



A Parent's Guide to Understanding Congenital Hypothyroidism

Children's of Alabama
Department of Pediatric Endocrinology



How did you get here?

Every baby born in the state of Alabama is required by law to undergo State Newborn Screening, and often this screening is done before your baby ever leaves the hospital. Newborn screening consists of a simple blood and hearing test that currently screens for over forty disorders including hearing loss. If the newborn screen indicates an abnormal result, your child's pediatrician is notified and often another blood or hearing test is required to confirm that abnormal result.



What is Congenital Hypothyroidism?

Congenital Hypothyroidism occurs when the body does not produce enough thyroid hormone. Often this is caused by failure of the thyroid gland to develop normally. It is important to know that babies with congenital hypothyroidism can look very healthy at birth, but still have this disorder. With early and ongoing care, your baby should develop normally both physically and mentally; however, babies who are not treated often have serious and permanent health problems.

Congenital hypothyroidism is fairly common, occurring in one in every 3,000-4,000 babies in the state of Alabama. Each year 30-40 babies in Alabama are diagnosed with congenital hypothyroidism. Typically, congenital hypothyroidism is diagnosed within a few days after birth due to newborn screening. Treatment is initiated as early as possible after diagnosis is confirmed. Early treatment helps to prevent the development of mental retardation, learning disabilities, and/or growth delays later in childhood. This condition is easily treated with daily thyroid hormone medicine that is taken by mouth.

The word "congenital" means that your baby was born with this condition. "Hypothyroidism" just refers to the fact that your baby's thyroid gland is producing too little thyroid hormone.

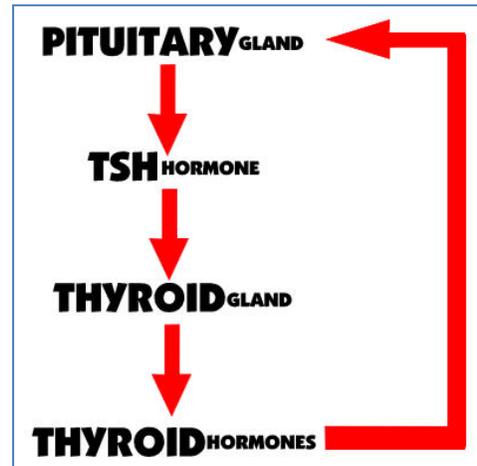


What is a thyroid and what does it do?

The thyroid gland is an endocrine gland that is shaped like a butterfly and is normally located in the neck. The thyroid gland's job is to produce hormones (chemical messengers) that affect many of the body's functions. One of these important hormones is called thyroxine or T4.

The thyroid gland is controlled by the pituitary gland, which is located at the base of the brain. The pituitary gland produces thyroid stimulating hormone (TSH). A healthy thyroid gland responds to increasing TSH by producing more T4. When these two glands are in balance, the body functions normally.

When the level of T4 is low in the bloodstream, the pituitary gland makes more TSH in an attempt to stimulate the thyroid to make more T4. Unfortunately, in babies with congenital hypothyroidism, this process does not work because the thyroid gland is absent, or too small, or cannot respond to the TSH. In most babies with congenital hypothyroidism, a blood test will show that the T4 level is very low and the TSH level is very high.



What does thyroid hormone do in the body?

Thyroid hormone is important in the daily functioning of the body. It controls the body's metabolism and affects the rate of the baby's development and growth. Especially in early childhood, the thyroid hormones are critical in brain development.



Helps Regulate
Body Temperature



Maintains a normal
Heart Rate

Helps maintain normal
functioning of the
digestive tract, including
bowel movements.



Provides normal development of
the brain and nervous system

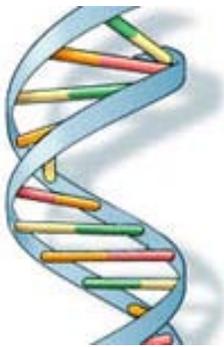


Provides an adequate appetite

Promotes the growth of bones, teeth, and muscles



Genetics: Could my child have inherited congenital hypothyroidism?



