



The HI Global Registry

Shared Experiences for Improved Care & Treatments for Congenital Hyperinsulinism

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Union
LightCure - 101080327



A Future Without Lows

The HI community needs:

Improved understanding of HI

Better treatment options

Clear clinical care guidelines

Improved recognition & faster diagnosis

How can we get there?



HI GLOBAL
REGISTRY

Participate in research!

Willow loves to swim,
but her mom worries about blood sugar drops
when she does.



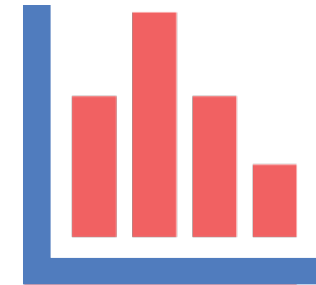
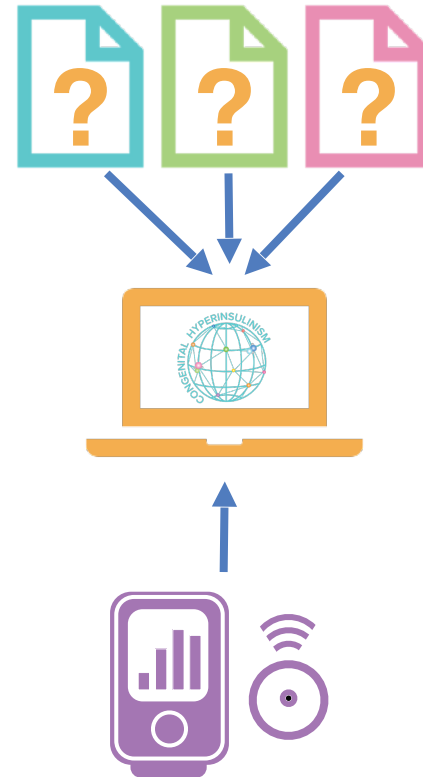
CHI Congenital Hyperinsulinism International
When too little sugar hurts, we help.™

#FutureWithoutLows™

What is the HI Global Registry?

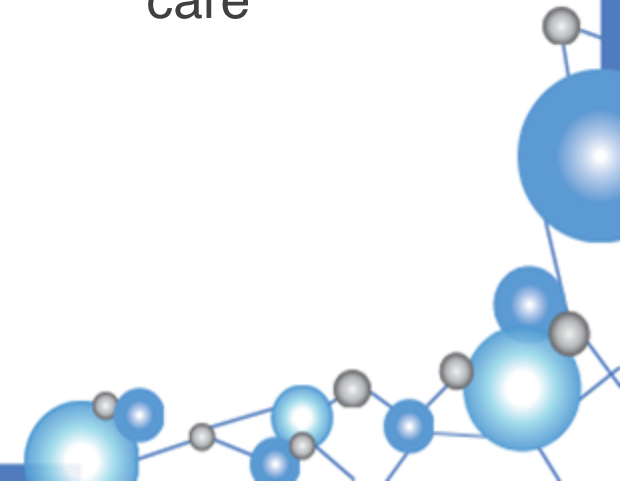


HIGR is the only patient-powered international registry for hyperinsulinism research



Qualified researchers can request the data for studies to learn more about HI, develop new treatments, and improve care

1. Surveys that people with HI or their caregivers complete online from home
2. Share glucose values (optional)



History of the HI Global Registry

In the beginning...

- Email support group
- First patient-reported data collection for HI

Congenital Hyperinsulinism International: A Community Focused on Improving the Lives of People with Congenital Hyperinsulinism

Congenital hyperinsulinism in infancy and childhood: challenges, unmet needs and the perspective of patients and families

