Congenital hypothyroidism and your child

Contributed by

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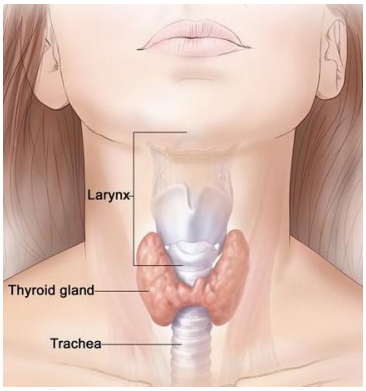
What is Thyroid?



The thyroid is a small butterfly shaped endocrine gland located in the neck, in front of the trachea. It produces a chemical substance called thyroxine, which when released into the blood, reaches various parts of the body and exerts its effects on different organ systems. This thyroid gland is under the constant control of a master endocrine gland called the pituitary, a tiny pea sized gland located in the brain.

Why do we need Thyroid hormones (Thyroxine - T3, T4)?

Thyroid hormones are essential for adequate functioning of different bodily systems. Thyroxine in our body maintains the energy balance. It decides how much energy must be used for breathing, circulation, digestion and other bodily functions. The lack of these hormones, or an excess, can cause problems. Too much of thyroid hormone makes the body work faster. Too little slows down body functions.

Thyroid hormone in children - What is special?

The most important effect of Thyroid hormone is its positive influence on the **development of brain** during fetal life (in the womb) and in the very young infant. It influences **physical growth and maturity** throughout childhood. In children most brain development occurs during the first two to three years of life. This is reflected in

timely attainment of developmental milestones like learning to sit, stand, walk, talk, and socialize. Thyroxine is of paramount importance for normal brain development and maturity during this period. Deficiency in a newborn baby, if not detected and treated early on, can result in severe and permanent mental retardation. *In older children, Thyroxine is needed for skeletal growth and pubertal maturation.*

HYPO-thyroidism: It is a condition resulting from **too little** Thyroxine.

There are two varieties of hypothyroidism:

Congenital (onset from birth), and
Acquired (onset during childhood)

Congenital hypothyroidism (CH) is a well-recognized entity. The incidence in India in various studies is reported to be anywhere from 1:2000 to as high as 1:500. The incidence was particularly high in south Indian babies.

It used to be one of the commonest causes of ***preventable mental retardation***, until the advent of newborn screening.

In the 1970s it was found that a simple test performed on the new born baby's blood can identify the problem. Over the next few decades, newborn screening for hypothyroidism has been universally adopted by the entire western world as well as by some developing countries. Recognizing thyroid hormone deficiency as soon after birth as possible, instituting therapy before 2-4 weeks of life, and maintaining adequate treatment throughout early childhood prevents mental sub-normality and helps the child reach his or her genetic potential for intelligence.

Unfortunately no such universal screening program exists in India, although it has been initiated by many private sector hospitals on smaller scales at local levels.

Hypothyroidism occurring in newborn babies can be temporary (transient) or lifelong (permanent).

Permanent CH

Thyroid gland develops by 22 weeks of fetal life (5 months of pregnancy). However, development can go wrong and some babies are born with no thyroid gland, and some

with a very small, and/or abnormally located gland (located elsewhere other than in the neck, usually at the base of the tongue). In these cases, the baby will have minimal or no thyroxine hormone production, and will need lifelong treatment.

Temporary CH

In other cases, even though the gland is formed normally, it may not be able to produce sufficient amounts of thyroxine. Some of these babies will ultimately be able to produce adequate amounts of hormone, while the rest continue to be deficient. In these babies it is important to give thyroid hormone replacement without failure for at least up to three years of age (the period of maximum brain growth). Once the child reaches an age when brain development reaches near completion at about 3 years, a trial off therapy can be considered.

How is CH detected?

A blood test is all that is needed. It can be part of the NBS (Newborn screening) test performed on day 3 or day 4 after birth. Once a problem is identified, a pediatric endocrinologist can evaluate further to identify the underlying cause.

