

Parent Fact Sheet

Severe Combined Immunodeficiency (SCID)

What is SCID?

Immune system disorders including SCID are genetic disorders that are found in a few babies each year. When a baby has an immune system disorder, his or her body cannot properly fight off infections. Even a cold or virus can become a major life threatening illness to a child with SCID. SCID is present at birth, but most newborns look healthy at birth. This is because the mother's immune system helps to protect them for the first few weeks of life.

How will I know if my baby really has SCID?

If your baby's newborn screen showed abnormal results, he or she is at an increased risk for SCID or another immune disorder. Depending on the results, the newborn screen may be repeated or your baby may be referred for additional testing. Your doctor will arrange for additional testing to be done by specialists in disorders like SCID.

What do I need to do?

You should avoid taking your baby to places where he or she could pick up illnesses such as colds, the flu or any virus. You should keep your baby at home and away from daycare, grocery stores, and places where there are a lot of people. Do not allow people who are sick or just getting over being sick into your home. Make sure you are washing your hands often. If your baby shows signs of being sick, call your doctor right away. You should also make sure that your baby is not given any live virus vaccines.

What is the treatment of SCID?

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 is the chance that my baby will have SCID?

The chance of a baby having SCID is about 1 in 58,000 births.

Where can I take my baby for care in Virginia?

Please speak with your baby's doctor to obtain a pediatric immunology referral.

Where can I find more information about SCID?

If you want to know more about this condition, please contact Virginia Newborn Screening Services, Virginia Department of Health. The website is <http://www.vahealth.org/gns>.

Other helpful websites may include:

The Immune Deficiency Foundation <https://primaryimmune.org/idf-publications/>

Baby's First Test

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



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