Global Registries in Hyperinsulinism

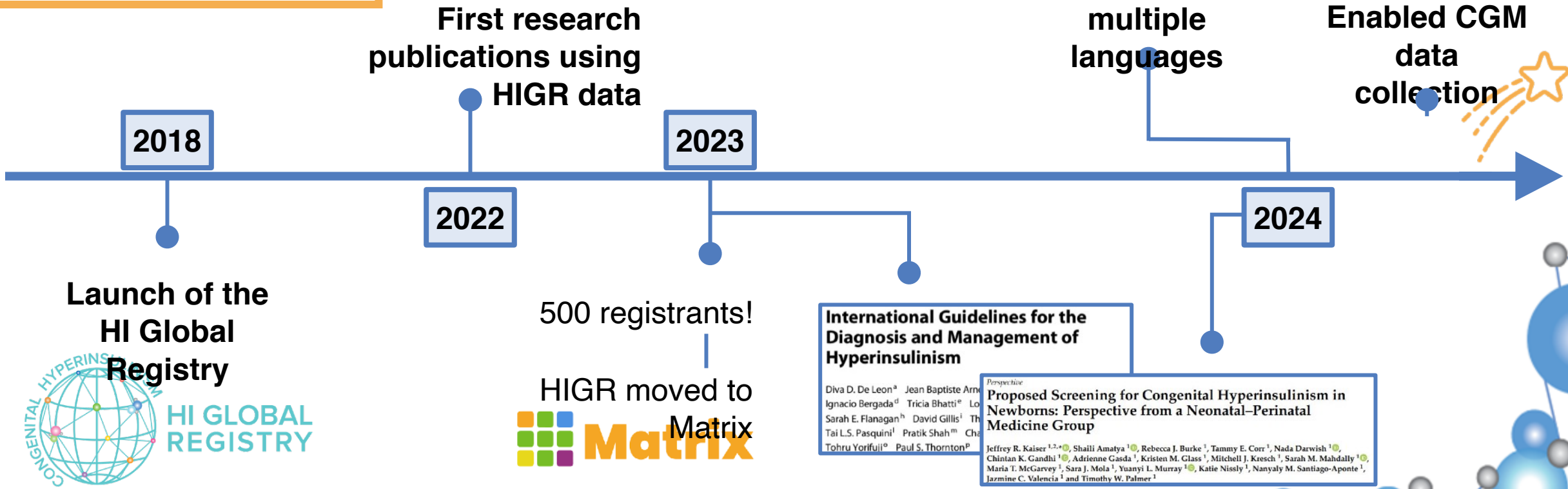
Tai L. S. Pasquini^a, Mahlet Mesfin, Jennifer Schmitt and Julie Raskin
Congenital Hyperinsulinism International, Glen Ridge, NJ, United States

Indraneel Banerjee^{1,2}, Julie Raskin², Jean-Baptiste Arnoux², Diva D. De Leon², Stuart A. Weinzimer², Mette Hammer², David M. Kendall² and Paul S. Thornton²

Our hyperinsulinism surveys are now available in seven languages!

SIGN UP FOR THE HI GLOBAL REGISTRY TODAY.

Share your glucose values for HI research!



International Guidelines for the Diagnosis and Management of Hyperinsulinism

Diva D. De Leon^a, Jean Baptiste Arnoux^b, Ignacio Bergada^d, Tricia Bhatti^e, Lo...
Sarah E. Flanagan^b, David Gillis¹, Th...
Tai L.S. Pasquini¹, Pratik Shah^{1m}, Cha...
Tohru Yorifuji^o, Paul S. Thornton^p

Perspective

Proposed Screening for Congenital Hyperinsulinism in Newborns: Perspective from a Neonatal-Perinatal Medicine Group

Jeffrey R. Kaiser^{1,2,*}, Shaili Amatya¹, Rebecca J. Burke¹, Tammy E. Corr¹, Nada Darwish^{1,3}, Chintan K. Gandhi¹, Adrienne Gasda¹, Kristen M. Glass¹, Mitchell J. Kresch¹, Sarah M. Mahdally¹, Maria T. McGarvey¹, Sara J. Mola¹, Yuanyi L. Murray^{1,4}, Katie Nissly¹, Nanyaly M. Santiago-Aponte¹, Jazmine C. Valencia¹ and Timothy W. Palmer¹

Who can join HIGR?

