

# PARENT INFORMATION about POSITIVE Newborn Screening Results for CONGENITAL PRIMARY HYPOTHYROIDISM (CPH)

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

## 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 number of babies screened will be identified as "positive" on screening. Some are later found not to have CPH. This is just a "screening" test and further testing must be done to determine if your child has CPH or not.

## What is the next step?

Be sure to follow your baby's doctor's instructions to get a new blood sample for further testing. CPH is a rare disease involving the endocrine (glands and hormones) system. Your baby's doctor might consult with or refer you to a pediatric endocrinologist.

## What exactly is CPH?

CPH is a disease of the thyroid gland that stops it from making 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 make 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 is very effective treatment available.

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. Your baby's doctors will help you manage CPH by adjusting the medication to help keep levels normal. Regular monitoring by a pediatric endocrinologist will be needed.

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. If your baby does have CPH the treatment, if given as directed, is very effective.**

For more information, talk with your baby's doctor. You can also contact the Nebraska Newborn Screening Program at (402) 471-0374 for information on Pediatric Endocrinologists available in Nebraska.

Internet information is available at: <http://www.dhhs.ne.gov/nsp/> and at <http://ghr.nlm.nih.gov/condition/congenital-hypothyroidism>

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