

When Baby Needs a Second Test for Congenital Hypothyroidism (Elevated TSH)

A small sample of your baby's blood was collected soon after birth and sent to the DHEC Public Laboratory for testing. This testing is called Newborn Screening. In SC, newborns are tested for several genetic and biochemical disorders. Sometimes, a second test is needed to help your doctor decide if your baby has one of the disorders. In many cases, the second test will be normal. However, if your baby does have one of the newborn screening disorders, early treatment will give him or her the best chance to grow up healthy.

Because a hormone called Thyroid Stimulating Hormone (TSH) was high in your baby's first test, he or she could possibly have a disorder called Congenital Hypothyroidism.

Please be aware that an elevated TSH can also be found in many babies who do not have Congenital Hypothyroidism. However, your baby needs to be retested quickly, as a precaution.

What is Congenital Hypothyroidism?

Congenital hypothyroidism is a disorder found in roughly **1 in every 2,000 babies** born each year. Most types of congenital hypothyroidism are not genetic disorders. This means that it is not passed to the baby from the mother and father's genes.

When a baby has congenital hypothyroidism, he or she cannot make enough of a biochemical (called a hormone) in the thyroid gland. Thyroid hormones are needed to keep the body's systems working like they should. This usually happens because the thyroid gland did not grow properly while the baby was still in the mother's womb.

If the baby is not treated, the baby's brain will not develop properly, causing severe intellectual disability. A baby who doesn't have enough thyroid hormones can also have growth problems.

How will I know if my baby really has Congenital Hypothyroidism?

If your baby's newborn screening result showed a very high TSH, he or she may have congenital hypothyroidism. The newborn screening test will be repeated, and additional tests may be done to help the doctor determine if your baby has congenital hypothyroidism. You may also be referred to a doctor who specializes in these kinds of disorders called an endocrinologist.

What do I need to do until I know the final results?

Your baby may not have any symptoms at first. But you will need to follow your doctor's instructions very carefully. If your baby seems to be getting sick, call your doctor right away.

How is Congenital Hypothyroidism treated?

Treatment for babies with congenital hypothyroidism is fairly simple. The baby is given medicine to make up for the thyroid hormone his or her body cannot produce. The baby may need to take this medicine for a short time, or for the rest of his or her life.

What else should I do to keep my baby as healthy as possible?

Don't forget to keep all of your baby's well check-ups! Seeing doctors regularly and giving your baby daily thyroid medicine are the best things you can do to help your baby grow and develop.

Internet Resource:

<https://www.babysfirsttest.org/newborn-screening/conditions/primary-congenital-hypothyroidism>