Spinal Muscular Atrophy (SMA)

(Sounds like SPAI-NUHL MUH-SKYUH-LR A-TRUH-FEE)



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 spinal muscular atrophy (SMA) 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 SMA?

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

SMA is a condition that affects the nerve cells that control your muscle movement. It causes muscle weakness, including weakness that gets worse over time (wasting). SMA affects your ability to crawl and walk. Over time, it may affect breathing and swallowing.

What causes SMA?

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

There may be no signs of SMA 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 may need to have a physical examination and their blood may be tested to check for SMA.

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

What if more testing shows my baby has SMA?

If testing shows that your baby has SMA 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 SMA treated?

A team of SMA specialists will give you detailed instructions about the SMA treatment available for your baby. This treatment will be specific to your baby's needs.





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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 SMA visit <u>babysfirsttest.org</u> and enter enter SMA 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		

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