

# Parent Information

## Positive Newborn Screening Test Result for Severe Combined Immunodeficiency (SCID)

### What is Newborn Screening?

After babies are born, five drops of blood are collected from the baby's heel to test for certain diseases. These conditions usually cannot be found simply by looking at or examining a baby.

### What is Severe Combined Immunodeficiency (SCID)?

Severe Combined Immunodeficiency or SCID (said like "skid") is a set of conditions that affect the body's immune system. The immune system fights off infections. A person with SCID is not able to fight off any infections. SCID is different for each child and can vary in the symptoms it causes. This is an inherited disorder but is often found in families with no history of such problems. SCID is inherited when one or both parents pass on a gene that causes SCID. Parents may not be affected by the change and can be unaware that they carry such a gene.

### What does a positive result mean?

A positive test means that your baby needs to have more testing to check for SCID. A positive test does not mean that your baby has SCID. There are other reasons why a baby might have a positive result. Some babies with a normal immune system will have a positive result as well. The "screening test" identifies the babies that need more testing. After additional testing is completed your doctor will have more information about your baby's immune system.

### What do I need to do now?

Your baby's doctor will tell you how to have the necessary tests done. Testing should be done without any delays even though your baby appears well. If your baby does have SCID finding out quickly will allow treatment to be started promptly.

It is also important to follow all of your baby's doctor's instructions about preventing infections. Check with your baby's doctor about the safety of breast feeding at this time. She/he may recommend using a breast pump and storing your milk until it has been determined safe.

Until it has been determined that it would be safe, your baby should not be given live vaccines which includes the Rotavirus vaccine.

### How is SCID treated?

SCID can be treated and is most successful if treatment is initiated promptly. The usual treatment is a bone marrow transplant. Your baby's doctors will determine the best course of treatment for your baby. Additional therapies may be necessary to prevent infections.

### Resources for parents

Immune Deficiency Foundation – [www.primaryimmune.org](http://www.primaryimmune.org)

[www.babysfirsttest.org](http://www.babysfirsttest.org)

[www.dhhs.ne.gov/nsp/](http://www.dhhs.ne.gov/nsp/)