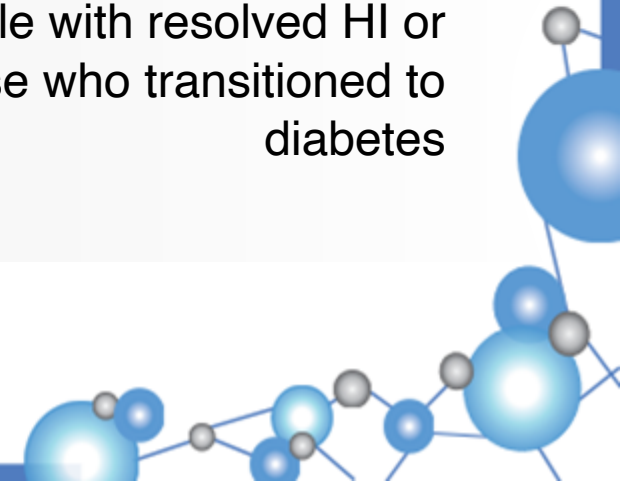
People with HI who are over
the age of 18



Caregivers of people with HI
who are under 18 or do not
have the capacity to consent to
research

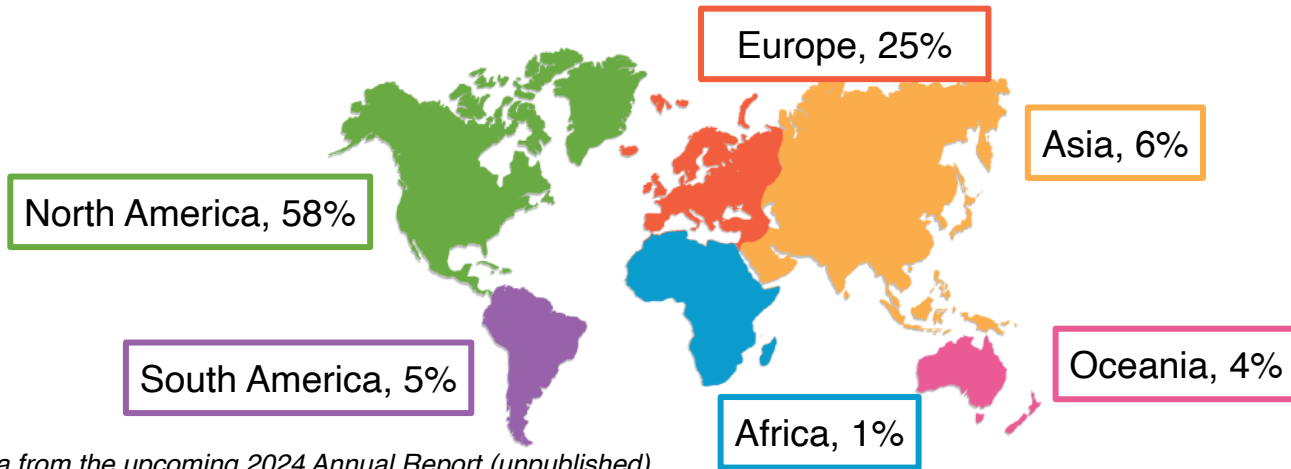
Additional caregivers of HIGR
participants
** Caregiver surveys only*

People with resolved HI or
those who transitioned to
diabetes



A truly global community

Over 500 registrants across 60 countries enrolled in the HI Global Registry



Data from the upcoming 2024 Annual Report (unpublished)



Welcome!
환영합니다! Bienvenue!
Bienvenue!
Bem-vindo!
Benvenuti!
Willkommen!
¡Bienvenido!

higlobalregistry.com



Have you ever asked....

Is the use of emergency/rescue glucagon routine for other HI families?



At what age are children typically diagnosed with HI?



How often do babies with HI need to feed?



How often do most parents check their child's blood sugar levels?



Are seizures common with HI?



Do families receive support when kids with HI start school?

How many people become diabetic after having subtotal pancreatectomy for diffuse HI?



Do kids with HI usually have G-tubes?



HIGR Surveys



Contact & Demographics



MaxHIGR



Pregnancy



Birth



Diagnosis



Other Medical Conditions



Development



Medication Management



Surgical Management



Diet & Feeding



Glucose Monitoring



Quality of Life - Caregiver



Quality of Life - Participant

NEW surveys coming soon!



Provides permission for CHI to contact physician



CHI asks physician to complete MaxHIGR Physician Form

Physician-reported data as a complement to patient-reported data

Verify patient-reported information

Fill in any gaps in information

Provides opportunity for conversation

Glucose Monitoring Data

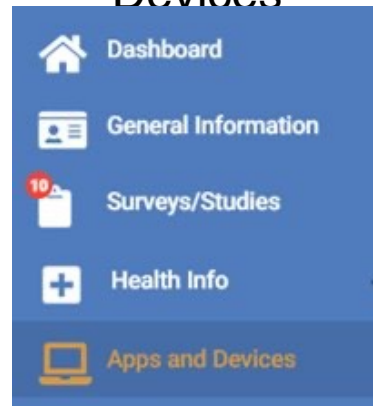


Share your glucose values for HI research!

