

Fact Sheet for Parents

Severe Combined Immunodeficiency (SCID)

Newborn Screening

A short time after your baby's birth, a newborn screen was performed to screen for certain medical conditions. This test involved a small sample of blood taken from your baby's heel. The goal of newborn screening is to identify conditions which, if caught early, can be treated and improve the health of infants.

Your Baby's Results

One test included in newborn screening is for a disorder called, Severe Combined Immunodeficiency, often abbreviated as SCID (pronounced "skid"). The result of your baby's newborn screen showed **Possible SCID**. This does not mean your baby has SCID. More testing will need to be performed to help find out if your baby has a medical condition such as SCID.

Severe Combined Immunodeficiency

SCID is a rare inherited disease, affecting the immune system. The immune system is responsible for fighting off infection. When the immune system is not working properly you have a greater risk of infections.

Recommendations

Your baby's doctor will recommend getting a repeat newborn screening sample in a couple weeks. In the meantime there are things that you and your family can do to help your new baby.

- Call your baby's doctor if you notice your baby has any signs of an infection. Symptoms of an infection would include...
 - High or low body temperature
 - Feeding poorly
 - Very sleepy and not waking for feedings
 - Irritable
 - Pale or grayish skin
 - Breathing faster than normal
- Your baby should not be around anyone who may be sick. This includes members of your immediate family. Anybody with symptoms such as vomiting, diarrhea, fever, cough or viral infections such as cold sores or shingles should not have contact with your baby.
- Your baby should avoid crowded areas and day cares.
- Your baby should avoid contact with all pets. No pets in your baby's bedroom. Practice good hand hygiene after handling pets.
- No live virus vaccines **for your baby or family members**. Vaccines to avoid include...
 - Rotavirus

- Varicella
- Measles, mumps, rubella (MMR)
- FluMist
- Yellow fever
- Typhoid
- Small pox
- Use boiled water (no well water) to mix your baby's formula.
- Practice good hand hygiene.
- If your baby were to need blood products please be sure all blood products are leukodepleted, irradiated and CMV negative.

Additional Information

If you have any questions or concerns about the information provided to you please discuss your concerns with your baby's doctor. You may also contact the South Dakota Newborn Screening program for any questions or concerns Monday- Friday at 605-773-3361.

For additional information you may also visit the following websites...

The Immune Deficiency Foundation

www.primaryimmune.org

Angels for Life Foundation

www.SCIDangelsforlife.com

American Academy of Allergy, Asthma and Immunology

www.aaaai.org

National Institute of Child Health & Human Development

http://www.nichd.nih.gov/publications/pubs/primary_immuno.cfm