



Newborn Screening FACT Sheet

Severe Combined Immunodeficiency (SCID)

What is SCID?

SCID results when a baby's immune system does not work. Babies with SCID are not able to fight infection. They appear healthy at birth but can become sick very quickly when exposed to common illnesses. SCID is so rare that medical providers might not diagnose it until it is too late to provide lifesaving treatment.

Screening Tests

All Texas newborns get two blood tests that screen for certain rare disorders. A positive newborn screen does not mean the baby has SCID, but it does mean the baby needs more testing to know for sure. The Primary Care Provider will be notified by the newborn screening program to arrange for additional testing.

Newborn screening will not detect all cases of SCID, and not all cases that screen positive for SCID will be diagnosed with SCID. If your child shows symptoms of SCID he/she should be evaluated by the specialist.

What Causes SCID?

SCID is a disorder that is passed on (inherited) from parents to child. One or both parents of an affected child carry a gene change that can cause SCID. Parents usually do not have signs or symptoms, or even know they carry the gene change. The genes that cause SCID prevent the immune system from maturing.

When SCID is an autosomal recessive genetic condition, a child must inherit two copies of the non-working gene, one from each parent, in order to have the condition. The parents of a child with an autosomal recessive condition each carry one copy of the non-working gene, but they typically do not show signs and symptoms of the condition. While having a child with SCID is rare, when both parents are carriers, they can have more than one child with the condition.

When SCID is an X-linked recessive genetic condition, a male must inherit one copy of the non-working gene from his mother to have the condition. A female must inherit two copies of the non-working gene, one from each parent, in order to have the condition. In X-linked conditions, the gene is carried on the X sex chromosome; therefore, the

condition affects males more than females. While having a child with SCID is rare, when one or both parents carry the non-working gene, they can have more than one child with the condition.

What Symptoms or Problems Occur with SCID?

Problems vary from child to child. These are some of the common ones:

- frequent fevers
- chronic skin infections
- persistent rash
- viral infections
- chronic diarrhea
- failure to thrive
- thrush

Until the test results are back the baby should:

- be kept at home
- not be taken to daycare
- use boiled tap water
- avoid transfusions if possible. Discuss with pediatric immunologist before transfusions if unavoidable
- babies with SCID should not receive live vaccines such as rotavirus, MMR, and Varicella Vaccine
- avoid contact with other family members who have received a live vaccine for example FluMist®

What is the Treatment for SCID?

SCID can be treated. The usual treatment is bone marrow transplant. Some babies who have a bone marrow transplant might still need lifelong treatment.

Medicines - Antibiotics to prevent infections, gamma globulin replacement (IVIG or SCIG).

Diet - Your baby should eat an age appropriate diet that is high in calories and protein. Discuss breast feeding with your pediatric immunologist. Do not use well water to mix baby's formula.

Things to Remember

Prompt treatment can improve a child's length and quality of life. It is very important for the Primary Care Provider to give clear instructions to the parent regarding follow up testing and treatment.