Congenital Hyperinsulinism Family Conference Friday, 8th May, 2026

Clare Gilbert, Clinical Nurse Specialist

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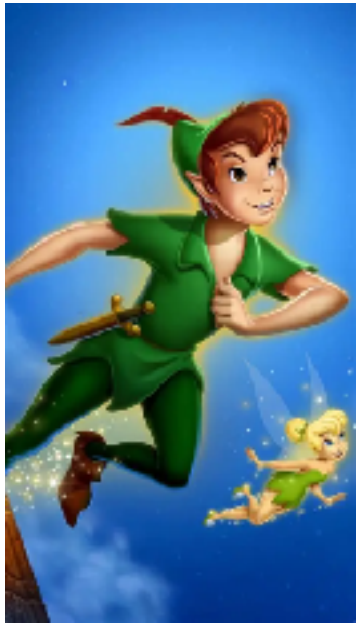


Why is it important to check blood glucose levels?

To identify

- the current blood glucose level
- treat any low blood glucose levels
- ensure the current treatment plan is working/guiding future treatment
- asymptomatic hypos

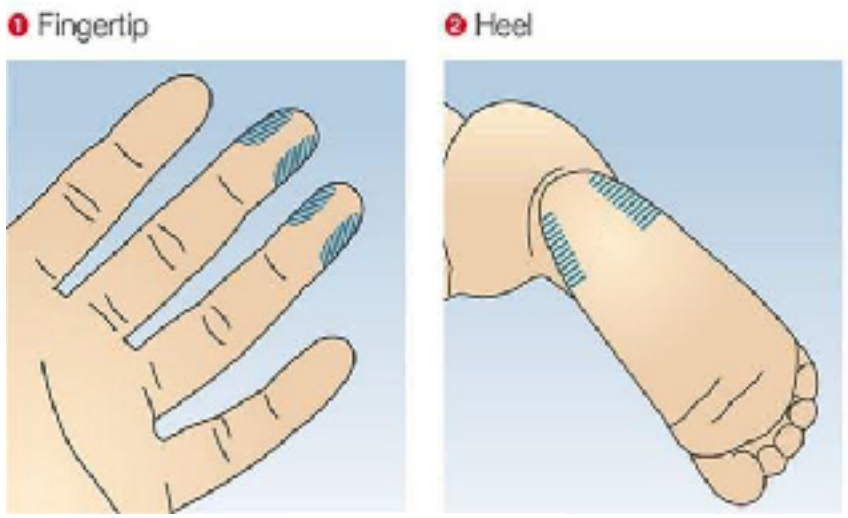
When should a blood glucose level be checked?

- Any time you are concerned about your child / symptomatic / saying “they do not feel right” or behaviour is not “normal”
- As instructed by your care team /tailored to individual – most commonly after fasting overnight and pre meal
- After treating a“low” to ensure hypo treatment has worked.
- At times of illness / reduced intake /if fasting longer than usual

Different types of glucose monitorir

Lab Blood sample	Gold standard for accuracy
Self-monitoring of blood glucose	Fingerstick
	Single “point-in-time”→ Fails to detect nocturnal/asymptomatic hypo
	Does not indicate direction or rate of change of glucose levels
	MARD (Mean absolute relative difference) 5-10% (The smaller the number the closer it is to the lab standard)
	Obtaining glucose data reliant upon the patient’s decision to self-monitor and share
Continuous Glucose Monitoring Devices	Sensor under the skin measures the glucose in the interstitial space
	Recording glucose measurements every 5 minutes
	Lag of approx. 5-10 minutes with the capillary glucose value
	MARD to the standard →Variable but continually improving / however remains higher than capillary sample
	Downloaded and can be shared Treatment can review remotely

Taking a blood glucose level



- Sample from outer aspects of the heels - less nerve endings (neonates – 1 year)
- Sample from outer aspects of fingers (>1 year) avoid pincer fingers
- Free flowing sample needed – Haemolysis (clotting) can result in falsely lower reading
- Ensure feet / hands are pink and warm (well perfused)
- Always recheck a lower reading to confirm accuracy
- Correct lancet device is needed to avoid injury and to obtain good blood sample. Inaccurate levels are often related to poor sample size.
- Ensure test strips stored correctly (away from heat and humidity) plus strips are in date
- Ensure no contamination on skin (eg food, baby wipes)

