Congenital Hypothyroidism

What is newborn screening?

Newborn screening is a blood test to check for conditions that might be hidden at birth. To do the screening, a nurse takes a few drops of blood from your baby's heel soon after birth. This blood sample is required for all newborn babies.

Newborn screening is not the same as diagnostic testing. A diagnostic test can tell with more certainty whether or not a child has a condition. On the other hand, a screening test simply indicates that a child may have a condition. The purpose of a screening test is to find babies that should have diagnostic testing. When a child with an out-of-range newborn screening result has a follow-up test result within the normal range, it is sometimes called a "false positive."

KEY POINTS:

- **You have just heard that your baby may have congenital hypothyroidism. Please understand that the newborn screening is just that---a screening test. Further testing is required to confirm or rule out the diagnosis.**
- **Many babies who have out of range newborn screens are healthy, and will not have congenital hypothyroidism.**
- **If treated early, children with congenital hypothyroidism can have healthy growth and development.**

What if my baby needs more testing?

If you are told that your baby needs follow-up testing, it does not necessarily mean that your baby is at risk. An out of range result may occur because:

- The sample was too small
- The sample was collected too early
- The sample was collected too close to a feeding
- The baby was born too early or had a low birth weight

Some babies who have follow up testing for congenital hypothyroidism are healthy, and will not have congenital hypothyroidism. However, out of range screening results CAN indicate a disorder, so it is important to follow your doctor's advice & get your baby tested quickly so that final results can be confirmed.

Connecticut Department of Public Health
Connecticut Newborn Screening Program • 860.920.6628
Connecticut Newborn Diagnosis and Treatment Network · 860.837.7870
Adapted, with permission, from the Minnesota Department of Public Health

What is congenital hypothyroidism?

Congenital hypothyroidism (CH) is a condition that affects the body's thyroid gland, a small organ in the lower neck. The thyroid gland makes thyroid hormone. People with CH are not able to make enough thyroid hormone. Thyroid hormone is needed for healthy growth and development.

What does this mean?

Although CH cannot be cured, it can be treated. The most common treatment for CH is a medication that replaces the thyroid hormone that isn't being made correctly. This will help to prevent health problems. If treated early, children with CH can have healthy growth and development.

What happens next?

Your baby's doctor may ask for your baby to have more testing. You will want to have these follow up tests done as soon as possible. In some cases, you may be asked to visit a specialist called an endocrinologist. The endocrinologist will talk to you about the best plan for your baby.

What are the signs and symptoms of CH?

Some babies don't show any symptoms of CH. Other babies might have trouble feeding or gaining weight, or become very sleepy. If untreated, children with CH may have jaundice (yellowing of the skin), muscle weakness, delayed growth, or learning disabilities. If you become concerned about your baby's growth, feeding or activity, please talk to your pediatrician.

What if I still have questions?

We understand that this can be an overwhelming and emotional process. Many families have questions and concerns. The Connecticut Newborn Diagnosis and Treatment Network (the Network) is available to put you in touch with the best resource. To reach the Network, you can call 860-837-7870, Monday-Friday, 8:30am-4:30pm. We also recommend the website www.babysfirsttest.org as an accurate and informative resource.

This fact sheet was written for information purposes only. It should not replace medical advice, diagnosis or treatment.

Connecticut Department of Public Health
Connecticut Newborn Screening Program • 860.920.6628
Connecticut Newborn Diagnosis and Treatment Network · 860.837.7870
Adapted, with permission, from the Minnesota Department of Public Health