Congenital Hypothyroidism (CH)

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. The purpose of newborn screening is to find babies that need diagnostic testing. Diagnostic testing will tell if a child has a condition.

KEY POINTS:

- **Your baby's newborn screen tells us that your baby may have congenital hypothyroidism.**
- **More tests are needed to tell if your baby has this disorder.**
- **If treated early, children with congenital hypothyroidism can have healthy growth and development.**
- **Tell your baby's doctor if you baby has trouble feeding, is very sleepy or has other problems.**

What if my baby needs more testing?

If you are told that your baby needs follow-up testing, it does not mean that your baby has the disorder. An out of range result can occur because:

- the heel-stick blood sample was
  - too small
  - collected too early
  - collected too close to a feeding
- the baby was born too early or had a low birth weight
- the baby had certain treatments in the hospital

Many babies who have follow up testing for congenital hypothyroidism are healthy, and do not have this condition. 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 treatment can start early if your baby does have congenital adrenal hyperplasia.

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What is congenital hypothyroidism?

Congenital hypothyroidism (CH) is a condition that affects the 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 the body doesn't make correctly. This helps 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 tests. 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 be very sleepy. If untreated, children with CH may have jaundice (yellowing of the skin), weak muscles, slow growth, or learning disabilities. Tell your baby's doctor if your baby has any of these problems.

What if I still have questions?

You may feel overwhelmed during this process. If you have questions, please call the Connecticut Newborn Diagnosis and Treatment Network (the Network). To reach the Network, call 860-837-7870, Monday-Friday, 8:30am-4:30pm. We also recommend the website www.babysfirsttest.org.

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

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