



Children's
of Alabama®

CONGENITAL HYPOTHYROIDISM

Children's of Alabama Parent's Guide



What is Congenital Hypothyroidism?

Congenital Hypothyroidism describes a condition where an infant is born with low thyroid hormone production. One in every 2,000-3,000 babies is born with congenital hypothyroidism.

Thyroid hormone plays an important part in brain growth and body functions. Temperature regulation, heart rate, the digestive tract, the brain, bones, teeth, muscles, and nervous system all rely on thyroid hormone to function properly.

Newborn screening detects low thyroid function, which is then confirmed with a blood sample. Once low thyroid function is confirmed, treatment is started immediately to replace the low thyroid hormone levels.

What causes congenital hypothyroidism?

Babies can have congenital hypothyroidism due to several reasons.

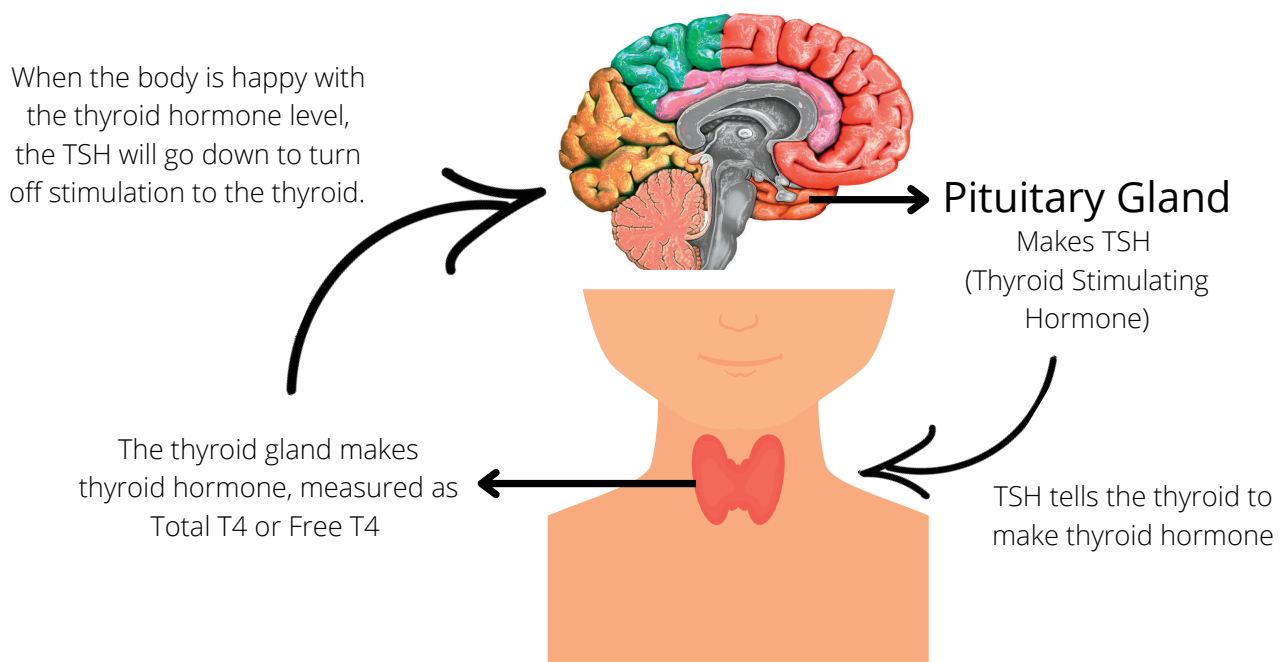
In about 85% of infants, congenital hypothyroidism is due to an abnormally developed thyroid gland--the thyroid can be completely absent, partially absent, small, or located in an abnormal position (ectopic).

In 10-15% of cases, the thyroid gland is present, but the hormones cannot be produced normally.

Occasionally, infants have congenital hypothyroidism because the brain is not making TSH, which signals the thyroid to produce thyroid hormone.

In some instances, children will "outgrow" congenital hypothyroidism, but we believe that it is very important that infants not stop thyroid hormone before 3-years of age.

It is important to know that there is nothing that can be done in pregnancy to predict or prevent the development of congenital hypothyroidism.



Signs and Symptoms

There are often no signs or symptoms of congenital hypothyroidism. Often screening will identify infants with congenital hypothyroidism before symptoms develop.

