Severe Combined Immunodeficiency (SCID)

(Sounds like SEVERE COMBINED IMMUNE-O-DE-FISH-IN-SEA OR SKID)



What is newborn blood spot screening?

This is a blood test, from a heel poke, that is done a day or 2 after babies are born to test for treatable conditions including severe combined immunodeficiency (SCID) that you, your doctor, or midwife can't see by just looking at your baby. This screening test is different from those done during pregnancy.



What does it mean if my baby needs more tests for SCID?

A baby needs to have more testing for SCID when their screening test result is abnormal or positive. This doesn't mean your baby has SCID. It means your baby has a higher chance of having the condition and will need more tests to find out if they have SCID or not.

It's normal to feel worried if your baby needs more testing. Your specialists and other healthcare providers are there to support you. They'll explain what will happen and answer your questions.

What is SCID?

SCID is a condition that affects your body's ability to fight infections. With SCID, some areas of your immune system don't work like they should. Your body can't fight enough germs to keep you from getting sick. When this happens, your body can get infections and sometimes they can be severe.

What causes SCID?

SCID is genetic. Babies have SCID when they are born with a change in genes of the immune system. SCID isn't caused by anything that happened during pregnancy.

There may be no signs of SCID at birth. It's important to remember that this condition can't be seen by looking at your baby.



What can I expect with more testing?

Everything that will happen with more testing will be explained to you. Your baby will need to have their blood tested to check if your baby has SCID.

This testing may be done at a clinic in Edmonton or Calgary that specializes in SCID.

What if more testing shows my baby has SCID?

If testing shows that your baby has SCID a specialized healthcare team will work with you to make a care plan for your baby. You and your baby will get the best care and support possible.

How is SCID treated?

Babies with SCID can get sick easier. Part of the treatment includes keeping your baby away from anyone that's sick. The SCID specialist will give you detailed instructions about how to manage your baby's health including any medications.

Is there anything I need to do before my baby has more tests?

To avoid germs:

- try to keep your baby away from crowded places
- keep your baby away from anyone who may be sick
- make sure hands are washed before anyone holds your baby





Severe Combined Immunodeficiency (SCID)



Be careful when you search for information on the Internet. Get information from trusted sources and learn where to find reliable information.

If you're ever concerned about your baby's health or need support for you or your family, speak with your family doctor, the specialized healthcare team, or call Health Link at 811.

To learn more about SCID visit <u>babysfirsttest.org</u> and enter enter SCID into Find a Condition, or scan this QR code.





Newborn blood spot screening is provided through the Alberta Newborn Screening Program (ANSP) within Alberta Health Services (AHS). The program helps your baby have the best start in life. Early screening for certain conditions makes sure your baby gets treatment when it can help the most.

To learn more about newborn screening visit ahs.ca/newbornscreening or scan this QR code.



N	0	te	S

This material is intended for general information only and is provided on an "as is", "where is" basis. Although reasonable efforts were made to confirm the accuracy of the information, Alberta Health Services does not make any representation or warranty, express, implied or statutory, as to the accuracy, reliability, completeness, applicability or fitness for a particular purpose of such information. This material is not a substitute for the advice of a qualified health professional. Alberta Health Services expressly disclaims all liability for the use of these materials, and for any claims, actions, demands or suits arising from such use.