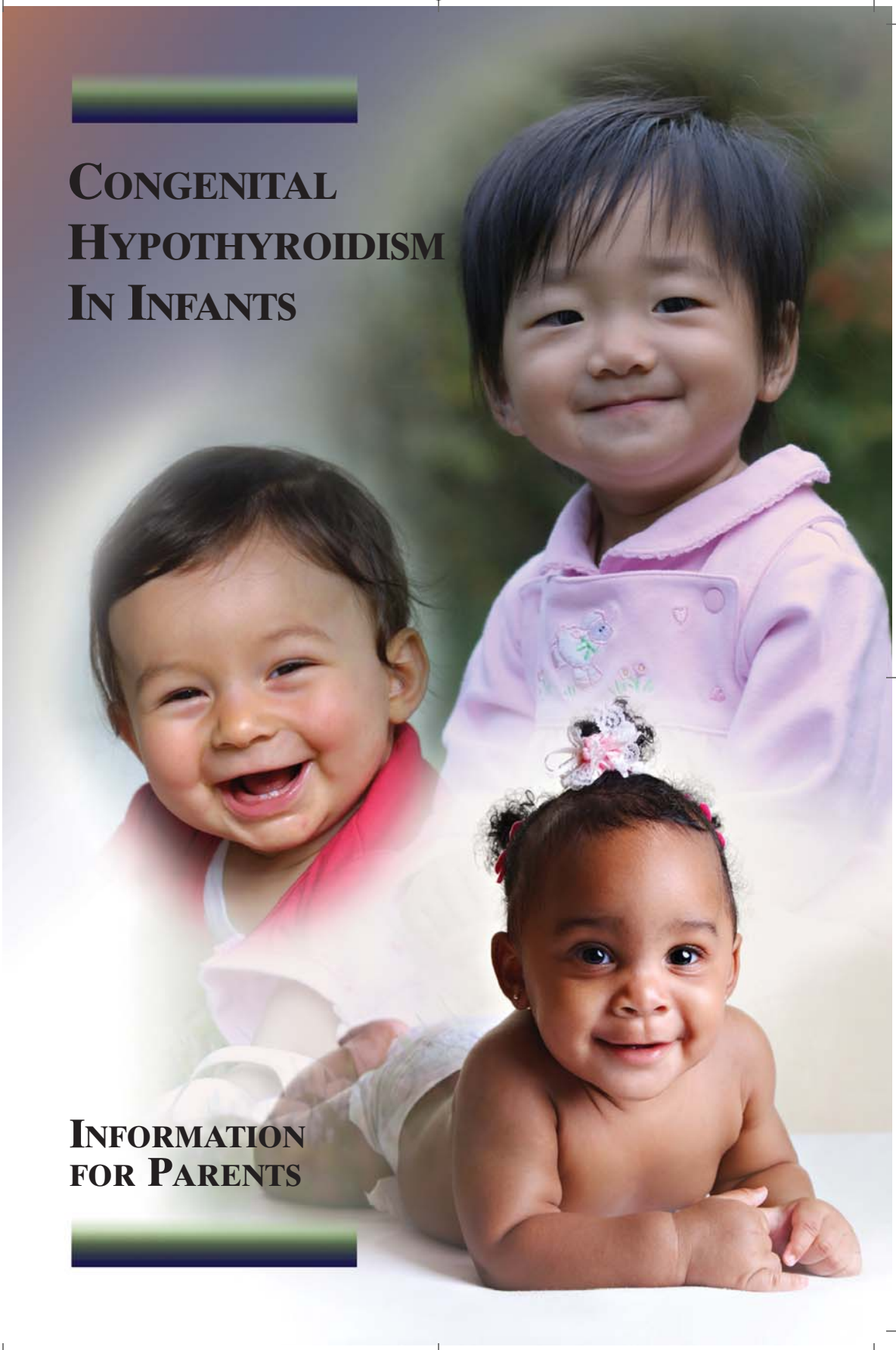
CONGENITAL HYPOTHYROIDISM IN INFANTS



INFORMATION FOR PARENTS

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Michigan Neonatal Thyroid Screening, Coordinating, and Follow-up Project

Reviewed and approved (January 2007)
by Pediatric Endocrine Advisory Council of Michigan

Supported by
The Michigan Department of Community Health

Newborn Screening Endocrine Follow-up Office
(734) 647-8938

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Information for Parents

Hypothyroidism in an infant means that the baby is not making enough thyroid hormone to grow and develop normally. The word congenital means that the baby was born with the condition. Symptoms of hypothyroidism in infants are very subtle. Most babies with the disorder look and act like any other baby. That is why testing for hypothyroidism is an important part of the state of Michigan's Newborn Screening Program. Babies with abnormal results can be evaluated, diagnosed, and quickly started on thyroid hormone.

