What Every Parent Should Know about Congenital Hyperinsulinism (CHI)

Why Is My Baby's Blood Sugar So Low? Understanding CHI

Imagine a baby who won't settle no matter what you try. A newborn who seems too sleepy to finish a feed, or whose tiny hands tremble faintly in her sleep. For most families, these are just the ordinary experiences of the first few weeks.

But for around 1 in every 50,000 babies born, these can be the earliest sign of congenital hyperinsulinism (CHI), a rare condition where the body produces far more insulin than it needs, and blood sugar can fall to dangerous levels.

Insulin is the hormone that controls how much sugar, called glucose, stays in the blood. In CHI, the cells in the pancreas that make insulin don't know when to stop. So, they keep releasing it even after the baby's blood sugar has already dropped too low. Left untreated, this steady drop can starve a baby's brain of the fuel it needs to grow and lead to developmental delay presenting in different ways.

Why Does This Happen, and Which Babies Are More at Risk?

In most babies, insulin release rises and falls with how much sugar is in the blood, more insulin when sugar is high, almost none when it's low. In congenital hyperinsulinism, that balance breaks down completely: insulin keeps flowing even when a baby's blood sugar has already fallen dangerously low.

The Genetic Causes Behind It

Changes in certain genes are one well-documented cause, though the exact trigger can vary from child to child. Some forms improve on their own within weeks or months; others need ongoing management for years.

Which Babies Are More Likely to Develop a Temporary Form?

- **Babies born small for their stage of pregnancy**: their bodies may have adapted to limited nutrition in the womb by producing extra insulin, a pattern that usually resolves as they grow.
- **Babies who had a difficult birth with reduced oxygen**: the stress of a hard delivery can temporarily push the pancreas into overdrive.
- **Babies born to mothers with diabetes**: their pancreas adjusts to the mother's higher blood sugar before birth, then can overshoot afterward.

Congenital hyperinsulinism is rare overall, but it isn't equally rare everywhere. Outside research has found that in communities with higher rates of parental consanguinity, it can affect as many as 1 in every 2,500 babies, around

twenty times more often than in the general population. Although, this wasn't specifically measured in the Armenian cases described here.

What Symptoms Should Make Parents Look Closer?

Because low blood sugar firstly affects the brain and many organs throughout the body, congenital hyperinsulinism can look like different conditions at first before anyone checks for congenital hyperinsulinism in babies.

The Early, Easy-to-Miss Signs

- Unusual sleepiness or difficulty waking for a feed
- Irritability or constant hunger
- A faster than normal heartbeat

Signs That Blood Sugar Is Dropping Further

- Confusion, or aggressive behaviour
- Tiredness that doesn't improve with feeding

When It Becomes a Medical Emergency

- Seizures or loss of consciousness (this requires immediate treatment)

Congenital hyperinsulinism is not yet part of routine newborn screening in most countries, including the UK, US, and most of Europe, though researchers are actively working to change this. That makes it even more important for parents and clinicians to recognize the warning signs above and ask for testing directly when suspicion arrises.

Why Getting an Early Diagnosis Changes Everything

If low blood sugar episodes happen often, or last a long time, they can affect a child's brain development for life. But that same fact cuts both ways: with early diagnosis and consistent treatment to prevent low blood sugar episodes, this damage can often be prevented entirely.

What Did Three Real Cases in Armenia Reveal?

The Story Behind the Data

The story of the children presented in this report weren’t hypothetical. The report described three real children with congenital hyperinsulinism, each with a different pattern of symptoms, marking the first time this condition had been formally documented in the country.

One of the three, a five-month-old girl, had first been sent to hospital with a diagnosis of epilepsy and investigated for seizures, before CHI was identified as the true cause. She had been having seizures for a reason no one had checked before: her blood sugar. Once clinicians tested for it, her treatment changed immediately.

The second child, a two-year-old boy, had a much gentler start: two brief episodes of weakness and tiredness that resolved on their own. When it was eventually checked, genetic testing found the cause, a brand-new change in a gene called GCK. This mutation had appeared spontaneously in him alone, and wasn’t carried by either parent.

His condition responded well to treatment, though occasional low blood sugar episodes have continued when the treatment routine hasn't been followed consistently. He is developing normally.

The third child, admitted at 8.5 months old, presented at the other extreme: severe weakness and a dangerously low blood glucose level that required emergency admission to intensive care. He had had unexplained seizures before, though no one had checked his blood sugar at the time. Genetic testing found no identifiable cause, yet he responded quickly and well to treatment, and is developing appropriately for his age.

What Comparing the Three Children Revealed

Looking at all three children together taught doctors that a genetic test result doesn't predict how severe CHI will be. The child with a confirmed genetic cause actually had the mildest, latest-starting symptoms of the three. The child with no identifiable genetic cause at all (the first child, whose seizures were originally mistaken for epilepsy) had the earliest and most severe presentation, and is the only one of the three with an ongoing developmental delay.

That contrast emphasizes that catching and treating low blood sugar early matters enormously for a child's long-term development. All three children responded well to the same medication, diazoxide, and the two children whose condition was recognised and treated earliest are both developing normally today. A common side effect of long-term diazoxide treatment, excess hair growth, appeared in all three children to differing degrees, but hasn't affected their overall health.

Final Thoughts

Congenital hyperinsulinism is rare, but it's also one of the more treatable causes of severe low blood sugar in babies, if it's caught in time. That same urgency is good news: because congenital hyperinsulinism responds so well to treatment, a fast diagnosis is often all it takes to put a baby on a completely normal path.

What to Do Next

If your baby or child has unexplained seizures, extreme sleepiness, or feeding difficulties without a clear cause, ask your pediatrician directly: could this be low blood sugar? A simple blood test can rule congenital hyperinsulinism out.

Interested to learn more? Click here to read the article on my website.

Written by: Sama Shamyar, MBBS

Published: *30/July/2026* **| Last reviewed:** *30/July/2026*

This summary is adapted from Navasardyan L.V., Flanagan S.E., Shamyar S., Hussain Kh. (2024). Congenital Hyperinsulinism: First case reports from the Republic of Armenia. The New Armenian Medical Journal, 18(2), 128–131. DOI: 10.56936/18290825-2.v18.2024-1284, rewritten in plain language for portfolio demonstration purposes.