



FAMILY FACT SHEET

What is a positive newborn screen?

Newborn screening is done on tiny samples of blood taken from your baby's heel 24 to 36 hours after birth. The blood is tested for rare, hidden disorders that may affect your baby's health and development. The newborn screen suggests your baby might have a disorder called SCID.

A positive newborn screen does not mean your baby has SCID, but it does mean your baby needs more testing to know for sure.

You will be notified by your primary care provider or the newborn screening program to arrange for additional testing.

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.

SCID is a disorder that is passed on (inherited) from parents to a 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.

What problems can SCID cause?

Babies with SCID can become extremely sick very quickly.

Early signs of untreated SCID are:

- Frequent fevers
- Viral infections
- Chronic diarrhea
- Failure to thrive
- Thrush

Until the test results are back, you should:

- Keep your baby at home
- Not take your baby to daycare
- Avoid contact with all sick people
- Use boiled tap water, not well water, to mix your baby's formula

Babies with SCID should not receive live vaccines, such as the rotavirus vaccine.

It is very important to follow your primary care provider's instructions for testing and treatment.

What is the treatment for SCID?

SCID can be treated. The usual treatment is a bone marrow transplant.

Some babies who have a bone marrow transplant might still need lifelong treatment.

Prompt and careful treatment helps children with SCID live the healthiest lives possible.

Michigan Resources and Support

Michigan Newborn Screening

Nurse Consultant

Toll-free: 1-866-673-9939

newbornscreening@michigan.gov

Children's Hospital of Michigan Coordinating Center for Primary Immunodeficiencies

Toll-free: 1-313-806-6571

Children's Special Health Care Services

Toll-free: 1-800-359-3722