Why Does My Baby Need More Testing for Severe Combined Immunodeficiency (SCID)?

State law requires that all babies have newborn screening tests before leaving the hospital. A few drops of blood were taken from your baby's heel and tested for certain diseases. This testing is being expanded to include a rare disorder called SCID. Your baby had a positive or questionable result for the SCID test. Your baby now needs more testing as soon as possible.

California
Department of
Public Health
Newborn Screening Branch
Genetic Disease Screening Program
www.cdph.ca.gov/programs/nbs

Why Does My Baby Need More Testing?

Your baby's screening test for SCID was positive or questionable. More testing is needed to find out if your baby has an immune problem related to SCID. Newborn Screening staff will work with you and your doctor to make sure the needed tests are done right away.

Babies can look healthy at birth and still have SCID or related disorders. If not recognized and treated, these diseases can cause severe health problems.

What Is SCID?

SCID stands for **S**evere **C**ombined **I**mmuno-**d**eficiency. It is sometimes called "bubble boy" disease. Babies with SCID are born with little or no immune system. This means that they cannot fight off infections. Babies with SCID do not usually have symptoms at first, since their mother's immune system protects them from infections for the first few weeks of life. Without treatment, even common infections can be life-threatening. For that reason, it's important that your baby have more testing as soon as possible. If your baby has SCID, a treatment plan can be started to help prevent the health problems it can cause.

What Other Immune System Problems Are Detected by Newborn Screening?

Other genetic disorders of the white blood cells called "T cells" may be found. These are not as severe as SCID, but are important to find out about and treat. Although these are immune diseases, they are not related to HIV or AIDS and are not infectious.

How Is SCID Treated?

Currently, the most effective treatment for SCID is a bone marrow transplant. It can cure babies of SCID and is most effective when done before a baby gets a severe infection. Other treatments can be used in some cases. Babies with less severe conditions may need to receive medication.

Is SCID Common?

Although not very common, about 8 - 12 babies are born with SCID each year in California.

How Will I Know My Baby's Results?

The Newborn Screening staff reports the results to your baby's doctor. The baby's doctor will let you know the results.

What Should I Do Right Now?

- Return to the doctor's office or hospital laboratory as instructed and have a blood specimen collected from your baby as soon as possible.
- Make sure your baby's doctor has talked to the Newborn Screening Staff before giving your baby any vaccines. The rotavirus vaccine or other *live* vaccines are not to be given to babies suspected of having SCID.

What If I Have Questions?

Call your doctor or the Newborn Screening Staff listed below if you have any questions or concerns about this testing.

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