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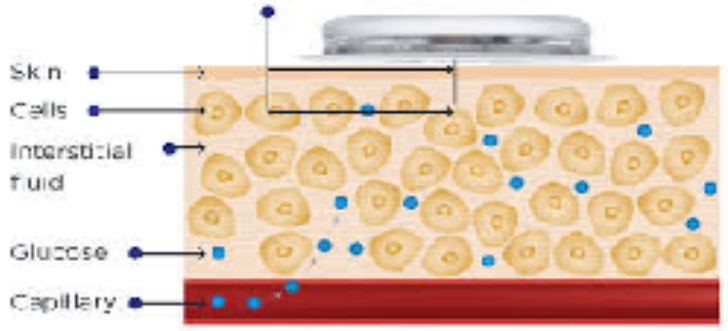
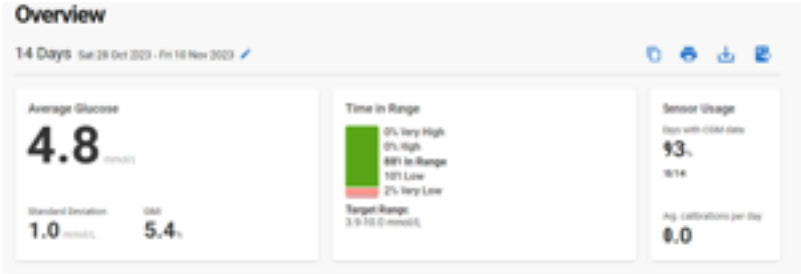
ntinuous Glucose Monitor (CGM)

Continuous Glucose Monitor (CGM)





- Sensor is placed just under the surface of the skin and measures the glucose in the interstitial fluid
- Readings are taken every few minutes – “continuous”
- Transmitted to a receiver, smartphone or smart device

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Benefits and Limitations of CGM

Benefits	Limitations
Real Time alerts	Not as accurate as capillary samples/ false lows (eg pressure lows)
Tracks trends	Alarm fatigue/ information overload/ may increase capillary checks
Can reduce number of capillary checks	Skin irritation
Data shared remotely	Cost / funding

Recommended if individual with Hyperinsulinism is

- At risk of frequent hypoglycaemic episodes and needs daily interventions
- Is on a continuous overnight feed or dextrose polymer
- Has a short fast duration

Works as a tool to guide but **DOES NOT REPLACE BLOOD GLUCOSE MONITORING**

Device	Dexcom One plus	Dexcom G7	Libre 2	Libre 3	Libre 3 Plus
Sensor	10 days	10 days	14 days	14 days	15 days
Monitoring	Real Time	Real Time	Flash with receiver Real time with smart phone	Real Time	Real Time
Receiver/ Phone	Yes/ Yes	Yes/ Yes	Yes/Yes	Yes / Yes	Yes/ Yes
Warm up period	30 mins	30 mins	60 mins	60 mins	60 mins
Glucose readings	Every 5 mins	Every 5 mins	Every min	Every min	Every min
Alerts	High & Low	High & Low	High & Low	High & Lows	Highs & lows
Follow me App	Yes (10)	Yes (10)	Libre link up (20)	Libre Link up(20)	Libre Link up (20)
Professionals sharing	Clarity	Clarity	Libre View	Libre View	Libre View
Funding	GP	Apply for Funding	GP	Apply for funding	Apply for funding

Studies relating to CGM

Clinical Trial > Horm Res Paediatr. 2019;92(5):319-327. doi: 10.1159/000506230.
Epub 2020 Mar 24.

Continuous Glucose Monitoring Systems: Are They Useful for Evaluating Glycemic Control in Children with Hyperinsulinism?

Arpana Rayannavar [1], Okan U Elci [2 3], Lauren Mitteer [1], Diva D De León [4 5]

- ✓ MARD was 17.47%
- ✓ CGM is not a reliable method to monitor for hypoglycemia, given the high number of false positive hypoglycemia readings.
- ✓ CGM can be useful in preventing unnecessary checks by glucose meter during times of normoglycemia. Therefore, the benefits of using CGM in patients with HI would be in guiding the need to check plasma glucose by glucose meter rather than point accuracy

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CGM User Feedback

> Front Endocrinol (Lausanne). 2022 Jul 19;13:894559. doi: 10.3389/fendo.2022.894559. eCollection 2022.

