

# Parents' Guide To Primary Congenital Hypothyroidism



California Department of Health Services  
Genetic Disease Branch  
[www.dhs.ca.gov/gdb](http://www.dhs.ca.gov/gdb)

## To Parents:

California State Law requires that all babies have the newborn screening test before leaving their hospital of birth. A few drops of blood were taken from your baby's heel. One of the tests was for primary congenital hypothyroidism.

Your health care provider may have told you your baby has primary congenital hypothyroidism. Babies can look healthy at birth and still have this disorder, but babies, who are not treated, often have serious and permanent health problems. With early and ongoing care, your baby should develop normally both physically and mentally.

This booklet was written to help parents learn more about this disorder. Use this booklet to learn more about how to care for your child.

For more information about the Newborn Screening Program or primary congenital hypothyroidism visit our website at [www.dhs.ca.gov/gdb](http://www.dhs.ca.gov/gdb) then click on Newborn Screening.

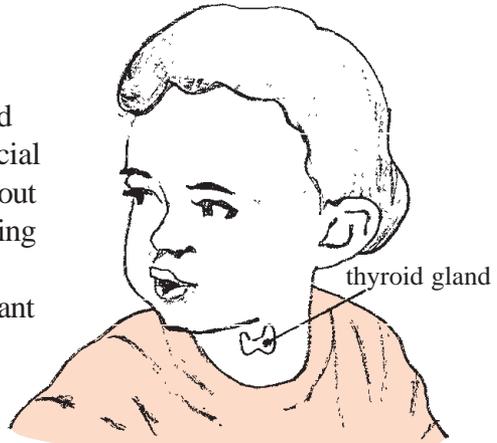
## What Is Primary Congenital Hypothyroidism?

Primary congenital hypothyroidism occurs when there is a deficiency of the thyroid hormone caused by the failure of the thyroid gland to develop normally. As a result, the thyroid gland does not produce enough thyroid hormone to meet the body's needs. "Congenital" means that it is present at birth.

Primary congenital hypothyroidism is fairly common, occurring once in every 2,700 newborn babies within California. About 200 babies in California are born with this disorder each year. It may be found shortly after birth through routine screening and follow-up testing required by California law. Treatment must be started within the first weeks of life of infants to prevent development of mental retardation, learning disabilities, and/or growth delays. This condition is easily treated by daily thyroid hormone medicine taken by mouth.

## How Does Thyroid Hormone Work?

The main thyroid hormones are made in the thyroid gland. The thyroid gland is normally located in the neck. Hormones are special chemicals that circulate throughout the body and affect the functioning of other organs. The thyroid hormones are extremely important in the development of the brain and central nervous system, for the growth of the bones and muscles as well as maintaining body temperature and metabolism. Without thyroid hormones, physical growth, mental development, and other bodily functions slow down or stop.



## Why Doesn't The Thyroid Gland Work?

A baby's hypothyroidism is usually due to a problem with the thyroid gland. The gland may be too small, located in the wrong place, or absent altogether. The existing gland does not make enough thyroid hormone or may not make any at all. In some cases, the thyroid gland appears normal but is unable to produce hormones normally. In rare instances, congenital hypothyroidism may not be permanent. Instead, it may be transient (temporary) and last only a few weeks or months. This transient problem may be due to substances from the mother's blood called antibodies, that block the baby's thyroid gland from working. Occasionally, the problem is caused by medications given to the mother.

## How Is Primary Congenital Hypothyroidism Diagnosed?

The screening test for primary congenital hypothyroidism measures a certain hormone Thyroid Stimulating Hormone (TSH). This hormone stimulates the thyroid gland to make more thyroid hormone. If this hormone is elevated on the newborn screening test, it means that further tests need to be done. In addition to repeating the TSH filter paper test, testing of the specific thyroid hormones and other indicators of thyroid function are done to confirm the diagnosis. Your baby's doctor will take a very careful history, examine the baby, and may also order other tests, such as a thyroid scan and or bone age (X-ray). In infants with suspected transient disease, antibody tests in maternal/mother's blood may be ordered.

