Questions?

Contact us to learn more. We can also help you find providers near you.

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Congenital Hypothyroidism The New York State Health Department's Newborn **Screening Program tests every baby born in the State** within a few days of birth for a variety of disorders. Congenital hypothyroidism is one of these disorders.

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What is congenital hypothyroidism?

When a baby is born without a thyroid gland, or it doesn't work properly, they have congenital hypothyroidism. The thyroid gland makes a hormone that babies need to grow and develop.

When hypothyroidism is found and treated early, babies grow and develop normally. If it is not treated early, a baby's development will be delayed and intellectual disability can result. Nearly one in 2,000 newborn babies has hypothyroidism.

Congenital (kuhn-JEN-ih-tuhl): Present at birth

Hypo: Less than normal

Thyroid (*THY-royd*): A gland in your neck that makes chemicals called hormones. These hormones help all the cells in your body work normally.

TSH: Thyroid-stimulating hormone

What causes hypothyroidism?

There are many reasons for hypothyroidism:

- Some babies are born without a thyroid.
- Some are born with the gland in the wrong place, such as near the tongue.
- In other babies, the thyroid is in the right place, but it does not work properly. It makes little or no thyroid hormone.

Normally, the correct amount of thyroid hormone is produced by a gland found in the brain – the pituitary *(puh-TOO-uh-ter-ee)*. It releases a hormone called TSH for short. It stimulates the thyroid gland to produce thyroid hormone.

Sometimes the thyroid gland is normal, but the pituitary gland does not work properly. It cannot make enough TSH to make the thyroid gland do its job correctly.

How is this disorder diagnosed?

Several drops of blood are taken from a baby's heel shortly after birth. A dried blood sample is sent to the New York State Department of Health in Albany. It is tested at the Health Department's Wadsworth Center for several diseases, including hypothyroidism. The tests are all part of New York State's Newborn Screening Program. It makes sure that diseases are detected early, and babies are treated quickly.

If your baby's thyroid screening test results are not normal, your baby's doctor will be called. The doctor may keep caring for your baby. Or they may send you to a special doctor called a pediatric endocrinologist (en-doe-kre-NAA-loh-jist). These doctors work at Endocrine (EN-doe-krin) Specialty Centers. In either case, your baby's complete medical history will be taken. Your baby will also have a full physical exam. The doctor will look for symptoms like:

- Poor appetite
- · Very sleepy and inactive
- · Rough, dry skin
- Yellow skin for a long time (jaundice)
- Constipation
- Belly button that sticks out too far (umbilical hernia)
- Puffy face

They will take another blood sample right away to confirm the screening test result.

The doctor may also order an imaging test, such as an ultrasound exam or a thyroid scan. The tests are done to find the specific cause of your baby's hypothyroidism. The imaging test will show if your baby has a thyroid, and where it is located. If the thyroid gland is normal, a test to check the pituitary gland may be done.

Is there a cure?

Many babies with hypothyroidism will never be able to make enough thyroid hormone. In those cases, hypothyroidism is permanent. But it can be treated with medicine provided by your baby's doctor. Your baby will need to take this medicine every day. It will give your baby enough thyroid hormone so they can grow and develop normally.

Your doctor will want to see your baby as they grow. If needed, the medicine will be adjusted to help your baby grow and develop normally.