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FACTS ABOUT CONGENITAL HYPERINSULINISM (HI)

- HI can cause developmental delay, brain damage, and even death. Early diagnosis and excellent treatment and management of the disorder reduce the chances of lifelong disabilities.
- HI is poorly understood by many physicians around the world. Raising awareness of the disorder among physicians will increase early diagnosis and improve care.
- Many children with HI are mistakenly diagnosed with epilepsy when the underlying cause of seizures is hypoglycemia.
- Maintaining blood sugar levels above 70 mg/dL (3.9 mmol/l) is crucial.
- Signs of HI may include: excessive hunger, irritability, sleepiness, shakiness, lethargy, seizures, and blood sugar levels below 70 mg/dL (3.9 mmol/l). Newborns with HI sometimes have larger than normal birth weight.
- In some cases HI can be cured with surgery. Medication and/or surgery help patients to achieve safe blood sugar levels.

Congenital Hyperinsulinism International

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Dedicated to improving the lives of children, adults, and families living with congenital hyperinsulinism.



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WHAT IS CONGENITAL HYPERINSULINISM?

Congenital Hyperinsulinism (HI) is a life-threatening genetic disorder that causes severe low blood sugar (hypoglycemia) in infants and children.

For those with HI, the beta cells of the pancreas secrete too much insulin in an unregulated manner. Excess insulin causes hypoglycemia. Prolonged or severe hypoglycemia can cause seizures, permanent brain damage, or even death, if left untreated. Due to the dangers of hypoglycemia, HI requires timely diagnosis.

Tragically, the disorder is often overlooked in newborns. Once diagnosed, HI can be treated and those living with it can go on to lead full lives. Medication, surgery, and diet often play a role in the treatment and management of the disorder. Early intervention and special education support are sometimes needed for children with the disorder.

HI is a rare disorder affecting an estimated one in every 25,000 to 50,000 births.



WHO WE ARE

Congenital Hyperinsulinism International (CHI) is a grassroots organization founded in 2005 by concerned parents of children with HI. CHI is supported in its work by a Scientific Advisory Group comprised of eleven of the leading HI world specialists.

CHI families work together to improve the lives of babies, children, and adults affected by the disorder. CHI families are committed to providing education, information and support to those living with the disease.

CHI advocates on behalf of patients for better treatments and access to care.

CHI is dedicated to increasing awareness of the disorder as it leads to more timely diagnosis and better care.

CHI supports medical research for improved therapies, potential cures, and timely diagnosis.

CHI works globally because we are stronger as an international community. Cooperation across borders fosters important advances in medicine. Moreover, every person born with the disorder deserves access to excellent care and support.

“Congenital hyperinsulinism is a very isolating condition because it is so rare. We found it extremely important to connect with other families dealing with the same issues we deal with. The support and knowledge we have gained from the experiences of other families have been invaluable to us. We are hopeful that by working together we can make a difference and improve treatment options for our kids.”

—THE PAREKH FAMILY, CANADA



HOW YOU CAN HELP

Better treatments for HI can be found. Better access to quality healthcare for those with HI can become a reality. Better educated physicians and parents can improve the quality of life for those born with the disorder. A supportive community does improve the wellbeing of HI families. We need your help in raising awareness of the disorder and the importance of timely diagnosis and treatment. We need your help to raise funds for programs and research that will improve the outcomes of all affected. We need your help to continue to support children and families under stress. Please go to our website, www.congenitalhi.org to make a donation and get involved.

Please become a part of the CHI Call to Action by:

- Sharing your story and the importance of improved treatments and diagnosis.
- Disseminating Congenital Hyperinsulinism International brochures to doctors and hospitals in your area to raise awareness of the disorder.
- Contacting government officials about the importance of funding rare disease research and quality healthcare for all.
- Making a donation to Congenital Hyperinsulinism International to help us raise funds for research, educational programs, and awareness events.
- Hosting an event locally to raise awareness and funds for congenital hyperinsulinism research, education, and support.