## What Is The Treatment For Primary Congenital Hypothyroidism?

Once this disorder is diagnosed, the doctor will prescribe thyroid hormone for the baby. Thyroid hormone, also called thyroxine or  $T_4$ , comes in tablets. The baby's doctor will tell you how much of the tablet or how many tablets to give your baby each day. It is very important that the baby receive enough thyroid hormone to grow and develop normally but not more than is needed. It is important to follow the doctor's instruction carefully.

With early and ongoing treatment, your baby should develop normally, both physically and mentally. In the majority of cases of primary congenital hypothyroidism, the treatment is lifelong. Blood tests will be done on a regular basis to determine if your child is getting the right amount of thyroid hormone. Remember that your baby is an individual and will develop his or her own growth pattern and intellectual ability. As he/she gets older her dose may change.

### How To Give Thyroid Hormone



Be sure to give your baby thyroid hormone medicine every day. Only thyroxine tablets should 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.

Give the tablets at the same time every day and make it a part of your routine so you do not forget.

With newborn infants, the tablets need to be crushed and given very carefully. When your infant is older, it will be easier to give. There are several ways you can give the thyroid medicine.

## For the Infant:

- Crush tablet(s) between two spoons then mix with a small amount of water, breast milk or formula\* that does not contain soy or iron. Give this mixture through a dropper on the side of the mouth between the cheek and gum. To be sure that all of the medicine is taken, draw up some water into the dropper after you have given the crushed tablet(s) and give this water to your baby. **Use room temperature water. DO NOT mix with hot water.**



Or

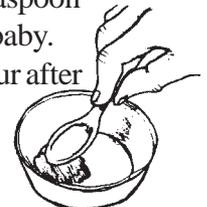
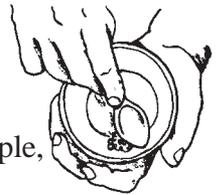
- Wash hands well. Finely crush the tablet(s) between two spoons. Moisten your fingertips with water and dip into crushed tablet(s). Let your baby suck the crushed tablet(s) off your finger and continue to dip your finger in the crushed tablet(s) until no powder is left. Offer the baby a small amount of water after giving the tablet(s).



## For the Older Infant and Toddler:

When your baby is on solid foods, you may want to try one of these methods.

- Place tablet(s) on a spoon and add a few drops of water to soften them. After a few minutes, add a few drops of water on the spoon then feed this mixture to your baby.
- Mix the crushed tablet(s) in a small amount of baby cereal, applesauce, breast milk or formula\* that does not contain soy or iron. Always keep this separate from the rest of your baby's food. For example, if your baby is taking two tablespoons of cereal in the morning, mix the crushed thyroid tablet(s) with a ½ teaspoon of cereal in a separate dish. Give this portion to your baby. Some doctors recommend waiting at least one half hour after giving the tablet(s) before feeding your baby the rest of the meal. That way, you will know that your baby has received all the hormone.



\*Talk with your doctor before mixing with soy-based formula or formula that contains iron.

**DO NOT put the tablet(s) into a whole serving of the baby’s food. DO NOT put the tablet(s) in the baby’s bottle. The baby may not eat or drink the whole amount.**



- When your child is older, he or she may take the whole tablet(s) by mouth. Since they are so small, they will either melt or be swallowed whole. The tablet(s) do not taste bad; they have very little taste. It is perfectly all right for the child to chew the tablet(s). Many children take thyroid tablet(s) in the morning just after they wake up and before breakfast.

