

SCID FACT SHEET FOR PARENTS

NEWBORN SEVERE COMBINED IMMUNODEFICIENCY (SCID) SCREENING

What is SCID?

Severe Combined Immunodeficiency (SCID), also known as “bubble boy” disease) is a condition in which the baby’s immune system does not work. Babies with SCID are not able to fight infection.

How did my baby get SCID?

SCID is a condition 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.

What if my baby has a positive screen?

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 (NBS Follow-Up Coordinator) about how to get more testing.

How will SCID affect my child?

Early signs of untreated SCID:

- ❖ Thrush (white spots on the tongue or cheeks due to a fungal infection)
- ❖ Failure to thrive (not growing or gaining weight)
- ❖ Diarrhea
- ❖ Fever

What problems can infections in SCID cause?

Infections in SCID infants may be life-threatening. You will not know the final test results right away, so until then you should keep your baby at home, avoid contact with all sick people, mix formula with boiled tap water and not well water. Babies with SCID **should not receive any live vaccines, such as the rotavirus vaccine.**

What is the treatment for SCID?

SCID can be treated. The usual treatment is a bone marrow transplant. In some cases, gene therapy can be performed. Prompt and careful care is very important for children with SCID.

North Carolina’s Newborn Screening (NBS) Program

- ❖ **NBS Follow-up Coordinator**
Phone: (919) 218-6460
Website: <http://www2.ncdhhs.gov/dph/wch/families/newbornmetabolic.htm>
- ❖ **N.C. State Laboratory of Public Health**
Phone: (919) 733-3937
Website: <https://slph.dph.ncdhhs.gov/>
- ❖ **Children and Youth with Special Health Care Needs Help Line**
Phone: 1-800-737-3028

Resources for Parents

- ❖ **Immune Deficiency Foundation** offers both information and support for families including more detailed info about SCID.
Website: <http://primaryimmune.org/>
- ❖ **SCID, Angels for Life Foundation** offers information and videos for families sharing their own experiences with SCID.
Website: <http://www.scidangelsforlife.com/>