# Parent's guide to Cook Children's Hyperinsulinism Center

Hypoglycemia, also known as low blood sugars, may be caused by a variety of medical conditions. Once your baby has been diagnosed with hypoglycemia, the next step is to find out what caused the hypoglycemia and how to treat it.

Congenital hyperinsulinism (CHI) is the most common cause of hypoglycemia in infants more than 3 days old. It is a rare and serious disease that affects nearly one in every 50,000 babies born in the U.S., each year. This condition can cause severe hypoglycemia, which could lead to brain damage in 20-40 percent of affected children. There are many forms of CHI and the treatment for each form is different, making it crucial to diagnose the exact form of CHI. We understand that a CHI diagnosis might seem overwhelming, and we're here to help.

Cook Children's Hyperinsulinism Center opened in 2010 and is one of two such centers in the country. Our center has a special team of doctors that include pediatric endocrinologists, surgeons, neurologists, neonatologists, gastroenterologists, pathologists and radiologists. We also have a CHI nurse, nutritionist, social worker, psychologist, Child Life specialists and feeding and speech therapists. Our goal is to provide the most recent technology and best quality of care for babies and children with CHI, while providing support and information to their families.

Since opening our hyperinsulinism center, we have consulted, evaluated and treated an extensive amount of children with hypoglycemia from unknown causes to recurrent hypoglycemia due to hyperinsulinism. We are the only specialized CHI center in the South and we know we can make a difference in your child's life.

#### How do I get to the Cook Children's Hyperinsulinism Center?

If your doctor suspects that your baby has CHI, we are happy to talk to him/her about starting treatment in your local hospital. The doctor may call or contact us by email. If treatment is not working and your baby is not safe to go home, we can help arrange transfer to our medical center.

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## Parent's guide to Cook Children's Hyperinsulinism Center (cont.)

### What can I expect when my baby gets to Cook Children's?

You will start by meeting with our CHI team where we will review your child's medical records and discuss what has happened to you and your baby prior to your arrival. We will confirm your child's CHI diagnosis and perform genetic tests to find the cause of your baby's CHI. Cook Children's is at the leading edge of clinical research in CHI and we will offer your baby the opportunity to participate in our research studies that may include our database, genetic and neurological outcome studies. Participation in our research studies is completely voluntary. You will receive the same medical care from Cook Children's no matter whether your child takes part in these studies. Our number one goal is to create a successful plan to get you and your baby home with a safe and manageable treatment program.

Your child's length of stay at our medical center will vary from 14 to 60 days depending on the type of CHI he/she has, the severity of the condition and the need for surgical management. Throughout the diagnosis and treatment process, your child and family will receive support from our staff and our parent support group.

Once a treatment program is established, we will prepare you to go home and make sure you are comfortable with the program. Preparation includes patient education, how to give your child his/her medication and equipment and a long-term care plan. The final step will allow you to care for your child with minimal help from our nursing team. This ensures that you understand all aspects of your child's care and will be able to safely treat your child at home.

Nurse educators and board certified physicians are available 24 hours a day to support your child's needs. You can call 682-885-4000 or email HICenter@cookchildrens.org if you have any guestions or concerns.



#### Contact us

- Cook Children's Hyperinsulinism Center: 682-885-7960
- For 24 hours a day emergency contact of the endocrinologist on call: 682-885-4000
- · New patient scheduling: 866-266-7948