This book was written to provide general information about the disorder. It is important to remember, however, that no two children are exactly alike. Specific questions about your child should be discussed with your doctor.

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For Your Information

MEDICATION STARTING DATE:

_____

PEDIATRICIAN:

Name _____

Phone _____

Address _____

PEDIATRIC ENDOCRINOLOGIST:

Name _____

Phone _____

Address _____

Comments by Your Child's Doctor

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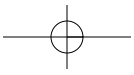
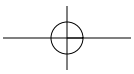
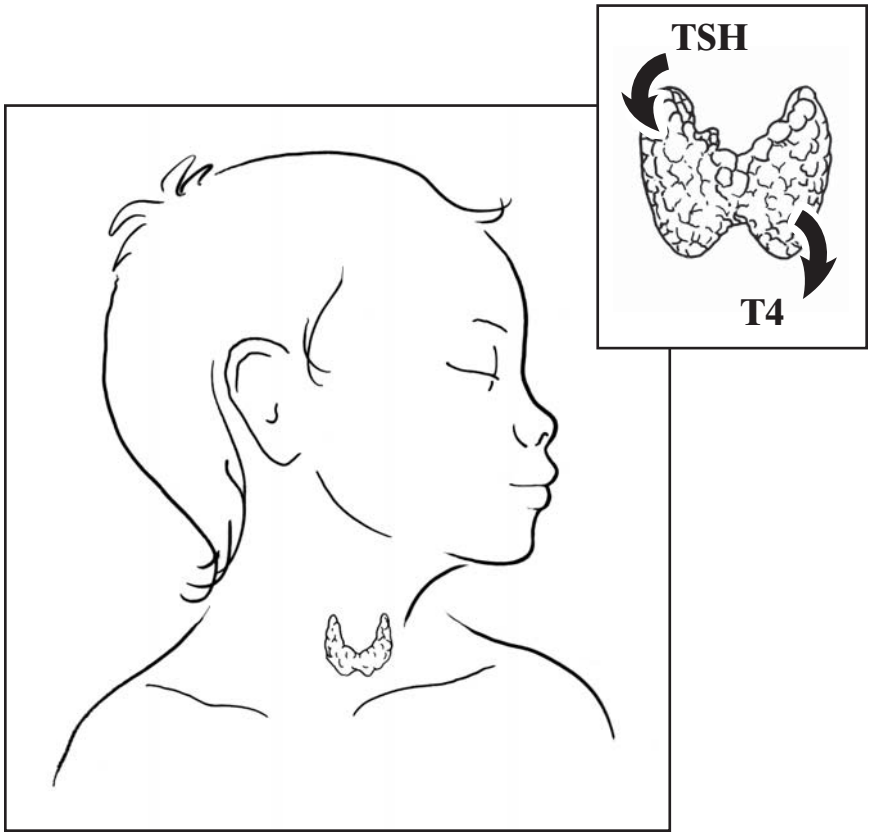




What does the thyroid gland do?

Glands produce special chemicals called hormones, which travel through the bloodstream and affect many of the body's functions.

The thyroid gland is shaped like a butterfly and is located in the front of the neck just below the larynx (voice box).



