

HI Global Registry (HIGR)

What is the HI Global Registry?

- The HI Global Registry (HIGR) is a patient powered registry led by Congenital Hyperinsulinism International that can be used to better understand the day-to-day experience of living with HI
- All information collected is kept on a secure system hosted by NORD
- Questions were developed by HI patients, clinicians, and researchers

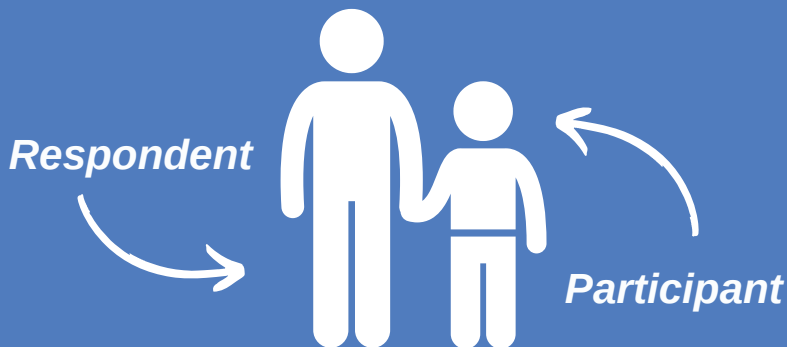
What are the benefits of HIGR?

- Generate new insights into HI
- Drive new research for treatments and cures
- Support the success of HI clinical trials
- Study and guide the standards of care
- Improve the lives of all those affected by HI

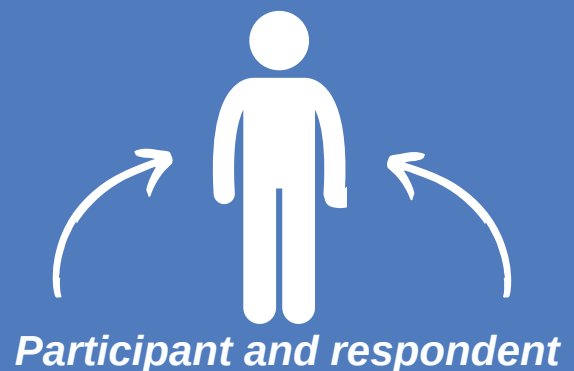
Who can join?

- Adults living with HI
- The parent or legally authorized guardian of a child living with HI

Parent of a child living with HI



Adult living with HI



How can I Join?

To join, scan the QR code to the right and click on the "register" button.

Join us to help advance HI research and find a cure!



Maximizing the Utilization of the Hyperinsulinism Global Registry (MaxHIGR)

What is MaxHIGR?

MaxHIGR adds physician-generated information to HIGR. This project is an international collaboration between leading HI centers and CHI. Any HI patient or caregiver who has completed the relevant HIGR surveys and is interested in participating can have their endocrinologist fill out the MaxHIGR form, which will be returned to them for upload into HIGR. MaxHIGR will add information from physicians to increase opportunities for HI research by complementing patient-reported responses in the registry.



Who can participate in MaxHIGR?

- A respondent (a person living with HI or their caregiver) who has consented to participate in HIGR and has completed all relevant HIGR surveys.
- The participant's physician must be willing to participate in MaxHIGR and complete a physician form.
- The respondent must be able to read and understand English.

How can I join?

1. Register for HIGR.
2. Complete all surveys.
3. You will receive an email inviting you to participate in MaxHIGR; log in to your HIGR profile and consent to join the substudy.
4. Complete the "MaxHIGR First Step" survey to have CHI contact your physician or view draft language to contact them yourself.
5. Your physician will provide you with the completed form that you can then upload to the "MaxHIGR Second Step" survey in your HIGR profile.

How do I learn more?

Scan the QR code to visit the MaxHIGR website. Participate to help advance HI research and find a cure!

