

# Newborn Screening for Severe Combined Immunodeficiency (SCID) and Conditions Associated with T Cell Lymphopenia

Babies can look healthy at birth and still have health problems that need to be recognized and treated. For this reason your baby had routine newborn screening tests done in the hospital before discharge. A few drops of blood were taken from your baby's heel and tested for a number of disorders. One of the tests performed is to detect problems with the immune system. Your baby had a result on this test that was either abnormal or did not give a clear result, and therefore additional testing needs to be done as soon as possible.

## *What Does An Abnormal Screening Test Mean?*

The screening test shows that your baby may have a low number of a type of white blood cells called "T cells." Low numbers of T cells can be associated with a genetic condition called Severe Combined Immunodeficiency or SCID (pronounced "skid") which would place your baby at extreme risk for serious, life-threatening infections. The screening test alone cannot be used to make a diagnosis of SCID, which is why a new blood test is needed to determine if your baby has a life-threatening immune disorder. You will receive instructions from your medical provider or your State newborn screening program about getting a new specimen without delay.



## *What is SCID?*

SCID is a set of more than a dozen different genetic disorders, all of which result in a failure to develop T cells and inability to make protective antibodies. Most newborns with SCID appear healthy at first because the mother's immune system protects them from infections for the first few weeks of life. However, without treatment, even common infections can be life threatening. If your baby has SCID a treatment plan can be started to help prevent infections and establish a functioning immune system.

## *What Other Immune System Problems Could My Baby Have?*

In addition to SCID, the screening test also picks up other conditions associated with low T cells. These are often not as severe as SCID, but are important to find out about and treat. Although these are immune diseases they are not related to HIV or AIDS and are not infectious.

## *How Common is SCID?*

In past years, it was believed that the incidence for babies born each year with SCID was 1 in 100,000. New data available from states that have initiated newborn screening programs for SCID suggest that the incidence may be somewhat more common.

## *How are SCID and Other Conditions Associated with T cell Lymphopenia Treated?*

The most effective treatment for SCID is a bone marrow transplant. This treatment can be done soon after birth and has a high success rate **when done in the first few months of life**. Some of the other conditions associated with low T cells will also be treated with bone marrow transplant, while others may be most appropriately treated with other therapies. A diagnostic evaluation by an immunologist will determine what kind of treatment your baby needs.



## ***What Do I Need to Do Right Now?***

Your doctor will tell you where to go for additional blood tests. Most likely your doctor will refer you to a specialist in pediatric immune deficiencies. It is important that you go to the doctor's office or hospital laboratory for a follow-up blood test **as soon as possible**.

Babies with a possible T-cell deficiency should not receive live vaccines until their immune system has been further tested and found to be normal. The rotavirus vaccine should not be given to any baby with a possible primary immune deficiency, such as SCID, even though it has been approved for infants as young as 2 months old.

## ***Who can I call if I have additional questions about newborn screening for SCID?***

**NAME**

**WEBSITE**

**CONTACT INFO**

For additional information about SCID and other conditions associated with T-cell lymphopenia contact:

Immune Deficiency Foundation  
110 West Road, Suite 300  
Towson, MD 21204  
[www.primaryimmune.org](http://www.primaryimmune.org)  
[IDFscidinitiative@primaryimmune.org](mailto:IDFscidinitiative@primaryimmune.org)  
800-296-4433

American Academy of Allergy, Asthma and Immunology  
414-272-6071  
[www.aaaai.org](http://www.aaaai.org)

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