

# THE HI GLOBAL REGISTRY (HIGR)

Bringing the lived experience of hyperinsulinism (HI) to the forefront of research.



## ? WHAT IS HIGR

The HI Global Registry (HIGR) is the only international, patient-powered registry for people with HI. HIGR consists of surveys that record various aspects of that patient and caregiver experience with HI. By participating in HIGR, you can contribute to research studies that may lead to improved care for people with HI.

**HIGR collects information on people with HI in 3 different ways:**

### Surveys for people with HI/their caregivers

Each HIGR survey is focused on a different aspect of life with HI. Your experiences with HI are unique and your voice matters. You can contribute your experiences to HI research.

### MaxHIGR - physician surveys

Your physician can complete an additional survey to verify clinical information and provide any information you may have forgotten or not know. This is optional and only done with participant permission.

### Glucose monitoring data

Share data on glucose levels from your glucometer and/or CGM. This is optional and only done with participant permission.

## HOW TO JOIN

Visit [www.higlobalregistry.org](http://www.higlobalregistry.org) and select "Request Account"

 Create an account

 Provide consent to participate

 Add a Participant (if you are a caregiver)


 Complete the surveys

 Update your survey responses when needed

## IMPACT

 HIGR data has been published in **5** academic papers

Including the International Guidelines for the Diagnosis and Management of Hyperinsulinism

 Annual Report shares HIGR data

Providing you with the most up to date information from HIGR every year

## AVAILABILITY

Anyone with HI is eligible to join, including transient and resolved HI

- Registry is mobile-friendly
- Participate from home
- Surveys can be completed in English, Dutch, French, German, Italian, Korean, Portuguese, and Spanish, with more coming soon!

## SECURITY

Participant data is stored on a secure cloud server and is always **de-identified** before being shared with researchers. That means any information that could identify you, such as your name, address, or date of birth, is always removed.

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It is important that you share your personal experience. We want to learn from you! Your contribution will truly make a difference and help clinicians and researchers develop better treatments and cures.”

**Dr. Diva de León-Crutchlow**  
Pediatric endocrinologist,  
Children's Hospital of Philadelphia

[WWW.HIGLOBALREGISTRY.ORG](http://WWW.HIGLOBALREGISTRY.ORG)