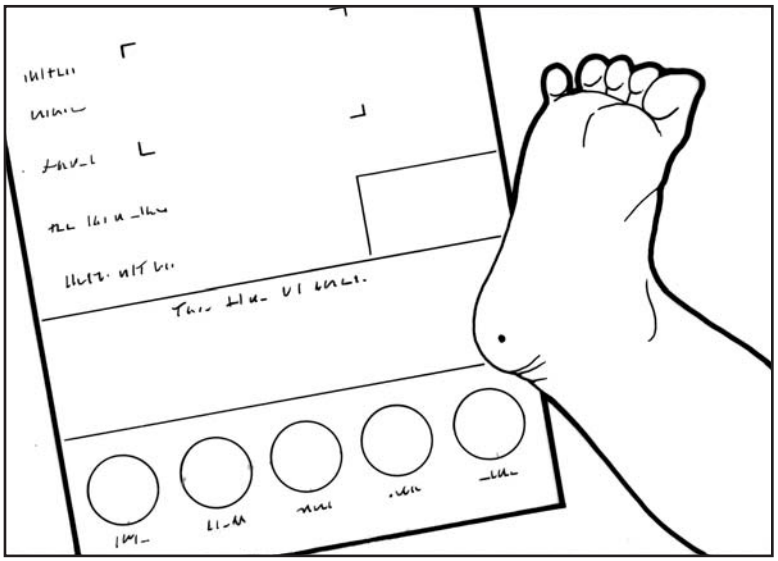
It uses iodine to make the hormone ***thyroxine*** (also called ***T_4***). The thyroid gland releases T_4 into the bloodstream when the body needs more to function normally.

The thyroid gland is controlled by the pituitary gland, which is located at the base of the brain. The pituitary gland makes ***thyroid stimulating hormone*** (also called ***TSH***). A healthy thyroid gland responds to TSH by making more T_4. When the two glands are in balance, the body functions normally.

When the level of T_4 is low in the bloodstream, the pituitary gland makes more TSH in an attempt to stimulate the thyroid to make more T_4. Unfortunately, this process doesn't work in an infant with hypothyroidism 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 T_4 level is very low and the TSH level is very high.

Why does the doctor suspect that my baby has a thyroid problem?

In Michigan, a few drops of blood are taken from each newborn baby's heel before leaving the hospital. The state's Newborn Screening Program then uses the blood sample to test the baby for hypothyroidism, phenylketonuria (PKU), and several other disorders. If the test for hypothyroidism is positive (i.e., abnormal), your doctor is informed and is advised to evaluate your baby for the disorder.



Could my baby's state screening test be wrong?

Results of the screening test are not final. A result showing extremely abnormal hormone levels usually indicates that the disorder is present, but borderline results are less conclusive. Further testing is always necessary to make an accurate diagnosis.

How is the diagnosis made?

A complete history and physical examination along with blood tests are usually completed first. In addition, your doctor may consult with a children's doctor who specializes in hormone disorders. This kind of doctor is called a pediatric endocrinologist.

The following tests will be ordered:

1. ***Free T4 and Thyroid Stimulating Hormone (TSH) levels*** are measured in a blood sample from a vein in the baby's arm or foot.

The following tests may also be ordered:

1. ***A Thyroid Scan*** is taken to determine if a thyroid gland is present and how well it is functioning. This test requires specialized equipment and is usually conducted at larger hospitals and medical centers. A thyroid scan requires that a small account of a radioactive substance be injected into a vein. The amount is less than the radioactivity in an X-ray and is quickly cleared out of the baby's body.

2. ***Bone Age*** is determined because thyroid hormone is essential for normal bone growth. An X-ray of the baby's knee and/or wrist is taken. The doctor can look at the X-ray to see if the baby's bone growth has been normal. Bone growth may be delayed in babies with congenital hypothyroidism. The amount of bone growth delay is thought to correspond fairly well with the length of time the baby has been thyroid deficient.

Will my baby have two doctors?

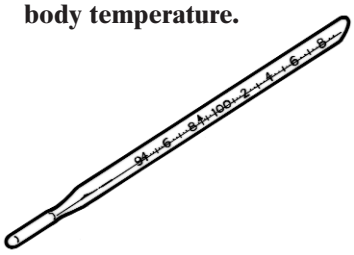
Your regular pediatrician may recommend that you take your baby to a pediatric endocrinologist for treatment of the hypothyroidism. A hormone specialist has more experience and knowledge about the treatment of thyroid disorders. It will benefit your baby to use both doctors if that is recommended.

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 growth and development.

Thyroid hormone plays a role in:

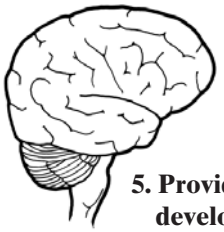
1. Regulating body temperature.



2. Maintaining the heart rate.

3. Maintaining normal functioning of the digestive tract, including bowel movements.

4. Providing an adequate appetite.



5. Providing normal development of the brain and nervous system.

6. Promoting the growth of bones, teeth, and muscles.

How common is congenital hypothyroidism?

Congenital hypothyroidism occurs in approximately one out of 4000 newborns. In Michigan, 60 to 90 babies are born with the disorder each year.

