

## When Baby Needs a Second Test for Primary Congenital Hypothyroidism Elevated TSH

A small sample of your baby's blood was collected soon after birth and sent to the DHEC laboratory for testing. This testing is called Newborn Screening. In SC, newborns are tested for several genetic and chemical 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 compound called Thyroid Stimulating Hormone (TSH) was high in your baby's first test, he or she could possibly have a disorder called Primary Congenital Hypothyroidism.*

*Please be aware that a higher than expected TSH can also be found in many babies who do not have Primary Congenital Hypothyroidism. Your baby needs to be retested quickly, though, as a precaution.*

### **What is Primary Congenital Hypothyroidism?**

Primary congenital hypothyroidism is a disorder found in around one out of every 4000 babies born each year. Most types of primary 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 primary congenital hypothyroidism, he or she cannot make enough of a chemical (called a hormone) in the thyroid gland. The thyroid hormone is 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 mental retardation. A baby who doesn't have enough thyroid hormone can also have growth problems.

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

If your baby's newborn screening result showed very high TSH, he or she probably has primary congenital hypothyroidism. The newborn screening test will be repeated and additional tests may also be done to help the doctors figure out if your baby has primary congenital hypothyroidism. The results of these other tests may take a while to come back. You will also be referred to a doctor who specializes in these kinds of disorders.

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

Your baby will probably 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 Primary Congenital Hypothyroidism treated?**

Treatment for babies with primary congenital hypothyroidism is fairly simple. The baby is given a medicine to make up for the thyroid hormone his or her body cannot produce. The baby will need to take this medicine 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 well baby check-ups! Seeing the doctors regularly and giving your baby thyroid medicine every day are the best things you can do to help your baby grow and develop.

### **Internet Resources:**

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