Families' Experiences of Continuous Glucose Monitoring in the Management of Congenital Hyperinsulinism: A Thematic Analysis

Sameera Hannah Auckburally [1 2], Chris Worth [1 S], María Salomón-Estebanez [1], Jacqueline Nicholson [4], Simon Harper [3], Paul W Nutter [3], Indraneel Banerjee [1 5]

- Patients and families with CHI using CGM noticed trends in glucose levels which motivated behavioural changes to reduce hypoglycaemia with advantages outweighing disadvantages
- They expected CHI-specific modifications to enhance utility

> Arch Dis Child. 2022 Oct 6;archdischild-2022-323872. doi: 10.1136/archdischild-2022-323872. Online ahead of print.

Case for funding of continuous glucose monitoring systems for patients with recurrent hypoglycaemia

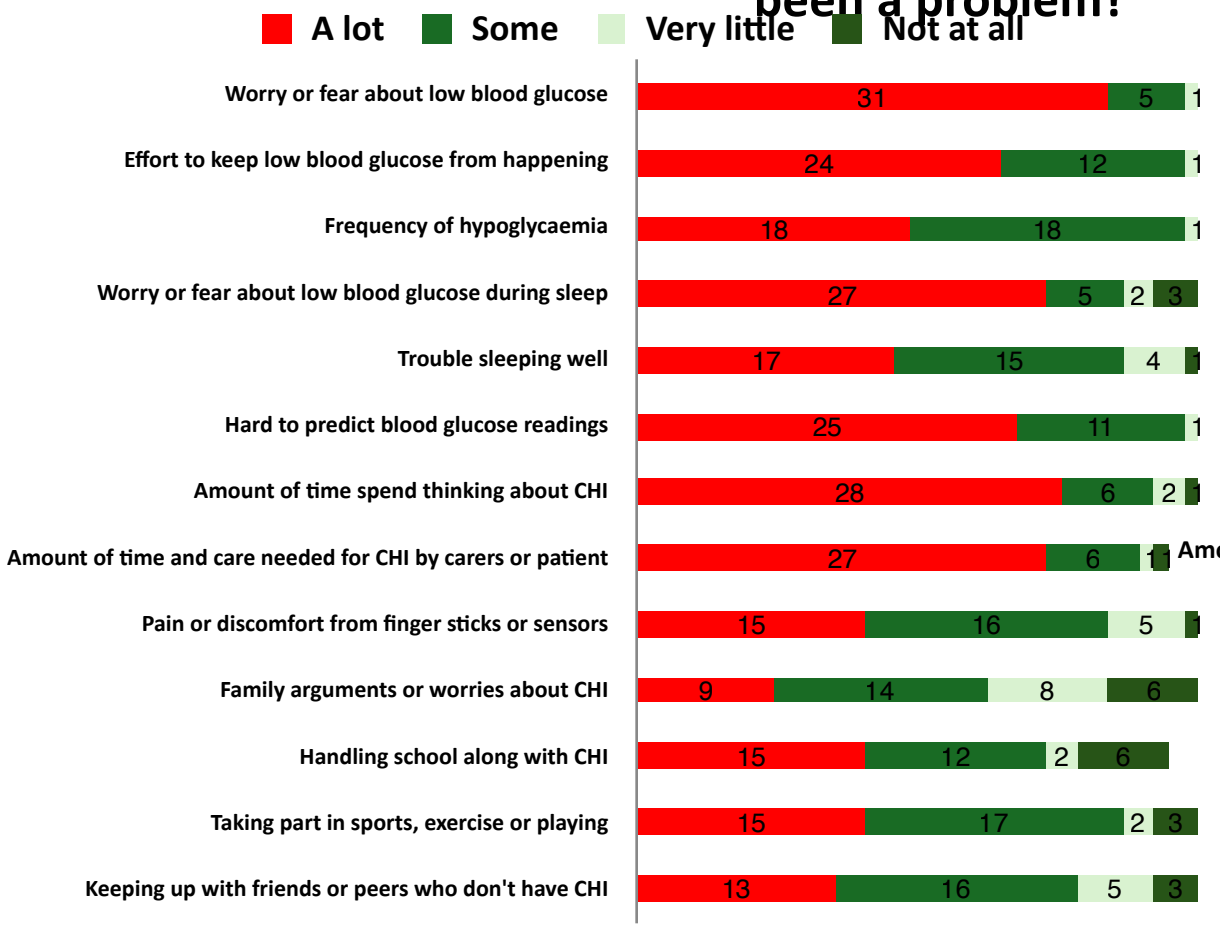
Sze May Ng [1 2 3], Sarah Dearman [4], Mark Fisher [4], Talat Mushtaq [5], Tabitha Randell [6], British Society of Paediatric Endocrinology and Diabetes UK and the UK Children's Hyperinsulinism Charity

