

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

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 that can appear at birth. One of the tests performed detects potential immune disorders. Your baby had a positive (abnormal) result on this test and additional testing is necessary to determine whether your baby has a serious primary immune disorder.

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

The screening test shows that your baby has a low number of T cells (T cell lymphopenia). These cells, sometimes called lymphocytes, are a type of white blood cell. 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 another blood test is needed right away to determine if your baby has a life-threatening immune disorder. Note that babies who are born prematurely can have low T cells at birth. If this is the case, the next blood test will be able to tell if that is the reason. If your baby is premature, it may be recommended that the test be repeated once your baby is full term to determine if a primary immune deficiency is present.



## ***What is SCID?***

SCID is actually a set of more than a dozen different disorders, all of which result in a failure of affected infants to develop T cells. It is a syndrome that results from a variety of genetic causes. Although most newborns with SCID appear healthy, the disorder is present at birth. Typically SCID includes problems with both T cell and B cell function, which can result in the onset of one or more serious infections in the first few months of life. T cells originate in the bone marrow, mature in the thymus gland, and then enter into the blood stream, where they help B cells kill infections and regulate the immune system. B cells, another type of white blood cell, are produced in the bone marrow. After they mature into plasma cells they produce immunoglobulins, or antibodies, that keep us well by killing germs such as viruses, fungi, and bacteria.

## ***What Other Diseases or Conditions are Detected by this Test?***

In addition to SCID, the screening test also picks up other conditions associated with T cell lymphopenia. This includes Complete DiGeorge Syndrome and other T cell deficiencies, some of which are not well defined. These other genetic disorders can also result in a baby having low T cells at birth. Babies with these disorders can also develop serious infections so additional testing and treatment is necessary.

## ***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 closer to 1 in every 30,000 births.

## ***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 T cell lymphopenia will also be treated with bone marrow transplant, while others may be most appropriately treated with other therapies or a thymus transplant. This is why it is important to follow up with diagnostic evaluation to 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. 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  
40 West Chesapeake Ave., Suite 308  
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)

