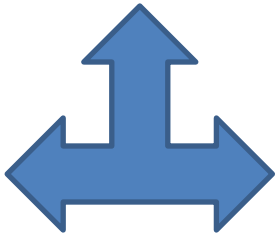

Control Group

Treatment Group