We haven't done NBS (Newborn Screening) test? Are there any symptoms that suggest if my baby might be suffering from CH?

The affected babies may have one or more of the following symptoms

- Excessive sleepiness
- Feeding difficulties like poor sucking and swallowing coordination
- Prolonged neonatal jaundice
- Umbilical hernia (protruding, large belly button)
- Large protruding tongue
- Constipation
- Developmental delay:
    - Not smiling while being talked to by 2 months of age
    - Not making eye contact by 6-8 weeks of age
    - Inability to self-support the head by 3-4 months

Unfortunately many of these symptoms and signs (except the developmental delay) can also be seen in normal and healthy newborns without hypothyroidism.

So, if newborn screening is not routinely performed it is important to remain vigilant and be aware of the possibility of this condition.

How is CH treated?

Very simple.

Thyroid hormone is given daily in tablet form, crushed and mixed with breast milk or formula. Thyroxine tablet is usually given at the same time every day, preferably on an empty stomach.

Soy based formulas, Iron and calcium supplements, medicines like certain laxatives, fiber supplements, and medicines like cholestyramine and sucralfate may interfere with absorption of thyroxine. Talk to your doctor if the baby is on any of these medicines.

Store your Thyroxine tablets in a clean and cool place. Prolonged exposure to sunlight will decrease effectiveness.

What if I miss a dose?

If you miss a dose, give it as soon as you remember. If you remember it the next day, give a double dose at that time. It is important not to miss doses too frequently.

For how long does my baby need treatment?

Lifelong in permanent CH.

In confirmed and suspected temporary CH, treat till the child is 3 years of age. A trial-off therapy can then be considered to evaluate the need of ongoing therapy.

How often we need to do blood tests?

Initially every 2-4 weeks after starting treatment.

Later , for the first six months, 1-2 monthly blood checkups may be required to avoid over/ under-treatment. Once thyroid hormone levels in the baby's blood are stabilized, it must be followed up once every three months, until three years.

Typically a blood test is repeated 3-4 weeks after any dose adjustment. Inadequate or interrupted treatment and irregular doses may lead to subtle mental changes in later life that manifests as learning difficulties. With early and appropriate therapy, near normal neuro-developmental outcome is possible.

I feel that my baby might be getting too much of thyroxine. Would that be a problem?

Over-treatment may result in poor weight gain, irritability, early closure of soft spot. Some studies have shown that prolonged over-treatment results in hyperactivity, aggression and poor attention, although others studies have revealed no such effects.

However, during treatment it is essential to maintain thyroid hormone levels in the upper end of reference ranges. Your doctor will be performing regular checkups to make sure over treatment doesn't happen.

Is my baby at risk for any other congenital problems?

Certain forms of CH can be associated with hearing defects and, uncommonly, congenital heart disease. Talk to your doctor if any other tests are needed.

If the mother has hypothyroidism, will that increase the risk of CH in the baby?

Not always

The causes for hypothyroidism in the mother are different from those in the baby.

Some mothers with hypo/hyperthyroidism can have high levels of thyroid blocking antibodies in their blood, which pass through the placenta and cause a form of temporary hypothyroidism.

Occasionally, if the mother is using anti-thyroid medication for hyperthyroidism, those drugs may pass through the placenta and cause temporary hypothyroidism in babies. Iodine deficiency or excess in mother can result in hypothyroidism in the newborn baby.

Talk to your doctor if you have any of these conditions. Even temporary hypothyroidism in babies must be treated.

Will having CH effect my child's growth and puberty?

No

If you are regular with your medication and blood check-ups, your child will grow and attain maturity just like any other child.

I have a baby with CH. Will it increase the risk of CH in my future baby?

Depends on the type of CH

In CH due to defective hormone production, your future baby has a 1 in 4 (25%) chance of CH.

If CH is due to absence of thyroid gland, the risk of CH for your future baby is the same as for any other baby.

Congenital hypothyroidism is a condition for which treatment is simple, cheap and accessible. With timely identification and regular thyroxine replacement, your child will achieve his or her full growth potential, like any other child.

We hope that our information booklet has helped you to understand this condition.