
Parent Guidebook to

Congenital Hypothyroidism

Next steps after diagnosis





THIS GUIDE DOES NOT PROVIDE MEDICAL ADVICE.



This guide has general information about congenital hypothyroidism (CH). Every child and family is different and some of these facts may not apply to your child specifically. Always check with your child's doctor before trying a new treatment or medication.



The information in this guide was adapted from materials by the Star G Project, and the California Department of Health Services.



Table of Contents

What is CH?	4
What causes CH?	4
A MISSING OR MISPLACED THYROID GLAND.....	4
HEREDITARY CAUSES	5
MATERNAL IODINE DEFICIENCY.....	5
MATERNAL THYROID MEDICATIONS.....	5
INHERTIANCE	5
How is CH treated?	6
Medication information	6
HOW TO GIVE TO YOUR CHILD	6
SIGNS YOUR CHILD’S DOSE IS TOO HIGH.....	7
SIGNS YOUR CHILD’S DOSE IS TOO LOW.....	7
MONITORING	7
DEVELOPMENTAL EVALUATION.....	7
OTHER THINGS TO KNOW	7
If left untreated:	7
Frequently asked questions	8
HOW MANY PEOPLE HAVE CH?.....	8
DOES CH HAPPEN MORE TO CERTAIN ETHNIC GROUPS?	8
DOES CH GO BY ANY OTHER NAMES?	8
WHAT ABOUT WHEN MY BABY GROWS UP?	8
Resources	8

● What is CH?

CH stands for Congenital Hypothyroidism.

Congenital means your child was born with it.

Hypothyroidism is a condition when a person's thyroid gland does not make enough thyroid hormone.

The thyroid gland is a butterfly-shaped organ at the base of the neck (see image below). It makes certain hormones that help the cells in the body function the way they are supposed to. The main hormone it makes is called thyroxine (T4), also called thyroid hormone. In babies and young chil-

dren this hormone is very important for normal growth and development of the brain and body.

Thyroid hormones:

- Help regulate body temperature.
- Maintain a normal heart rate.
- Help with normal development of the brain and nervous system (spine and nerves).
- Help maintain normal functioning of the digestive track, including bowel movements.



Thyroid gland

● What causes CH?

CH can be the result of a few different things.

A MISSING OR MISPLACED THYROID GLAND:

Most babies with CH are born without a thyroid gland, or have a thyroid gland that did not develop normally: it might be smaller or located in the wrong place.

A normal, healthy thyroid gland is located in the center, front of the neck, near the top of the windpipe (see image above). In some children with CH, the thyroid is located under the tongue or on the side of the neck. This is a birth defect, and the reason it happens is still unknown. It is usually not inherited. When the thyroid gland is

missing or in the wrong place it can't produce enough thyroid hormone for the body.

HEREDITARY CAUSES:

Less often, CH is caused by changes in a gene or pair of genes. Genes carry the all of the information that decides a person's traits. Genes are passed on to babies — or inherited — from parents. We have no control over which genes are passed on to babies during pregnancy.

In this case, even though the thyroid gland is the right size and in the right place, it does not make enough thyroid hormone.

MATERNAL IODINE DEFICIENCY:

If a mother does not get enough iodine while she is pregnant her baby's thyroid gland might not be able to make enough thyroid hormone, which results in CH after birth. This is very rare in the United States because our table salt is supplemented with iodine ("iodized salt").

MATERNAL THYROID MEDICATIONS:

In a very small number of cases, CH is caused because the mother is given anti-thyroid medication when she is pregnant. This might be to treat her own thyroid problem.



INHERTIANCE

For about 15-20% of children with CH, their thyroid gland appears normal, but it is not producing enough hormone. These cases are more likely to be inherited, but not always. If your child's doctor thinks that it is inherited in your child, you will be referred to a genetic doctor or genetic counselor to confirm.

In about 80-85% of children with CH, it is caused by a thyroid gland that did not develop at all, is misplaced, or is too small. Most of the time these cases are not thought to be inherited.



● **How is CH treated?**

Your baby's primary doctor might work with a pediatric endocrinologist, a doctor with training in treating children with thyroid/hormone conditions, to care for your child.

The main treatment for CH is thyroid hormone replacement. If this is started immediately after your child is diagnosed, treatment can prevent many or all of the effects of CH. If damage to the brain and nerves happens, because treatment is delayed, it is usually permanent and cannot be reversed.

