Frequently Asked Questions:
Newborn Screening for
Severe Combined Immunodeficiency (SCID)
Information for Parents

What is newborn screening?

Every state has a newborn screening program to identify infants with rare disorders, which would not usually be detected at birth. Early diagnosis and treatment of these disorders often prevents serious complications.

What is severe combined immunodeficiency?

SCID is one of over 40 disorders included in newborn screening in New York State. It is a rare genetic disorder. Children with SCID have an immune system that does not work well. The immune system's job in the body is to fight off infections. Therefore, children with SCID have an increased risk to develop serious infections. There are usually no clues at birth that a baby has SCID.

How does New York State screen for SCID?

T cell receptor excision circles (TRECs) are usually found in every newborn's blood. As part of the NYS newborn screen, a special test measures the amount of TRECs in each baby's blood. TRECs are made by T cells, which are an important part of the immune system. Babies with SCID have little to no TRECs in their blood.

My baby had a positive newborn screen for SCID. Does my baby definitely have SCID?

A positive newborn screen does not mean that your baby definitely has SCID. However, it means that additional blood tests are needed. Low levels of TRECs in the blood can be caused by SCID, prematurity or other, less serious immune disorders. It is also possible for a baby to have a positive newborn screen for SCID, but have a normal immune system.

How do I find out if my baby has SCID?

Your doctor will ask you to take your baby to see a special doctor, called an immunologist or an infectious disease specialist because they are experts at diagnosing and treating SCID. Additional blood tests will be ordered by the specialist to find out if your baby has SCID. ***The additional tests are very important.*** If diagnosis and treatment for SCID are delayed, it can lead to serious infections. In some cases, these infections are life threatening.

What is the treatment for SCID?

Children with SCID are treated with a bone marrow transplant.

No one else in my family has SCID or immune system problems. Is it still possible for my baby to have the condition?

Even if no one in your family has SCID, it is possible for your baby to have the condition. In fact, most babies who have SCID do not have a family history of the disorder. If your baby is diagnosed with SCID, your doctor may suggest genetic counseling to discuss the chance for your future children to have SCID.

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

Your baby's doctor or the NYS Newborn Screening Program are resources for additional questions about newborn screening for SCID.

Newborn Screening Program staff can be contacted at 518-473-7552, Monday through Friday, 8 am until 5 pm.

State of New York
Department of Health