Cystic Fibrosis (CF)

(Sounds like SIS-TIC FY-BRO-SIS)

What is newborn blood spot screening?

This is a test, from a heel poke, that is done a day or 2 after babies are born to test for treatable conditions including cystic fibrosis (CF) 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 CF?

A baby needs to have more testing for CF when their screening test result is abnormal or positive. This doesn't mean your baby has CF. It means your baby has a higher chance of having the condition and will need more tests to find out if they have CF or not. In many cases, babies are carriers of the CF gene but don't have the condition.

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.

You will get a phone call from a nurse to talk about more testing at a specialty clinic, called a pediatric cystic fibrosis clinic.

What can I expect with more testing?

A test called sweat chloride is used to find out if your baby has CF. This test measures the amount of sodium and chloride in sweat. People with CF have high amounts of sodium and chloride in their sweat. The test takes 20 to 40 minutes to complete. The results are usually ready in 3 to 4 hours.

Getting ready for this test includes making sure your baby is well hydrated before the test. Don't put any cream or lotion on your baby's skin on the day of the test. Bring a heavy blanket to help your baby keep warm during the test. A nurse will explain what will happen, and they'll answer any questions you may have before, during and after the test.

What if more testing shows my baby has CF?

If testing shows that your baby has CF 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.

Alberta Health Services

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Cystic Fibrosis (CF)

What is CF?

CF is a condition that causes thick, sticky mucous to build up in the lungs, digestive tract and other areas of your body. This causes problems with how your baby breathes and digests food.

What causes CF?

CF is genetic. This means babies with CF are born with a gene from both parents, which has a change in it. If only 1 gene gets passed down, the person is considered a carrier of the CF gene and doesn't have the condition. CF isn't caused by anything that happened during pregnancy.

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

What are some early signs of CF?

Your baby may:

- find it hard to feed well and gain weight
- have large, greasy and smelly stools

How is CF treated?

Every baby with CF is different. A team of CF specialists will work with you to make a care plan for your baby.

Taking care of your baby, if they have CF, **may** include:

- help clearing mucus from the lungs
- the use of digestive enzymes
- medicine for the lungs
- vitamins
- physical therapy

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 CF visit cysticfibrosis.ca, 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.

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