

rare find

Congenital hyperinsulinism (HI) is the most common cause of severe, persistent hypoglycemia in newborns and children. HI is rare, affecting one in 25,000 to 50,000 babies. This can make it a challenge for families and physicians to locate specialists with the expertise to offer the most advanced treatments and potentially cure the disease.

As the only facility of its kind in the country, the Congenital Hyperinsulinism Center at The Children's Hospital of Philadelphia is one of the few centers worldwide with the knowledge and capability to successfully cure patients with focal lesions of congenital hyperinsulinism.

Referrals

To make a referral or schedule an appointment, please call 215-590-7682 or visit us at <http://hyperinsulinism.chop.edu>.

We have an ongoing commitment to education for both parents and healthcare professionals. Please see our Web site for more information.

A RARE DISEASE — AN UNCOMMON EXPERTISE

The specialists at the Congenital Hyperinsulinism Center are pioneers in the diagnosis and treatment of congenital HI, offering groundbreaking approaches that have set standards for care worldwide. The Center is staffed by a sophisticated team of pediatric endocrinologists, surgeons, pathologists, anesthesiologists, radiologists, nurses and researchers all working closely together to provide a full spectrum of services, allowing patients to receive seamless treatment. Children's Hospital's family-centered approach to care offers parents the opportunity to actively participate in their child's treatment and in the decision-making process.

Although Congenital HI is rare, the professionals at Children's Hospital's Congenital Hyperinsulinism Center have performed more than 200 surgeries in the past 10 years, making ours the largest program of its kind in the world. This experience, combined with unique expertise in areas such as gene research, surgery and innovative treatment strategies, puts the Center at the forefront of clinical care for this rare disease. The Center also has a strong educational mission, hosting international symposia and sponsoring parent conferences.

A PRECISE DIAGNOSIS — A HOPE FOR A CURE

In recent years, researchers have uncovered several types of congenital HI. The two most common are:

- **Diffuse KATP hyperinsulinism** — In this form of HI, all beta cells in the pancreas are affected, usually requiring removal of 98 percent of the pancreas.
- **Focal KATP hyperinsulinism** — In this form of HI, only a small area of the pancreas is affected; remaining beta cells in the pancreas are normal. Surgery is often performed to remove only the small area of affected cells, leaving most of the normal pancreas behind and potentially curing the disease.

The experts at the Center use the latest testing available, allowing them to determine with extreme precision whether patients have diffuse or focal HI. The distinction is critical — children who undergo the more extreme operation are at higher risk for diabetes. The Center's technologically advanced equipment and testing improve the likelihood of a cure and significantly reduce the chance that children with focal HI will develop diabetes.

“If you're in America, this is the only place you can go. It's the best chance you can give your child.”

Lisa Robertson, whose son Richard was successfully cured — *St. Louis, Mo.*