

# Congenital Hypothyroidism Fact Sheet for Parents

All babies born in North Carolina are screened at birth for certain medical conditions that can be treated to prevent serious illness. This is called newborn screening. The newborn screening result showed that your baby might have Congenital Hypothyroidism. Your baby will be referred to a specialist for more testing to know for sure.

*There may not be signs of Congenital Hypothyroidism in some newborns, although it may show up later.*

## What is Congenital Hypothyroidism?

Congenital hypothyroidism (CH) is a condition present at birth where a child's thyroid gland does not make the right amount of thyroid hormones (important chemicals in the body). The thyroid gland is found at the base of the neck. Most of the time, babies with CH have a thyroid gland that did not fully develop. Thyroid hormone, called thyroxine (T4) is important for normal growth and development of the brain and body. Babies with congenital hypothyroidism make too little T4 with either too high or too low TSH.

If left untreated after the first few weeks of life, this condition can lead to developmental issues.

## What are the symptoms of Congenital Hypothyroidism?

People with CH may have a range of symptoms, or signs of the disease. Newborns with CH often have no symptoms at birth. Symptoms may include:

- Sleeping longer/very tired
- Constipation
- Poor feeding
- Large tongue
- Yellow skin (jaundice)
- Bulging at the belly button (umbilical hernia)

## What happens next?

Your baby's doctor will examine your baby for symptoms and collect a blood sample to confirm if your baby has CH.

If your baby has CH you doctor will set up an appointment with a specialist who treats children with thyroid and hormone conditions, called a pediatric endocrinologist. The specialist will help you take care of your baby and will start your baby on medication.

## How is Congenital Hypothyroidism treated?

The treatment for CH is thyroid hormone replacement with levothyroxine. If this is started early it can prevent many or all of the effects of CH. Your baby will need to take hormone replacement medication each day for at least the first three years of life and possibly lifelong.

## Where do I go for more information?

Use your smart phone's camera to scan the QR codes below.



**American Thyroid Association:** <https://www.thyroid.org/wp-content/uploads/patients/brochures/congenital-hypothyroidism-brochure.pdf>



**Pediatric Endocrine Society:** <https://pedsendo.org/wp-content/uploads/2020/06/E-Congenital-Hypothyroidism.pdf>



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