

## When Baby Needs A Second Test for Tyrosinemia Type I (TYR I) Elevated SUAC

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. Some times, a second test is needed to help your doctor decide if your baby has one of these 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 succinylacetone (SUAC) was high in your baby's first test, he or she could possibly have a disorder called Tyrosinemia Type I (TYR I). Tyrosine (TYR) may be within the normal range or it may also be high.*

### What is Tyrosinemia Type I (TYR I)?

TYR I is a genetic disorder that is found in a few babies born each year. TYR I can be identified when certain compounds are measured in a baby's blood. To identify TYR I, two types of compound are measured: amino acids and succinylacetone (SUAC). Amino acids are the "building blocks" of protein. When a baby has TYR I, he or she cannot completely use one of the amino acids found in foods including breast milk and infant formula. This amino acid, tyrosine (TYR), forms other compounds that build up in the baby's blood and can cause the baby to have feeding problems, poor growth and liver disease. When TYR cannot be broken down enough, SUAC builds up. This makes measurement of SUAC the best test to find TYR I.

### How will I know if my baby really has TYR I?

If your baby's newborn screening result showed high SUAC, he or she very likely has TYR I. The newborn screening test will be repeated and additional tests will be done to help the doctors figure out if your baby has TYR I. Usually the results of these tests take a few days 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 TYR I treated?

TYR I is usually treated with a special diet. At first, babies must be fed a special formula. When they begin to eat solids, the protein in their diet will need to be controlled. They will still need to drink their special formula to make sure they get everything they need to grow properly. A dietitian will help the family learn which foods the baby can eat. Babies with TYR I usually take a medication called NTBC too.

### 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 following your baby's diet plan carefully are the best things you can do to help your baby grow and develop.