● **Medication information**

L-thyroxine is a synthetic form of thyroid hormone. It is given in a tablet form to everyone with CH. How much your baby needs to take will be determined by your doctor and endocrinologist, and will increase as they grow up. L-thyroxine is given in a tablet form, and needs to be taken every day for your child's whole life.

According to the American Academy of Pediatrics' recommended guidelines, there are no Food and Drug Administration (FDA) approved liquid forms of thyroid medication. Thyroid suspensions prepared by individual pharmacists may lead to unreliable dosage. Please do not try to use these suspensions (liquids).

HOW TO GIVE TO YOUR CHILD:

When your baby is too young to chew the tablets, you can:

- Crush the tablets, using the back of a spoon, into a fine powder. Wash your hands well, then moisten one of your fingers and dip it into the crushed tablets. Let your baby suck the crushed tablets off. Repeat until all of the powder is gone.
- Mix the crushed powder with a small

amount of formula, milk, or juice. Give this mixture through a dropper on the side of the mouth.

Do not mix the crushed tablets into a large amount of liquid, like a bottle. He/she might not finish the whole thing, and won't get all of the medication.



SIGNS YOUR CHILD'S DOSE IS TOO HIGH:

Taking too much L-thyroxine can cause body functions to speed up. Some signs include:

- Trouble sleeping
- Shaking (tremors)
- Weight loss
- Irritability (crabby)
- Diarrhea
- Very hungry

SIGNS YOUR CHILD'S DOSE IS TOO LOW:

- Sleeping too much
- Constipation
- Cold, dry skin
- Gained weight very quickly
- Low energy/activity level

MONITORING:

Your child will need regular visits to the doctor to check their weight, height, development, and overall health. Regular blood tests will probably be needed to check the

levels of thyroid hormone. Blood tests are usually done every one to three months for the first year, then every two to four months until age three. After age three these tests can usually be done less often.

DEVELOPMENTAL EVALUATION:

Your doctor might suggest a formal evaluation of your child's development. If he or she shows delays in certain areas of learning or speech, extra help can be arranged. There are early intervention programs available in Minnesota that provide services for children before they reach school age.

OTHER THINGS TO KNOW:

A dried thyroid hormone from animal tissue was given before a synthetic form was available. A dose of the hormone in this form is not consistent (the same every time), so it is not as safe as the synthetic (artificial) form.

It is important to tell your doctor if you are giving your baby soy-based formula or iron supplements. These can reduce the amount of thyroid hormone your baby absorbs from the medication.



● **If left untreated:**

It is not recommended to leave children with CH untreated. Children with CH who remain untreated usually become intellectually, mentally, and/or physically disabled. Many will also have speech delays and behavior problems, along with other physical and cognitive complications.

Frequently asked questions

HOW MANY PEOPLE HAVE CH?

About one in every 3000-4000 babies born in the U.S. each year has CH. Twice as many girls have it than boys.

DOES CH HAPPEN MORE TO CERTAIN ETHNIC GROUPS?

It is more common in parts of the world that do not have enough iodine in their food and water (see page 4). It is also more common in babies of Hispanic or Native American descent. It is less common in babies of African-American descent.

DOES CH GO BY ANY OTHER NAMES?

- CHT
- Cretinism
- Endemic Cretinism
- Congenital Myxedema

WHAT ABOUT WHEN MY BABY GROWS UP?

Sometimes the hypothyroidism is not a permanent condition and there is no evidence of the disease after around three years of age. The safest approach is to give your baby medication through the time of crucial brain development.

Do not stop the medication on your own. Your endocrinologist may decide to stop the medication for a few weeks and do blood tests. If hormone levels are normal your child will no longer need medication. If not, your child can start on medication again without getting any damage during those weeks.

Most children born with CH grow up to lead healthy, happy lives. Each family deals with it differently, so it is important to communicate with your child and the rest of your family, and maintain a strong support system of friends and health providers.

Resources

- MAGIC (Major Aspects of Growth in Children) Foundation
www.magicfoundation.org
- Baby's First Test | Congenital Hypothyroidism
www.babysfirsttest.org
- National Library of Medicine's Genetics Home Reference
ghr.nlm.nih.gov
- Region 4 Genetics Alliance
www.region4genetics.org

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