Participate in HI Research

Scan the Qr code to share your child's glucose data with the **HI Global Registry (HIGR)** to help improve CGM for people with HI.

HIGR is the only patient-powered hyperinsulinism registry, and your input can drive critical input.

HIGR data is de-identified, meaning that any information that may identify you, such as your name, date of birth, address, etc., is removed

Join the HI Global Registry

higlobalregistry.org

Questions? Contact us:

info@higlobalregistry.org

HI GLOBAL REGISTRY

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

From HI parents

CGM technology has developed rapidly over recent years and improves with each new device generation – a trend we expect to continue. It has already transformed everyday life for many HI families, and we hope that sharing data will help it go further.

About the CHI CRN. This guide is prepared as part of Congenital Hyperinsulinism International's (CHI) Collaborative Research Network (CRN) – an international group of HI experts and patient advocates working to solve the research questions that lead to the best outcomes for people living with HI. It draws on discussions with hundreds of parents, young people, doctors, nurses and other professionals around the world.

REFERENCES

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De Leon, D. D. et al. International Guidelines for the Diagnosis and Management of Hyperinsulinism. Horm. Res. Paediatr. (2023) doi: 10.1159/000531766.

CHI CRN Congenital Hyperinsulinism International Collaborative Research Network

CONTINUOUS GLUCOSE MONITORING

CGM

A Tool to Support HI Families

A guide for parents and carers of children and young people with hyperinsulinism (HI).

Written by HI parents Helen Couch and Michael Ferguson, as representatives of the CHI CRN Glucose Monitoring Workgroup.

What is CGM?

Continuous glucose monitoring (CGM) devices are wearable technology that use a tiny sensor under the skin to send glucose readings to your smartphone or receiver. Knowing how your child's blood glucose is changing – the trend over time – can support you, and your child, in making informed everyday decisions.

Why is it important?

In HI, blood glucose levels shift quickly and unexpectedly. Children and young people with HI are often unaware that their blood glucose is low when no symptoms are present. Detecting and minimizing low blood glucose is important to prevent brain damage; this can be done with blood glucose testing and feeding regimens.

Alongside this, children and young people with HI endure medication side-effects and long hospital admissions, with the goal of keeping their blood glucose in the normal range. It is important to have routines and tools to support families in everyday life, and CGM can be helpful in achieving this.

> **Remember:** CGM is there to support you and your child in everyday life. It works **alongside** blood glucose checks and watching for symptoms – not instead of them.

For families in the US and Canada who have trouble accessing CGM, the CHI CGM access program may be able to help. Read more by scanning the QR code:

How can CGM help you?

1. **Improve understanding of your child's condition:** CGM lets parents see how their child reacts to feeds or meals, medicines, activity, stress, the weather and illness. You may also notice patterns – for example, times or days of the week when they are more vulnerable to lows.
2. **Real-time tracking and trends:** viewing glucose changes over time can help in many situations, such as prompting timely blood glucose checks. Awareness of trends may encourage breaks and snacks during activity.
3. **Immediate alerts:** children with HI often need support to recognize (hypoglycemia unawareness) and treat their lows. Between routine checks, alerts may help caregivers identify episodes of low blood glucose – especially helpful for children who depend on feeding pumps overnight, as CGMs can catch feed-delivery issues from equipment failures or human error.
4. **Optimised blood glucose checks:** regular finger-prick checks can be painful and interrupt high-demand activities such as sports. CGM can help focus checks on vulnerable periods – for example, pre-feed, in response to signs or symptoms, or to changing CGM trends and alerts.
5. **Enabling independence:** remote monitoring provides information on how your child's HI is managed in their school or childcare setting.
6. **Information sharing with your HI team:** your team can review your child's data remotely to help tailor their advice and support.

Are there any limitations?

There are limitations to consider with CGM use in HI, such as potentially missing episodes of low blood glucose. For this reason it helps to also watch for signs and symptoms of a low and to perform blood glucose checks. You are encouraged to discuss CGM's current limitations with your team.

1. **Devices:** your child wears a small device on their body. Every 7–14 days the sensor and adhesive patch are changed, which can cause discomfort for some children. To collect readings, the receiver or smartphone must be nearby.
2. **Alarms:** the device alarms when readings are low, and sometimes if the sensor is compressed during sleep. Some families find frequent alarms overwhelming, causing alarm fatigue.
3. **Accuracy:** CGM is a useful tool alongside blood glucose checks. Many families find the trend arrows (rising or falling) and alerts more helpful than individual readings. Point accuracy still needs to improve before CGM can replace blood glucose checks in HI – follow your endocrinologist's advice on check frequency, and confirm low readings before treating.
4. **Faults:** sensors may fail, have issues on insertion, or get pulled out. If this happens, replace the sensor promptly and contact the company for a replacement.

> For more detailed "how-to" guidance, see **"Continuous Glucose Monitoring for Children with Hyperinsulinism: A Practical Guide for Families & Professionals"** and the CHI website, **congenitalhi.org**, for links to parent support forums.