### Other Recommendations

1. Some doctors recommend waiting at least one half hour after giving the tablet before feeding your baby solid foods. Wait an hour if your baby has a tendency to spit up the feedings.
2. If your baby spits up just after giving the medicine, then give another dose.
3. Some foods and supplements may interfere with the absorption of thyroid hormone medications\* when taken together. Talk with your baby’s doctor about any foods to avoid.
4. Keep a record of when you give the medicine. You can mark a calendar when the tablets have been given. If you forget to give a dose on one day you can give twice the dose the next day. But never give more than twice the dose. Too much medicine can be just as dangerous as too little.



\*See References on page 9 for actual articles

5. Call your doctor or nurse if your baby has any of the following symptoms for more than 24 hours:

- ◆ diarrhea
- ◆ shorter sleeping periods
- ◆ irritability or nervousness, or
- ◆ if there is anything else that worries you.



6. Always keep an extra supply of the tablets for emergencies. Keep extra medicine in your diaper bag and with your emergency/earthquake supplies. Do not forget to check the expiration date.

7. 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.

8. Be sure to bring the bottle of thyroid tablets with you to each doctor's appointment.

### Follow-Up

Your doctor will check the blood thyroid hormone levels on a regular basis. These blood tests help the doctor to adjust the medicine so your baby will get the correct amount. The dose may be adjusted as your baby grows.

Although it is not always possible to determine the cause of congenital hypothyroidism at the time of diagnosis, your doctor will not want to delay treatment. Further studies may be done after the child is a year of age. These studies may include blood hormone tests, bone age test, thyroid scans, and biochemical or genetic tests.

If you have any questions in the meantime, please call the person listed below.

## Glossary

**Bone age** - An X-ray of the hand or knee bone to measure growth.

**Hormone** - A chemical with a specific effect on other organs. A hormone is produced by a gland in the body.

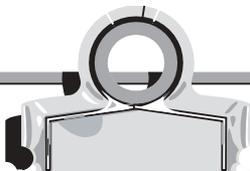
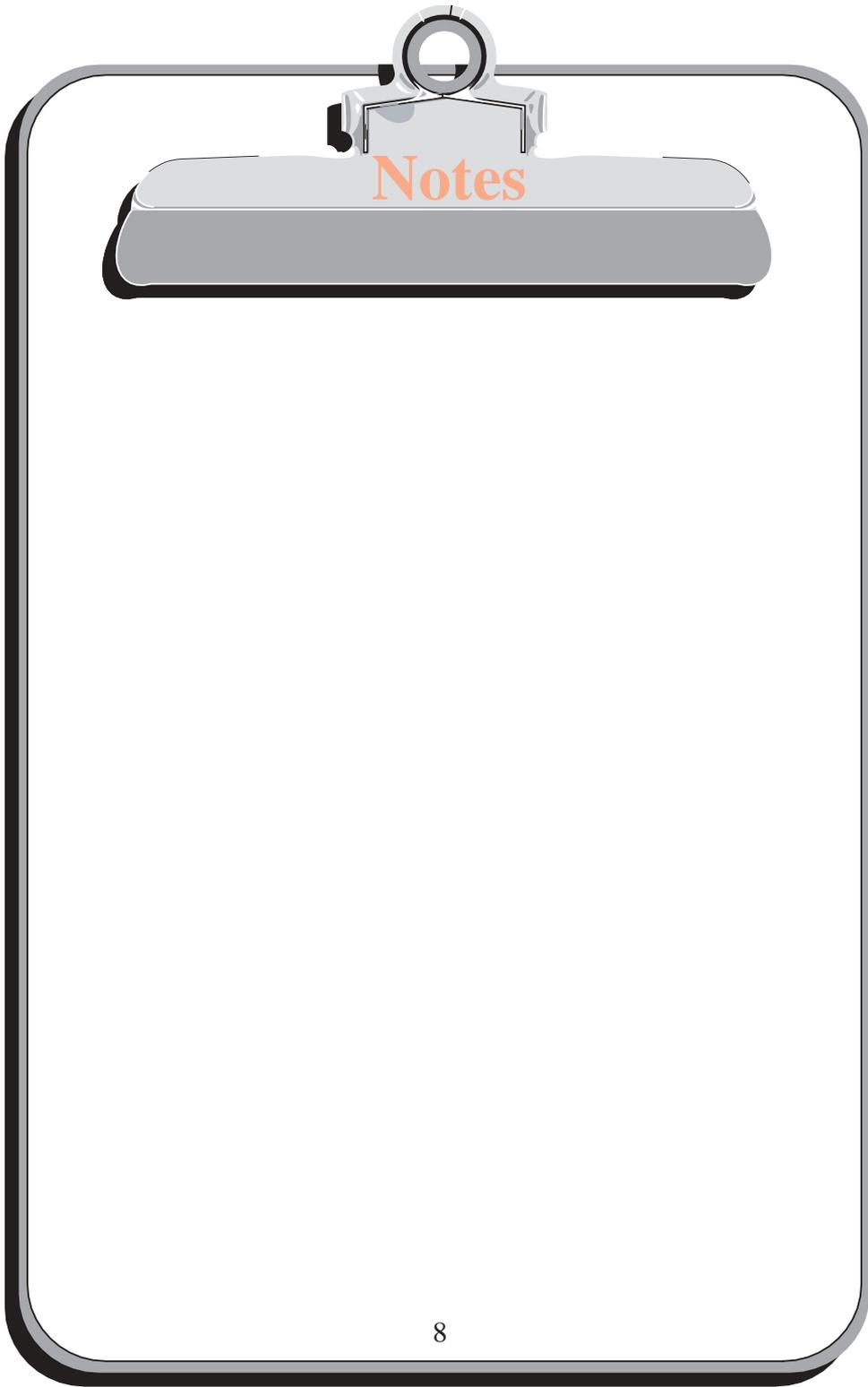
**Thyroid gland** - An internal organ in the body in the front part of the lower neck. It makes thyroid hormones that control many of the body's functions.