What is the cause?

The most common cause of congenital hypothyroidism is failure of the thyroid gland to develop normally. Before the baby is born, the thyroid gland is formed initially at the base of the brain. It then moves down the neck to its usual location below the larynx (voice box). When this normal development does not occur, the thyroid gland can be found to be missing completely (called **aplasia**), present in only a very small amount (called **hypoplasia**), or present in an abnormal location (called an **ectopic thyroid gland**). An ectopic thyroid gland is most commonly present at the base of the tongue (called a **lingual thyroid gland**).

Two of the uncommon causes of congenital hypothyroidism are failure of the thyroid gland to make and release thyroid hormone (**dyshormonogenesis**) and failure of the pituitary gland to stimulate the thyroid gland to make thyroid hormone (**TSH deficiency**).

All of the causes of congenital hypothyroidism result in insufficient thyroid hormone production.

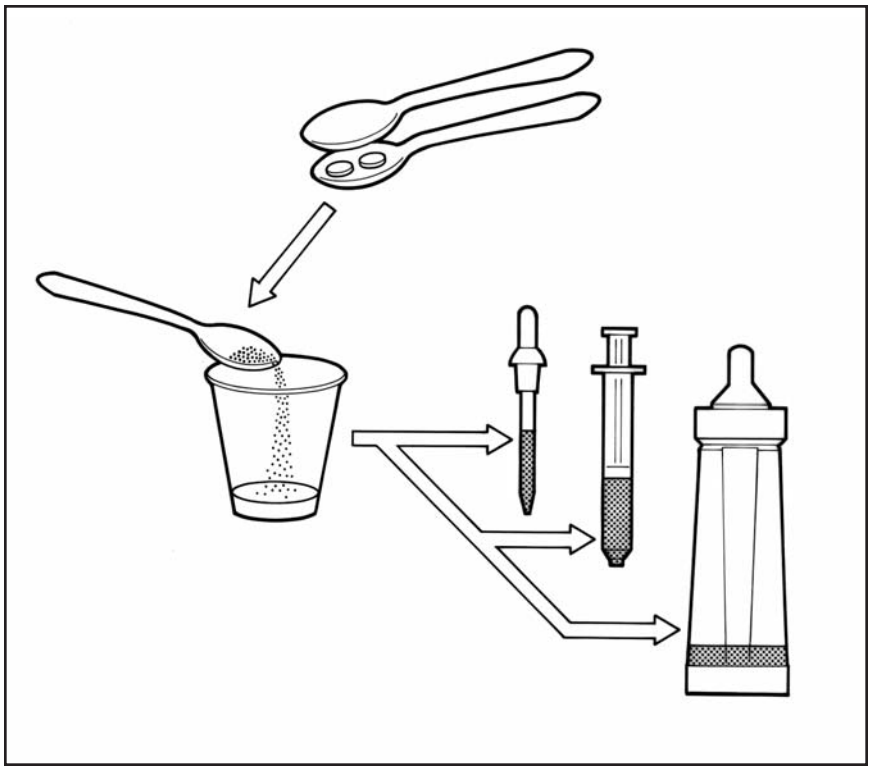
MEDICATION AND TREATMENT

How is hypothyroidism treated?

Once a baby is diagnosed with congenital hypothyroidism, he or she is immediately started on thyroid hormone replacement. The most common thyroid hormone tablet prescribed by doctors is levothyroxine (name brands are Synthroid or Levothroid). Levothyroxine is a synthetic thyroid hormone that is exactly like the hormone made by a thyroid gland. Since this is a normal body substance, it is tolerated very well. There are usually no side effects when the levothyroxine is given in the correct amount.

How do I give the medication to my baby?

Levothyroxine is only available as a tablet. The tablet can be crushed between two spoons and mixed with a teaspoon of water, formula, or breast milk. This mixture is given to the baby with an eyedropper or small syringe, placing the liquid on the side of the baby's mouth or tongue. Another way to give the medication is to mix it with a small amount of liquid and feed it to the baby from a bottle.



If you do this, a little more liquid should then be added to the bottle and fed to the baby to ensure that the baby takes all of the thyroid hormone. The crushed tablet should not be mixed in a full bottle since the baby may not take the whole amount in the bottle. You may also pick up the crushed pieces of medication with a moistened fingertip and swab the inside of the baby's cheek. When the baby gets older and is taking solid foods, the tablet may be crushed and mixed with a spoonful of cereal or fruit. Older children will just chew the tablets. The tablets have no taste of their own.

