

Congenital Hyperinsulinism International

- ✓ Promoting proper diagnosis of hyperinsulinism
- ✓ Providing educational material for doctors, hospitals, schools & parents
- ✓ Raising awareness of the life impact of hyperinsulinism
- ✓ Supporting research of hyperinsulinism

We are a 501(c)(3) charitable organization. In the United States, contributions to CHI are tax deductible (subject to IRS limits).



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Congenital Hyperinsulinism Awareness



Seizures and Permanent Brain Damage in Babies Linked to this Rare Disease

Keep blood sugar levels ABOVE 70 mg/dl or 3.7 mmol/l

"Even though this is a rare disease, it would be nice to see progress in the amount of time it takes from showing symptoms to having a diagnosis. Taking a simple blood sugar level is so inexpensive and non-invasive."

- Jennifer, Mom to Cole (treated for epilepsy prior to HI diagnosis)

For more information:

Visit

- www.sur1.org

Read

- [The Causes of Neonatal Hypoglycemia](#). Stanley C.A., Baker L. New England Journal of Medicine, 1999 Apr 15; 340(15):1200-1201.
- [Acute Hypoglycemia Masquerading as Head Trauma: a Report of Four Cases](#). Luber S.D., Brady W.J., Brand A., Young J., Guertler A.T., Kefer M. American Journal of Emergency Medicine 1996 Oct; 14(6):543-7.
- [Effects of Hypoglycemia on Developmental Outcome in Children with Congenital Hyperinsulinism](#). Steinkrauss L., Lipman T., Hendell C.D., Gerdes M., Thornton P.S., Stanley C.A. Journal of Pediatric Nursing, 2005 Apr; 20(2):109-118.
- [Hyperinsulinaemic hypoglycaemia: biochemical basis and the importance of maintaining normoglycaemia during management](#). Hussain K., Blankenstein O., De Lonlay P., Christesen H.T. Archives of Disease in Childhood, 2007 Jul; 92(7):568-570.

Protecting Children from Low Blood Sugar Levels

"My son was diagnosed at 16 months of age after months of agony and misdiagnosis (brain virus, epilepsy). He was fine at birth, although born one month early, but now that I know, I think he started having symptoms at age 3 months: crying, hungry, not sleeping, shaking. When he had a real seizure at 16 months, we finally got the diagnosis."



- Mary,
Mom to Eric

Congenital Hyperinsulinism (HI)

also known as nesidioblastosis or PHHI (persistent hyperinsulinemic hypoglycemia of infancy),

is a rare disease, currently diagnosed in approximately 1 in 50,000 births.

It is mainly characterized by the presence of low blood sugar with low ketones with or without inappropriately high levels of insulin.

If it's so rare, why do we care?

Each undiagnosed child is at risk of irreversible brain damage from persistent low blood sugars.

Many children are erroneously diagnosed with a seizure disorder when the underlying problem is actually hyperinsulinism.

Symptomatic clues pointing to hypoglycemia:

- Excessive hunger
- Irritability
- Sleepiness
- Shakiness
- Lethargy
- Seizures
- Possible macrosomia

With HI, and ANY episode of hypoglycemia, keeping blood sugars **ABOVE 70 mg/dl or 3.7 mmol/l** is crucial!

Important Facts About HI:

- Children with HI often present with seizures to the emergency room. Ask for ketone and insulin levels to be drawn along with the glucose level.
- Children with HI **do not make sufficient ketones** to protect their brain and other organs when they have low blood sugar levels.
- Maintaining safe blood sugar levels in HI can be achieved by use of medication or by surgery to remove part of the pancreas.

"Diego was diagnosed at 2 weeks of age but even while in hospital, his blood sugar levels were not kept at a safe range. At 19 months, he had just begun to crawl."

- Sandra,
Mom to Diego