- Quality of life improved as CGM reduced worry, provided reassurance, improved sleep patterns, improved ability to participate in school and social activities and leisure time.
- CGM lessen the burden of frequently finger-pricking, reducing unplanned hospital admissions and reducing out of hours appointments as a result of hypoglycaemia

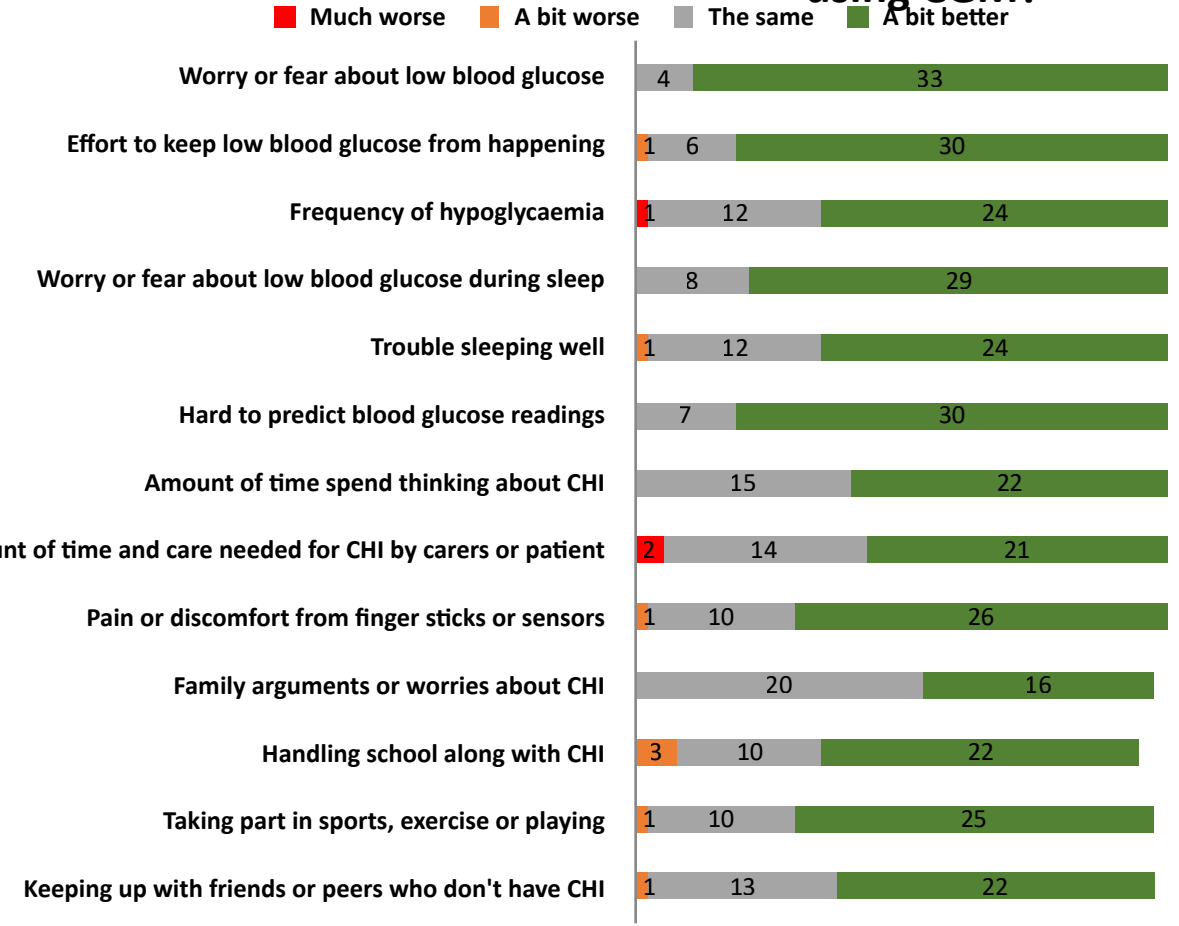
User-Feedback Survey- National UK Survey among 3 CHI HSS centres

80% (37/46 families)

Before using CGM has this been a problem?