How often is the medication given?

Your baby's doctor or pediatric endocrinologist will usually prescribe the levothyroxine to be given once a day. It is important that your baby receive the medication as prescribed. Some parents find it useful to keep a calendar by the medication bottle and mark off each day as the child takes the medication. Other parents use a pill box that separates out each day's dose for a week at a time.

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

If a dose is missed on one day, you may give twice the dose on the following day. But you should never give more than two times the dose. Too much thyroid hormone can be as dangerous as too little. Giving more thyroid hormone than prescribed **WILL NOT** help your baby grow and develop faster.

Who decides the amount of medication my baby takes?

Your doctor and/or pediatric endocrinologist 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 four to six times during the first year, three times during the second year, and one or two times a year after age two.

The amount of thyroid hormone required will increase as your baby grows. This is especially true during the first two years of life as the brain and nervous system mature.

What medication problems should I look for?

It is possible that your baby could react differently to the dosage of medication than the doctor expects. You can help your doctor by looking for signs of too much or too little medication. You should telephone your pediatrician or endocrinologist if you notice any of these signs continuing for more than a few days. **Do not** change the amount of medication on your own. If your pharmacy gives you a pill that looks different than 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 a weight gain, and frequent stooling or diarrhea.

Should I be concerned about what my baby eats?

Your child does not need to be on any 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. If your baby takes soy formula, do not give levothyroxine within 1-2 hours.

Can I give the thyroid medication (levothyroxine) with other medications and foods?

There are no restrictions on giving your child other medications that are prescribed by a doctor. Your baby should receive routine immunizations and regular checkups like any other child.

Certain foods and other substances can interfere with absorption of the levothyroxine. Avoid giving your baby calcium and iron supplements within 4 hours of the levothyroxine.

How long will my child have to take thyroid medication?

Usually, children with congenital hypothyroidism take thyroid hormones for the rest of their lives. The disorder is not something they will outgrow. As mentioned previously, thyroid hormone is essential during the first two years of life for brain development. After age two, the dose does not have to be increased as frequently.

GENETICS

Could my child have inherited hypothyroidism?

Congenital hypothyroidism is not an inherited disorder except in very rare cases. Your doctor should be able to tell you if your child's case is inherited. The cause of the noninherited type is unknown. Research has shown, however, that it does not result from anything done by the parents during pregnancy.

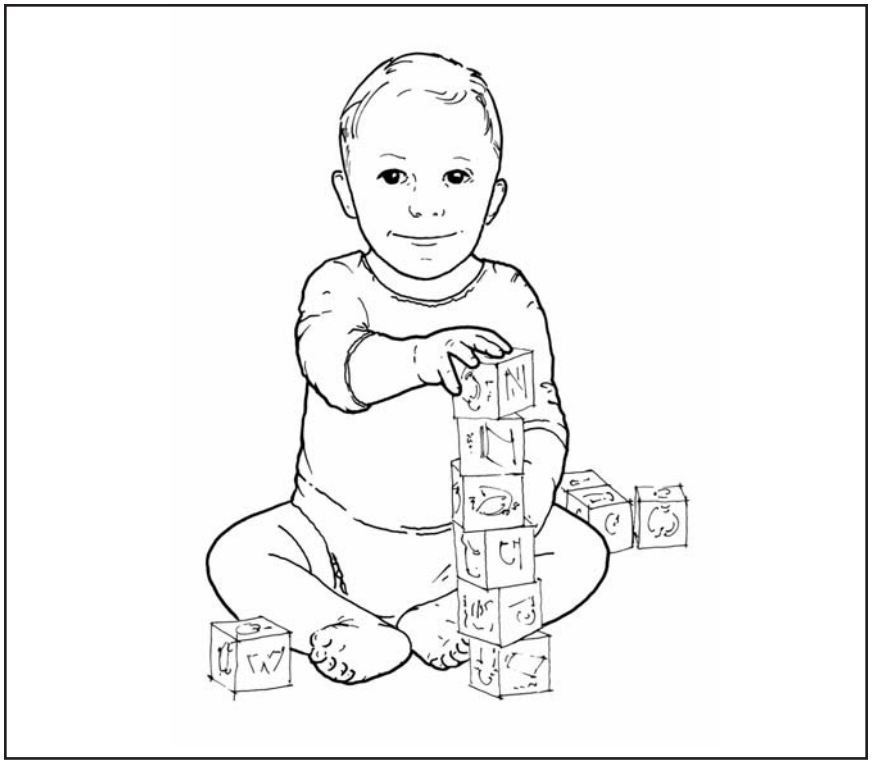
Will our next child have hypothyroidism?

