

Sickle Cell Disease (SCD)

(Sounds like SICK-ILL CELL DIS-EASE)



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 sickle cell disease (SCD) 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 SCD?

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

SCD is a condition that affects how blood carries oxygen in your body. Red blood cells help carry oxygen from your lungs all through your body. With SCD, some red blood cells have a sickle shape that looks like a crescent. These sickle cells are very delicate and can get stuck moving through your body. Some parts of your body may not get enough blood and oxygen and this can cause serious health problems.

What causes SCD?

SCD is genetic. This means babies with SCD are born with a gene from both parents, which has a change in it. This change stops the gene from working properly. SCD isn't caused by anything that happened during pregnancy.

There may be no signs of SCD 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 for SCD.

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

What if more testing shows my baby has SCD?

If testing shows that your baby has SCD 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 SCD managed?

A baby with SCD will need to take medicine to help prevent infections. A specialized healthcare team will give you detailed instructions about how to manage your baby's health.

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

If your baby has a temperature of 38°C or higher or looks unwell, take your child to the emergency room before more testing is done.



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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 SCD visit babysfirsttest.org and enter SCD 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.



Notes