How has it changed since using CGM?



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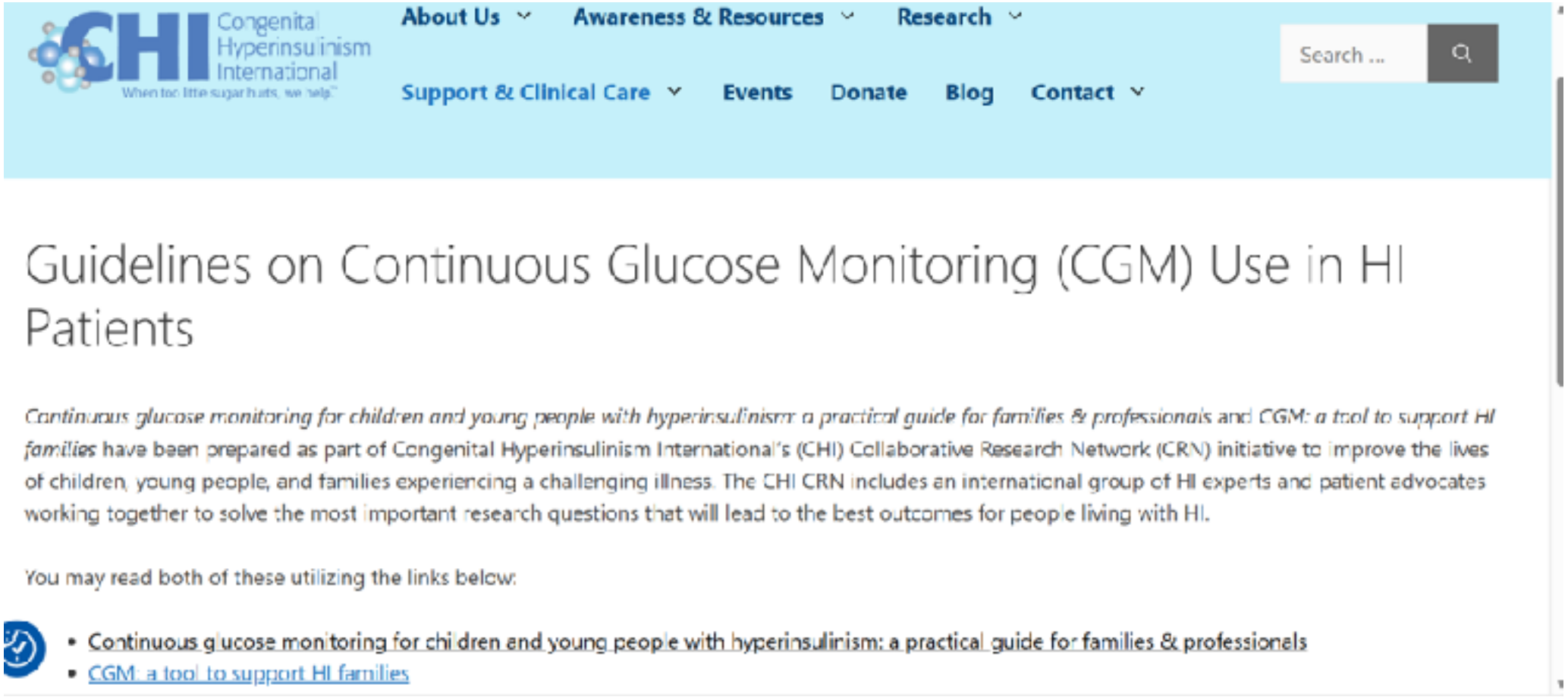
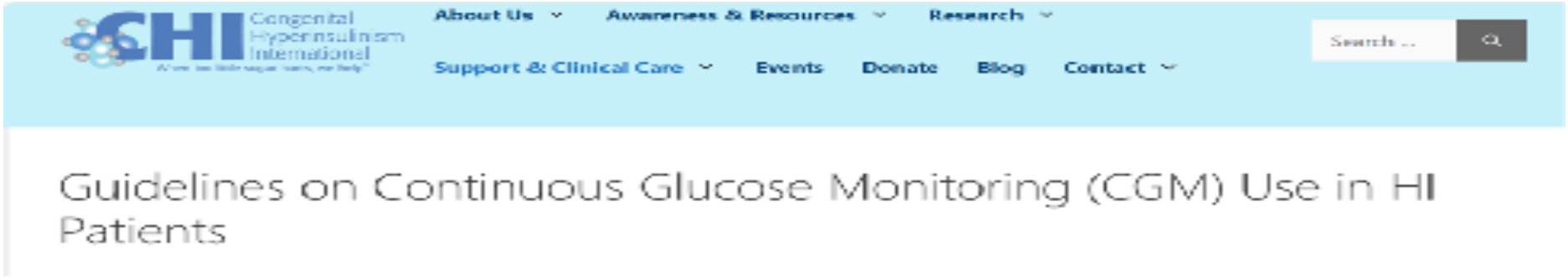
Some parent quotes regarding CGM

