

## **PARENT INFORMATION for POSITIVE newborn screening results for CONGENITAL PRIMARY HYPOTHYROIDISM (CPH)**

When your baby was born a small sample of blood was taken from your baby's heel to test for certain diseases. These diseases usually cannot be found simply by looking at your baby, so that is why the blood test is so important.

The results of your baby's screening test were "positive" for a disorder called congenital primary hypothyroidism (HY-po-THY-roid-ism) or CPH. It is important to remember this is only a screening test. A new blood sample will be collected from your baby and a new test will be done to find out if your baby has CPH or not.

### **What does a "positive" screen mean?**

A positive test means that your baby needs to have a new blood test to check for CPH. A small percent of all babies screened will be identified as "positive" on screening. Some are later found not to have the disorder. This is just a "screening" test and further testing must be done to determine if your child has CPH or not. Keep in mind that the new test could show that your baby does not have CPH.

### **What is the next step?**

Be sure to follow your baby's doctor's instructions for getting a new blood sample for further testing. CPH is a rare disease involving the endocrine system, so your baby's doctor might consult with or refer you to a pediatric endocrinologist.

### **What exactly is CPH?**

CPH is a disease that causes the thyroid gland to not make enough thyroid hormone. Thyroid hormones play an

important role in body growth and brain development. A baby with CPH usually appears normal at birth. By the time symptoms develop, damage may already have occurred. If left untreated, a child can have mental retardation or may not grow normally. A baby will usually develop normally if treatment begins in the first weeks of life.

### **What should I do?**

**The most important thing that you can do is to be sure that your baby has a new blood sample collected and tested as soon as possible.** If it turns out your baby does have CPH, there are very effective treatments available, and your baby's doctors will be able to help you manage this through checking the blood levels and adjusting the medication to help keep hormone levels normal.

Therapy should NOT be started before getting the results from the additional test(s). NO treatment should be started unless a physician recommends it. In an infant CPH is treated by giving the synthetic hormone levothyroxine and regular monitoring by a pediatric endocrinologist.

You have probably already done this, but now is also a good time to be sure your baby is covered by your health insurance provider.

Remember this could be a false alarm, but if it turns out your baby does have CPH, the treatment is very effective. For more information talk with your baby's doctor or you can contact the Nebraska Newborn Screening Program at (402) 471-0374 for information on Pediatric Endocrinologists available in Nebraska.

