



Cook Children's is the only facility in the South and the second in the country to use an investigational drug combined with a PET-CT scan to diagnose focal lesions in children with congenital hyperinsulinism.

Investigational drug ^{18}F DOPA with PET-CT scan now available

Because only a small amount of the pancreas is affected with focal congenital hyperinsulinism (CHI), it can be cured with surgery. However, special testing using the investigational drug ^{18}F DOPA, as part of a clinical research trial, combined with a PET-CT scan is needed. Once located, the surgeon can remove the focal lesion. This leaves most of the normal pancreas behind, which may prevent the development of diabetes and cure the child.

When to make a referral

Contact our CHI team if you have a baby with CHI who does not respond to diazoxide and is unable to maintain safe glucose levels. We can arrange transport to Cook Children's Medical Center in Fort Worth, Texas, and through the PET-CT scan, determine if the child will need surgery.

Hyperinsulinism Center
Medical Director Paul Thornton, M.D.
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682-885-7960

Hypoglycemia < 50 mg/dL is confirmed

Treat with oral feeds and IV glucose to keep glucose > 70 mg/dL.

Once glucose is stable > 70 mg/dL wean off IV if possible.

If glucose < 50 mg/dL after 48-72 hours of life, determine etiology of hypoglycemia (measure plasma glucose, insulin, lactate, betahydroxybutyrate, growth hormone and cortisol levels and perform glucagon stimulation test).

Diagnose with hyperinsulinism

Treat with diazoxide 5-15 mg/kg/day and evaluate after five days.
Monitor for pulmonary hypertension, fluid overload, neutropenia and thrombocytopenia.

Patient responds;
ability to fast 9 hrs
with glucose > 60 mg/dL

Patient doesn't respond

Persistent hypoglycemia

Send home and request follow-up
with local endocrinologist.

1. Refer to Cook Children's Hyperinsulinism Center for 18F DOPA PET study: cookchildrens.org/professionals
2. Send DNA for hyperinsulinism gene screen:
Order a rapid turnaround test for Tier 1 screen (ABCC8, KCNJ11) with results in 4-7 days and send parental DNA with child.
(Rapid turnaround testing currently available from University of Chicago genetic lab or Athena Diagnostics)

Diagnosis: Diffuse hyperinsulinism
Surgery or conservative
Average length of stay: 28 days

Diagnosis: Focal hyperinsulinism
Surgery and potential cure
Average length of stay: 24 days

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For referring clinicians' consult
and non-emergent transfer needs,
call Cook Direct Connect:
682-885-1940



Scan to download
the referral form.