- “Have more control”
- “Able to predict when hypos might happen”
- “Able to manage at nursery /school”
- “Follow me App allows more normality, such as attending nursery, school, parents going back to work”
- “Feel able to monitor in real time during increased activity and sport”
- “Less worry especially overnight”

CHI CRN Guidelines on CGM





If CGM readings cannot replace glucometer checks, what will it add?

“CGM helps families and specialist teams understand how an individual’s glucose trends are impacted by everyday life: feeds or meals, medicines, activities, illness and the environment. This extra layer of information, especially when supported through review and discussion with their team, can help families to identify longer term patterns that may lead to HI management changes by the specialist team and help HI families to make behaviour changes to reduce vulnerability to episodes of low blood glucose. The ability to remotely monitor blood glucose levels provides reassurance to parents that blood glucose levels are being managed appropriately when attending childcare or school settings”.

Important limitations of using CGM

“Because CGM has not been designed for use in low blood sugar conditions, the accuracy of CGM has not been demonstrated in the hypoglycaemic range. Nor has the use of CGM and its role in HI management in its current form been thoroughly evaluated”

Advancing Continuous Glucose Monitoring for Children and Young People with Hyperinsulinism – A White Paper from the Congenital Hyperinsulinism International Collaborative Research Network

	SMBG		CGM	
Scenario	**Strengths**	**Limitations**	**Strengths**	**Limitations**
Neonatal care	Gold standard for immediate point accuracy; quick confirmation of Hypo/hyperglycaemia	Painful, limited space on lateral border of foot for heel prick sampling, invasive; intermittent readings; miss asymptomatic and brief hypoglycaemic episodes	Enables continuous glucose trend monitoring; reduces SMBG, identifies asymptomatic hypoglycaemia	Sensor lag, rapid fluctuations, staff require training; device size and placement considerations; fragile skin in premature neonates; skin reactions

	SMBG		CGM	
Scenario	**Strengths**	**Limitations**	**Strengths**	**Limitations**
Home management (Infants/young children	Immediate, direct glucose measurement; widely available	Requires frequent finger pricks (4-12+), including overnight; stressful for child and caregiver, missed episodes of hypoglycaemia between checks	Continuous real time monitoring with alerts; identifies asymptomatic hypoglycaemia, supports remote monitoring; enables personalised specialist virtual advice	Risk of alarm fatigue; cost and training required

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	SMBG		CGM	
Scenario	**Strengths**	**Limitations**	**Strengths**	**Limitations**
Childcare/ preschool setting	Simple, familiar device for caregivers: portable	Large number of staff to train: no trend data: episodic testing misses silent hypoglycaemia	Remote data sharing allows caregiver oversight; alerts warn child and staff early	Device management complexity; sensor displacement risk; alarm management challenges

	SMBG		CGM	
Scenario	**Strengths**	**Limitations**	**Strengths**	**Limitations**
School age (classroom environment)	Portable. Discrete testing achievable	Lost class time; must carry on person; no early warnings; risk of missed events during activity	Enables more autonomous glucose monitoring; alarms and remote alerts can notify caregivers/ school nurse; discretion via smartphone apps and wearable devices such as watches	Acceptance by peers; alarm interference; device maintenance; some perceived stigma

