



CGM: A Tool to Support HI Families

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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, with 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 minimising 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 to achieve this.

How can CGM help us?

- 1. Improve understanding of your child's condition:** CGM allows parents to see how their child reacts to feeds or meals, medicines, activity, stress, the weather and illness. You may also notice patterns e.g. times or days of the week when they're more vulnerable to lows.
- 2. Real-time continuous tracking and trends:** real-time monitoring viewing glucose level changes over time can be helpful in many situations e.g. prompting timely blood glucose checks. Awareness of trends may encourage breaks and snacks during activity.
- 3. Immediate alerts:** children and young people with HI often need support to recognise (hypoglycaemia unawareness) and to treat their lows. Between routine checks, alerts may help caregivers identify episodes of low blood glucose. This is particularly helpful for children who depend on feeding pumps overnight, as CGMs can catch issues with feed delivery due to equipment failures or human error e.g. forgetting to start a feed on time.
- 4. Optimised blood glucose checks:** Children and young people with HI often have very regular blood glucose checks which can be painful and cause interruptions during high-demand activities such as sports. CGM can allow checks to be focussed on vulnerable periods e.g. pre-feed, in response to signs or symptoms, and to changing CGM trends or 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 HI 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 in HI, such as missing episodes of low blood glucose. For this reason, it is helpful to also monitor for signs and symptoms of low blood glucose and perform blood glucose checks. You are encouraged to discuss CGM's current limitations with your team.

- 1. Devices:** your child will wear a small device on their body. Every 7-14 days the sensor and adhesive patch are changed, which can cause discomfort for some children. Also, to collect the readings, the receiver/smartphone must be near them.
- 2. Alarms:** The device will alarm when glucose readings are low, and sometimes if the sensor is compressed while sleeping. Some families have found frequent alarms to be overwhelming, causing alarm fatigue.
- 3. Accuracy:** CGM is a useful tool alongside blood glucose checks, Many families find the glucose trend arrows (rising or falling) and alerts to be more helpful than individual CGM readings. The point accuracy of CGM still needs improvement to replace blood glucose checks in HI. We suggest you follow your endocrinologist's advice regarding frequency of blood glucose checks and to 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.

CGM technology has developed rapidly over the last few years and improves with each new device generation – a trend we expect to continue. For more detailed "How-to" guidance on getting started with CGM refer to "**Continuous Glucose Monitoring for Children with Hyperinsulinism: A Practical Guide for Families & Professionals Managing Hyperinsulinism**" as well as the CHI International website (<https://congenitalhi.org>) where you can find links to parent support forums.

References

- Ng, S. M. *et al.* Paediatric Society and Hyperinsulinism Charity National Surveys on CGM Access for Patients With Recurrent Hypoglycaemia. *J. Endocr. Soc.* 7, bvad021 (2023).
- De Leon, D. D. *et al.* International Guidelines for the Diagnosis and Management of Hyperinsulinism. *Horm. Res. Paediatr.* (2023) doi:10.1159/000531766.

CHI Collaborative Research Network

This information on CGM: A Tool to Support HI Families is prepared as part of [Congenital Hyperinsulinism International's \(CHI\) Collaborative Research Network \(CRN\) initiative](#) to improve the lives of children, young people, and families experiencing a most challenging illness. The CHI CRN includes an international group of HI experts and patient advocates working together to try and solve the most important research questions that will lead to the best outcomes for people living with HI. The need for this statement arises from discussions with hundreds of parents, young people, doctors, nurses and other professionals from around the world.