**Thyroid scan** - A test that is used to find the presence and location of the thyroid gland.

**T<sub>4</sub>** - Another name for thyroxine.

**Thyroxine** - The main hormone produced by the thyroid gland (also called T<sub>4</sub>).

**Thyroid Stimulating Hormone (TSH) or thyrotropin** - A hormone produced by the pituitary gland that stimulates the thyroid gland to produce T<sub>4</sub>.



# Notes

## Parent Resource

The Magic Foundation, [www.magicfoundation.org](http://www.magicfoundation.org), or parent help line at 800-3 MAGIC 3 (800-362-4423).

## References for Physicians

1. 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](http://aappolicy.aappublications.org/cgi/reprint/pediatrics;91/6/1203).
2. Jabbar MA, Larrea J, Shaw RA. Abnormal Thyroid Function Tests in Infants with Congenital Hypothyroidism: The Influence of Soy-based Formulas. *J. Am Coll Nutr* 1997; 16:280-2.
3. Cambell NR, Hasinoff BB, Stalts H, et al. Ferrous Sulfate Reduces Thyroxine Efficacy in Patients with Hypothyroidism. *Ann Intern Med* 1992; 117: 1010-3.

## Other Resources for Physicians

1. Singh N, Singh PN, Hershman JM. Effect of Calcium Carbonate on the Absorption of Levothyroxine. *JAMA* 2000 Jun 7; 283 (21): 2822-5.
2. Liel Y, Harman-Boehm I, Shany S. Evidence for Clinically Important Adverse Effect of Fiber-enriched Diet on the Bioavailability of Levothyroxine in Adult Hypothyroid Patients. *J Clin Endocrinol Metab* 1996; 81: 857-9.
3. [Http://www.medscape.com/druginfo/](http://www.medscape.com/druginfo/)  
Type in Levothyroxine for search then click go. Click on patient handout on the left side.

## Acknowledgements

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