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	SMBG		CGM	
Scenario	Strengths	Limitations	Strengths	Limitations
Independent living	Enables confirmatory checks as needed; immediate feedback	Impractical for frequent monitoring; may lead to missed asymptomatic lows; no alerts; no real time data or alert sharing; no overnight alerts	Supports self management with the trend analytics; predictive alerts; overnight alerts; follower sharing of alerts	User adherence critical; risk of alarm fatigue or disengagement; technical literacy required

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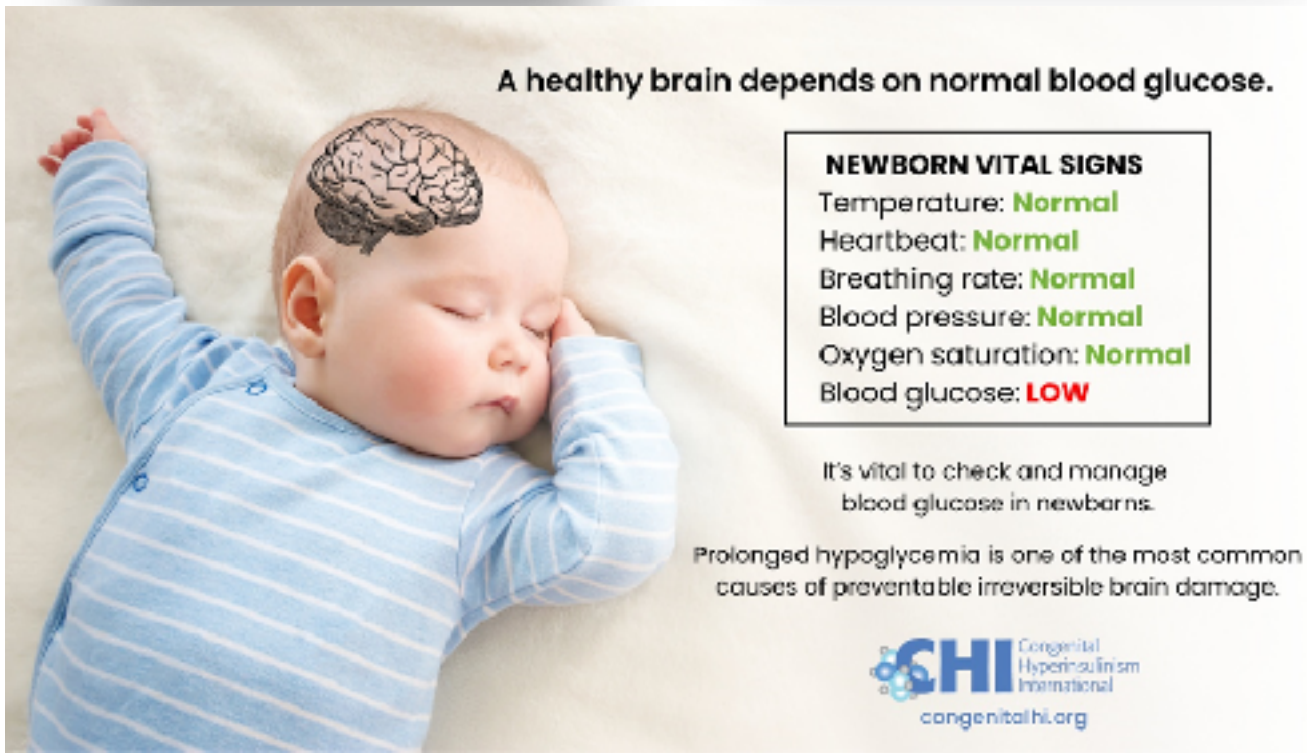
Examples of "Hypo" Treatment

Product	Age of patient	Recommended hypo management (glucose in gram)
Glucogel (10g of glucose in each tube)	Neonate – 6 months	1/3 tube 3.33g
	6 months – 2 years	½ tube 5g
	2-5 years	1 whole tube 10g
	5 years and over	1 ½ tube 15g
Glucojuice® (15g of glucose in 60mLs)	2-5 years	40mLs (10g)
	5 years and over	60mLs (15g)
Glucose tablets (4g of glucose)	2 -5 years	2 ½ tabs (10g)
	5 years and over	4 tabs (16g)

Importance of glucose monitoring



Acknowledgements

Patients and families
GOSH CHI Team

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http://www.gosh.nhs.uk/medical-information/hyperinsulinism

Outpatients (SOS H)
Gym