Your risk of having another baby with congenital hypothyroidism is extremely small unless the disorder was inherited.

LONG-TERM EFFECTS

Will my baby grow up to be normal?

In the past, babies with congenital hypothyroidism were not screened at birth nor immediately treated with hormones. As a result, their development was hampered, and they grew up to be mentally retarded. All that changed in the 1970's, when Michigan and other states began screening newborns and starting treatment immediately. Now children born with 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 be retarded.



In fact, studies of children who have received adequate/appropriate treatment soon after birth, seem to indicate that they have suffered no serious mental impairment. The children seem to have normal IQ's, although they may have some subtle learning disabilities. These disabilities, however, do not appear to be serious enough to affect normal functioning and do not require special schooling.

In other words, it appears from evidence available now that children with congenital hypothyroidism who are started on treatment at an appropriate age and who receive appropriate medication and careful follow-up by their doctors are likely to grow and develop normally and to function normally as adults.

What can I do to help my child?

It is extremely important that your child receive the thyroid hormone as prescribed by the doctor. The doctor and/or pediatric endocrinologist will request follow-up visits and blood tests. You will help your child by regularly making these appointments and by discussing your concerns, questions, and problems with the doctor. Except for the need to take thyroid hormone replacement, your child should be treated like any other child.

Glossary

Aplasia: The failure of an organ to develop, which results in the complete absence of the organ in the body.

Bone age: A measurement of the normal growth and development of bones through an X-ray of the knee and/or hand bones.

Congenital: Refers to anything present since the time of birth.

Dyshormonogenesis: A defect in the manufacture or use of a hormone in the body.

Ectopic thyroid gland: A thyroid gland that is in an unusual position away from its normal location in the neck.

Free T_4: Active portion of T_4.

Gland: An organ that produces and secretes materials that affect other organs and cells in the body.

Hormone: A special chemical made by a gland that travels though the bloodstream and affects many of the body's functions.

Hyperthyroidism: An abnormal condition caused by greater than normal amounts of thyroid hormone in the body.

Hypoplasia: The incomplete development of an organ, which results in a smaller than normal organ in the body.

Hypothyroidism: An abnormal condition caused by lower than normal amounts of thyroid hormone in the body.

Iodine: A chemical element needed by the thyroid gland to make thyroid hormone.

Larynx: Upper part of the trachea (wind pipe), which contains the vocal cords. Sometimes called the Adam's apple.

Levothroid: A trade name for a synthetic thyroid hormone tablet.

Levothyroxine: The generic name for synthetic thyroid hormone used for replacement therapy in hypothyroidism.

Lingual thyroid gland: A thyroid gland located near the tongue instead of the usual location in the neck.

Newborn Screening Program: A program in Michigan requiring that all newborn infants be tested for several serious disorders including hypothyroidism.

Pediatric endocrinologist: A children's doctor who specializes in hormone disorders.

Phenylketonuria (PKU): An inherited disorder where the body cannot change one of the protein building blocks (called phenylalanine) into a usable form.

Pituitary: A small gland located at the base of the brain that controls the function of the thyroid gland and several other glands.

Synthroid: A trade name for a synthetic thyroid hormone tablet.

T_4: Another name for thyroxine, which is a hormone made by the thyroid gland.

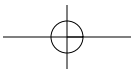
TSH: An abbreviation for thyroid stimulating hormone, which is a hormone made by the pituitary gland.

TSH deficiency: Failure of the pituitary gland to make enough TSH to stimulate the thyroid gland.

Thyroid scan: A test that uses a small amount of a radioactive substance to detect the presence and location of a thyroid gland.

Thyroid stimulating hormone: A hormone produced by the pituitary gland that regulates the amount of thyroxine (T_4) made by the thyroid gland.

Thyroxine: A hormone made by the thyroid gland. Also referred to as T_4.



2ND EDITION

Prepared by
Michigan Marketing & Design
Argus 1 Building
535 W. William Street
Suite 2100
Ann Arbor, MI 48103-4943