

## When Baby Needs A Second Test for an Immune System Disorder Low TRECs

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 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 blood components called TRECs (T cell receptor excision circles) were low in your baby's first test, he or she could possibly have Severe Combined Immunodeficiency (SCID) or other immune system disorder.

Please be aware that lower than expected TRECs can also be found in babies who do not have an Immune System Disorder. Your baby needs to be retested quickly, though, as a precaution.

### **What are immune system disorders?**

Immune system disorders like SCID are genetic disorders that are found in a few babies born each year. Some of these disorders can be identified when blood components like TRECs are measured in a baby's blood. When a baby has an immune system disorder, he or she cannot fight off infections. Even a minor cold virus can become a major illness in a child with SCID.

### **How will I know if my baby really has SCID?**

If your baby's newborn screening result showed very low TREC levels, he or she is at increased risk for SCID or a similar disorder. The newborn screening test will be repeated and additional tests may be done to help the doctors figure out if your baby has SCID. 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?**

You should avoid taking your baby to places where he or she could be exposed to someone who has an illness such as a cold, the flu, or any other infection. You should keep your baby at home and not take him or her to daycares, stores, churches or other places where there are lots of people. If you are breastfeeding, your doctor may have you pump and freeze your breast milk until the results of some tests are known. If your baby seems to be getting an infection, call your doctor right away.

### **How is SCID treated?**

The best treatment for a baby with SCID is a bone marrow transplant. It works best when done before the baby gets a severe infection. Babies with other immune system disorders are sometimes given medications.

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

Follow your doctors' instructions carefully! Babies with SCID can get sick very fast. Treating illnesses before they become serious are the best things you can do to help your baby grow and develop.

### **Where can I find more information about SCID?**

There are many resources on the internet for health issues. Some of the best ones for SCID are as follows:

*Baby's First Test*

<http://www.babysfirsttest.org/newborn-screening/conditions/severe-combined-immunodeficiency-scid>

*Immune Deficiency Foundation*

<http://primaryimmune.org/idf-advocacy-center/idf-scid-newborn-screening-campaign/>

*The SCID Homepage*

<http://www.scid.net/>