Congenital hypothyroidism is not an inherited disorder except in very rare cases. If your child did inherit congenital hypothyroidism, your doctor will be able to give you that information. Research has shown that congenital hypothyroidism does not result from anything done by the parents during pregnancy.

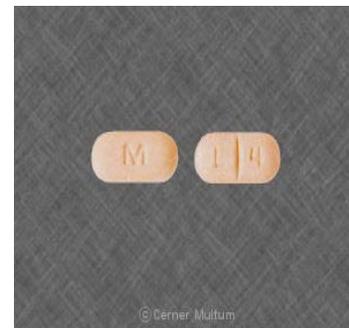
Your risk of having another child with congenital hypothyroidism is no higher than the average risk for any child (1:4,000).

What tests might be ordered for my baby?

1. **TSH and Free T4 levels**: These levels are measured in a blood sample from a vein. These levels are checked often in the first year of life. Most recommendations state that these levels are checked every 4-8 weeks during the first year of life.
2. **Thyroid Ultrasound**: This test is a simple ultrasound test used to visualize the thyroid gland. It is helpful to identify if a thyroid gland is present, and if it is present, it helps us to know if the thyroid is in the correct location and of normal size. It also will identify if there are any cysts or abnormalities in the thyroid gland. This test is performed once, typically at your second visit with the pediatric endocrinologist.

What is the treatment for Congenital Hypothyroidism?

Once a baby is diagnosed with congenital hypothyroidism he or she is immediately started on



thyroid hormone replacement. The most common medication prescribed for this is Levothyroxine or the brand name medication Synthroid. Levothyroxine is a synthetic thyroid hormone that is exactly like the hormone made by the thyroid gland. It is a normal body substance, and therefore it is tolerated very well by the body. There are typically no side effects when the medication is given in the correct amount.

In the majority of cases the treatment for congenital hypothyroidism is lifelong. Occasionally, at three years of age, your child may be tried off of treatment to see if the thyroid can make hormone on its own. It is very important, however, that you never take your child off medication unless told to do so by your doctor.

Is there a liquid form of medication?

Yes, however, it should NEVER be used! According to the American Academy of Pediatrics recommended guidelines, there are no Food and Drug Administration-approved liquid forms of thyroxine. Thyroxine suspensions prepared by individual pharmacists may lead to unreliable dosage. Please do not try to use these suspensions.

How do I give the medication to my baby?

Levothyroxine or Synthroid are both available as tablets. You will need to give the tablets at the same time every day and make it a part of your routine so that you do not forget.

With newborn infants, the tablets need to be crushed and given very carefully. Most pharmacies have pill crushers available for purchase, or you can always use two spoons to crush the medication.



We recommend that the crushed tablets be mixed with a small amount of water, formula*, or breast milk and given to your baby by either a dropper or small syringe. It is not recommended to mix the medication in a bottle, since you are unable to know if your infant will get the entire medication dose.

Another way to give the medication is to pick up a small amount of the crushed tablet with a moistened fingertip and swab the inside of the baby's cheek.

When your baby gets older and is taking solid foods, the tablets may be crushed and mixed with a spoonful of cereal or food. Older children will just chew the tablets. The tablets have no taste.

Remember to wash your hands well before preparing your infant's medication.

*Please speak with your doctor if your child is on a soy based formula or a formula containing extra iron. We will likely recommend you mix the medication with water rather than formula.

Other Recommendations:

1. Some foods and supplements, such as those containing soy, calcium, and iron may interfere with the absorption of thyroid hormone medications when taken together. Talk with your baby's doctor about any foods to avoid.
2. Keep a record of when you give the medication. You can mark a calendar when the medication has been given, or use a pill box to know if medication has been given.
3. Keep an extra supply of tablets for emergencies. Keep extra medicine in your diaper bag. Do not forget to check the expiration date.
4. Always examine the tablets when the prescription is filled. Note the color and the number on the tablet to be sure it is the right dose.
5. Be sure to bring the bottle of thyroid tablets with you to each doctor's appointment.



What do I do if I forget to give the medication?



Did you forget something?

If you forget a dose of medication, or your child spits up or throws up after taking the medication, you may give twice the dose on the following day. However, you should never give more than two times the dose. Too much thyroid hormone can be as dangerous as too little.

