

Severe Combined Immunodeficiency (SCID): What Parents Need to Know

Your baby had a newborn screening result that means he or she could have a condition called SCID. Your baby needs more tests as soon as possible to confirm if he or she has SCID.

Talk to your baby's doctor right away about getting more testing.



What is SCID?

SCID stands for *Severe Combined Immunodeficiency*. Babies who have SCID have little or no immune system and can get seriously sick from common illnesses like a cold or flu. SCID is a genetic condition, meaning it is passed from parents to children through genes.

Is SCID Treatable?

SCID is treatable. If doctors find SCID early, they are better able to treat babies with SCID. Talk to your doctor about more tests as soon as possible.

What does this newborn screening result mean?

Your baby had routine newborn screening tests done to check for serious medical conditions. Your baby's test result showed low levels of immune cells which are used to fight infections. **Screening tests are a first step and are not a diagnosis.** A result that is not normal on the newborn screening test does not always mean that your baby will have SCID. The screening test also picks up other conditions associated with the immune system, but these are often not as severe as SCID. But it is very important to do the next test for your baby.

How do I find out if my baby has SCID?

Your baby will need another test to tell for sure if he or she has SCID or a different condition that may be causing a lack of immune system. If these tests

confirm that your baby does have SCID, your baby's doctor will likely connect you with a doctor who specializes in SCID. Babies with SCID need special care to stay as healthy as possible.

How do I keep my baby safe right now?

Because your baby may have little or no immune system, the most important thing to do right now is to keep your baby from getting sick.

To keep your baby from getting sick:

- Keep your baby away from other people, especially anyone who may be sick.
- Wash your hands before touching or being near your baby.
- Talk to your doctor about whether it is safe to breastfeed. Mothers sometimes carry a virus called CMV in their breast milk. Boiled water instead of bottled water should be used with formula. Bottled water may still contain some bacteria which could be harmful to your baby.
- Talk to your doctor about whether your baby should get certain vaccines. Do not have your baby or other people in the household get a live vaccine. Live vaccines carry a live, weakened part of a virus. A child with little or no immune system can get sick from a live vaccine. The COVID-19 vaccines are not live vaccines.

Where do I go for more information?

Visit scidcompass.org 

Email scidcompass@primaryimmune.org