Some rare symptoms may be:

- Large soft spots (fontanelles)
- Low body temperature
- Feeding difficulties
- Constipation
- Jaundice
- Excessive sleepiness

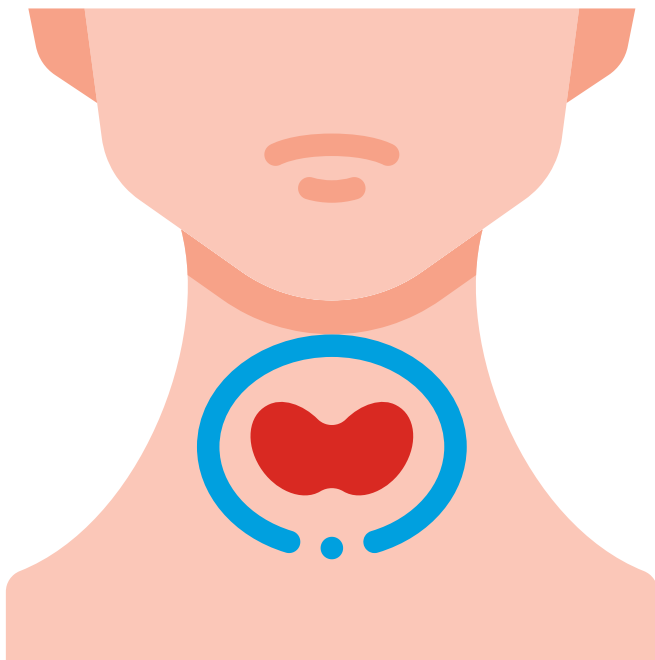


Diagnosis and Tests

Newborn Screening is critical to detecting congenital hypothyroidism early. Blood testing is then required to diagnose congenital hypothyroidism.

Thyroid Stimulating Hormone (TSH) and Thyroxine (Total Thyroxine; T4 or Free Thyroxine; Free T4) are done to measure how the thyroid is functioning.

Thyroid ultrasound or other specialized imaging of the thyroid gland may also be ordered to examine the thyroid gland anatomy and function.



Treatment



The treatment of Congenital Hypothyroidism is simple and effective.

Infants are prescribed a medication to replace the thyroid hormone that their body cannot produce.

Tablets are commonly prescribed to treat congenital hypothyroidism, because they are known to be effective and are readily available.

There are now liquid treatment options available through specialty pharmacies.

If you feel your infant is struggling to take the tablet form of the medication, please discuss this with your provider.

The beginning of treatment can be a stressful time for many parents, but know that you will develop a medication routine that will work for you and your infant.

This is also a time you may begin noticing changes in your child's behavior. Often infants may begin to have more awake time or may seem more "fussy" than prior to starting treatment. These changes are not a side effect of the medication, but rather a sign that your infant's thyroid hormone levels are improving. Remember to have patience with yourself and your child as you both adjust to these changes.

Consistency is very important when giving thyroid hormone. It is best to not miss doses of medication. We recommend "making up" any missed doses as soon as possible. You should also discuss any changes to the medication routine with your provider, as these variables may change how the medication is absorbed.

Monitoring

You may see the following symptoms if your baby is getting too much thyroid medicine:

- Poor sleeping
- Tremors (shaking)
- Weight loss
- Irritability
- Diarrhea
- Excessive hunger
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You may see the following symptoms if your baby is not getting enough thyroid medicine:

- Excessive sleeping
- Constipation
- Cold, dry skin
- Excessive weight gain
- Decreased energy/activity

Keep in mind that all of these symptoms can be seen with normal infant development, but if symptoms are happening frequently or if you notice a change in your child's normal behavior, you should contact your child's provider.



Pointers

- It is best to not give medication in a full bottle--this way you can ensure that your infant gets their full dose.
- Speak with your provider regarding any changes to your infant's formula or medications (even vitamins).
- As your infant grows, the medication may be administered differently. Review medication administration with each clinic visit.





The Future

Your child has a bright future. Thanks to newborn screening and readily available thyroid hormone replacement, infants who are born with congenital hypothyroidism grow and develop the same as other children.

The important thing to remember is that consistent medication administration and routine lab evaluation and follow-up are key to excellent outcomes in childhood and beyond.

Resources

Alabama Department of Public Health: Newborn Screening
www.adph.org/newbornscreening.

Baby's First Test www.babysfirsttest.org.

American Thyroid Association www.thyroid.org.

The Magic Foundation www.magicfoundation.org.