1. Log into HIGR



2. Apps and Devices



3. Connect to Dexcom



It takes just a few clicks to share your CGM values for HI research.



www.higlobalregistry.org

- Dexcom app on smart device: Continuous data stream
- Handheld receiver: Requires monthly upload to Dexcom Clarity

Glucose Monitoring Data

Why share your glucose monitoring data?



Help to expand **access** to CGM



Improve understanding of **glucose patterns** in HI



Improve CGM **accuracy** in the low range



Comparator arm for **clinical trials**



www.higlobalregistry.org

HIGR Data for Research Studies

HIGR Annual Report

CHI-led Research Studies

Physician-led Research Studies

Industry Data Requests

14

Requests for HIGR data in 2024!

73%

of people living with hyperinsulinism report having feeding issues

HIGR Annual Report 2023



22%

of people with HI report having hypoglycemia more than once a day

HIGR Annual Report 2023



98%

of people taking diazoxide* report at least one side effect

HIGR Annual Report 2023

*the most common medicine used to treat HI



41%

of families are struggling to pay for the costs associated with hyperinsulinism

HIGR Annual Report 2023



Data Privacy & Security

DATA COLLECTION



HIPAA
compliant

GDPR
compliant



Qualified
Researchers

GCP Ethics
Training

Data security
policies

Restricted
access
profiles

DATA SHARING



Qualified
Researchers



Deidentified

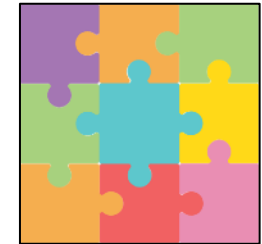
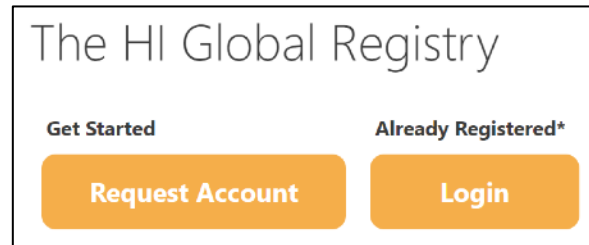


Summary
Data



Data Use
Agreement

How to Join the HIGR Community



1. Visit higlobalregistry.org

2. Click “Request Account”

3. Complete the registration forms

4. Complete all surveys!



5. Connect your CGM (optional)



Helpful Resources – CHI website



The screenshot shows the CHI website's navigation bar with links for About Us, Awareness & Resources, Research, Support & Clinical Care, Events, Donate, Blog, and Contact. A search bar is also present. The main content area is titled "The HI Global Registry" and features two buttons: "Request Account" and "Login". A note states: "*New password required: If you have previously registered to participate in HIGR but have not logged in since before November 10, 2023, please click the Login button and click on the link to 'Reset your password'". Below this is a section titled "What is the HI Global Registry?" with a paragraph explaining the registry's purpose. A "QUICK LINKS" section lists: "Share your glucose values for HI research!", "Frequently Asked Questions", "Guides & Tutorials", "Annual Reports & Publications", "Steering Committee", "Registry Objectives", and "Community".

higlobalregistry.org



Frequently Asked Questions



Video Tutorials



PDF Help Guides with screenshots



Annual Reports

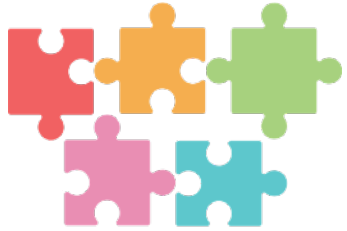


What's Next?



HI GLOBAL
REGISTRY

Join the HI Global Registry!



Complete / Update all Surveys



Connect your Dexcom & share
glucose values for HI research



info@higlobalregistry.org

**Your
experience
with
hyperinsulinism
matters.**



Join HIGR today and complete surveys in
English, Spanish, Italian, French, Portuguese,
German, or Korean.

higlobalregistry.org