How is my baby's dose determined?

The pediatric endocrinologist will decide what dosage of medication your baby needs. They make their decision based on blood test results, history of symptoms, and physical examinations. Usually, thyroid levels are monitored every two months during the first year of life, every four months during the second year of life, and every six months thereafter.

The amount of thyroid hormone required will increase as your baby grows, and occasionally dose changes will be made. This is a normal process and is expected. However, when dose changes are made, additional blood tests will be performed 4-6 weeks after starting the new dosage.

What medication problems should I look for?

You can help your doctor by looking for signs of too much or too little medication. Do not change the amount of medication on your own. If your pharmacy gives you a pill that looks different that you usually get, call your doctor for advice.



Signs of too little medication: Decreased activity, sluggishness, increased sleeping, tiring easily, constipation, decreased appetite, or slow feeding.

Signs of too much medication: Jitteriness, hyperactivity, difficulty sleeping, increased appetite without weight gain, and frequent stooling or diarrhea.



Call your pediatric endocrinologist or nurse practitioner if your child has any of the above symptoms that continue for more than a few days. Many of these symptoms can be normal in a healthy infant, therefore the only way to determine if the medication dosage is correct is by checking blood thyroid levels.

Other Concerns

1. Your baby does not need a special diet and does not need to receive extra iodine. As with any child, a healthy nutritious diet is important for growth, mental development, and good health.

2. If your child takes a daily multivitamin containing iron and/or calcium, we would recommend that the multivitamin be taken at least 4 hours after the Levothyroxine.
3. There are no restrictions on giving your child other medications that are prescribed by a doctor. Your child should receive routine immunizations and regular checkups like any other child.

Will my baby grow up to be normal?

Today, children born with congenital hypothyroidism who are started on treatment at a very young age and who receive careful follow-up by their doctors do **not** grow up to have severe developmental and growth delays.

In the past, congenital hypothyroidism was not screened at birth, and was not immediately treated with hormones. As a result, children with congenital hypothyroidism had severely delayed development and mental retardation.

Children with congenital hypothyroidism who are treated with thyroid hormone and carefully followed by their doctors are likely to grow and develop normally and to function normally as adults.

Follow-up: Will my child always have two doctors?

Yes, children with congenital hypothyroidism are followed closely, not only by their general pediatrician, but also by a pediatric endocrinologist. Pediatric Endocrinologists specialize in the body's hormone production. They tend to have more experience and knowledge about the treatment of thyroid disorders in infants and children. It will benefit you to use both doctors for your child's overall health.



We, as your child's pediatric endocrinologist, will want to check thyroid levels every two months in the first year. Typically we will work with your child's pediatrician, so that every other lab can be done locally at their offices. Every

four months you will be required to bring your child for follow up with his or her pediatric endocrinologist. This is critical to assessing your child's growth and development, as well as determining the correct medication dosage.

How can I help my child?

It is extremely important that your child receive the thyroid hormone as prescribed. You will help your child by making and keeping follow-up appointments, having labs checked as ordered, and discussing your concerns, questions, and problems with your pediatric endocrinologist.

Other Resources

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

Magic Foundation- Thyroid Disorders Information
http://www.magicfoundation.org/www/docs/114.125/thyroid_disorders

American Academy of Pediatrics Section on Endocrinology and Committee on Genetics, and American Thyroid Association Committee on Public Health
Newborn Screening for Congenital Hypothyroidism: Recommended Guidelines
Pediatrics 91 (6): 1203-1209.
<http://aappolicy.aappublications.org/cgi/reprint/pediatrics; 91/6/1203>

Medscape Drug Information: Levothyroxine <http://www.medscape.com/druginfo/>
Type in Levothyroxine for search then clinic go. Click on patient handout on the left side.

Yahoo Private Forum for Parents of Children with Congenital Hypothyroidism
<http://health.groups.yahoo.com/group/Congenital-Hypothyroidism/>

Congenital Hypothyroidism Info
<http://www.thyroidsymptomsfacts.com/congenital-hypothyroidism.html>

Congenital Hypothyroidism: Olivia's Story
<http://voices.yahoo.com/congenital-hypothyroidism-olivias-story-3279300.html>

