

Family action sheet for severe combined immunodeficiency (SCID)

A newborn blood screening result shows that your baby could have a serious condition called **Severe Combined Immunodeficiency (SCID)** or a related condition. This result does not mean that your baby has one of these conditions, but more tests are needed.

All babies born in California have a routine blood screen shortly after birth. The goal of this newborn screening is to find those at risk for serious medical conditions. Babies can look healthy at birth and still have one of these conditions. Babies with these conditions benefit from early diagnosis and treatment.



Newborn screening takes blood from a newborn's heel to screen for medical conditions

What is severe combined immunodeficiency or SCID?

Babies with SCID are born with little or no immune system. They can get very sick from common illnesses like a cold or flu. There are several causes of SCID based on gene changes. Genes are inherited or passed down like hair and eye color from parents to babies. They make us who we are.

Babies with SCID may not have symptoms at first. Their mother's immune system may offer some protection. If left untreated, children with SCID can develop very serious infections.

Is there treatment for SCID?

Yes, there are treatments for SCID. If doctors find SCID early, treatment is more successful. A doctor who specializes in SCID will tell you if your baby has it and will discuss a treatment plan.



Next steps

- 1. Your baby's doctor's office will help arrange more testing as soon as possible**
 - ✓ These tests will let you know if your baby has SCID or a related condition.
- 2. Work closely with your baby's doctor's office and follow recommendations**
 - ✓ Your baby's doctor's office may refer your baby to a doctor with experience in SCID.
 - ✓ Your baby's doctor's office may give advice on how to keep your baby safe. This could include staying away from crowds, waiting to breastfeed and waiting to get live vaccines until further testing is done.

Where can I get more information?

Your baby's primary care doctor or SCID specialist is the best person to teach you about SCID. Find more information at these websites:

- [Baby's First Test](https://www.babysfirsttest.org) (https://www.babysfirsttest.org). Type "SCID" into the "Find a Condition" Box. Follow the link. For Spanish, click on the top right black box marked "en Español."
- [SCID Compass: Understanding SCID](https://youtu.be/-8jD-RnM9BM) (https://youtu.be/-8jD-RnM9BM). An animated video.

