

# Why does my baby need to be screened?



### Alberta's Newborn Metabolic Screening Program

**Newborn blood spot screening is a blood test that is done a day or 2 after babies are born.** Screening helps your doctor or midwife find out if your baby is at risk of having certain conditions that can't be seen by just looking at your baby. **These conditions are treatable.** When your baby is treated early, it can prevent health problems, improve your baby's health, and maybe even save your baby's life. This screening test is different from those done during pregnancy.

## Does my baby really need newborn blood spot screening?

Your baby may look and act healthy, but they could still have a treatable condition, even if there's no family history of one. Finding and treating these conditions early can help prevent health problems.

## What conditions does newborn blood spot screening look for?

This screening test looks for treatable conditions, including:

- Metabolic conditions that cause problems with how your body uses food to make and store energy.
- Endocrine conditions that cause problems with how your body makes hormones.
- Cystic fibrosis which causes problems with how you breathe and digest food.
- Sickle cell disease which affects your blood and causes damage to your heart, lungs, and kidneys.
- Severe combined immunodeficiency which affects your ability to fight infections.
- Spinal muscular atrophy which causes muscle weakness, including weakness that gets worse over time (wasting).
   Screening for spinal muscular atrophy is part of a 1-year pilot program starting in 2022.

For a complete list and more information about each condition, go to <u>myhealth</u>. <u>alberta.ca/Alberta/Pages/What-Conditions-Are-Screened-For.aspx</u> or scan this QR code.



#### What causes these conditions?

These conditions are often genetic. Usually babies are born with them when they inherit a gene, which has a change in it, from both parents. This change stops the gene from working properly. Sometimes the conditions can happen for no reason. The treatable conditions aren't caused by anything that happened during pregnancy and are not detected during prenatal tests.

There may be no signs of these conditions at birth. It's important to remember that many conditions can't be seen by looking at your baby.

### What happens during newborn blood spot screening?

The screening has 3 steps:

- 1. Collecting a few drops of blood.
- 2. Testing the blood for certain treatable conditions.
- Helping your baby get more tests and treatment if they need it.

#### When should this screening be done?

The best time to do the newborn blood spot screen is when your baby is between 24 and 72 hours old. It is important to find the conditions as early as possible.

Ideally, the blood spot collection happens at the hospital before your baby goes home. If it doesn't happen at the hospital, it will be done at a home visit, a clinic visit, or a lab in your community.





### How is my baby's blood collected for the screen?

Your baby's blood is collected quickly and safely. The healthcare provider doing the screening will:

- Poke your baby's heel using a small plastic object called a lancet.
- Collect a few drops of your baby's blood onto a blood spot card. Sometimes, another poke is needed to get the right amount of blood.
- 3. Put a cotton gauze on your baby's heel to stop the bleeding.

#### How can I help my baby during the heel poke?

You can help your baby by comforting them, keeping them warm, and holding them close against your skin. Feeding your baby during and after the heel poke often helps, too.

#### What happens after the screen is done?

The blood spot card is sent to the newborn screening lab in Edmonton for testing and the results become part of your baby's health record.

#### How will I find out my baby's results?

Your doctor or midwife will have the results by the time your baby is 2 weeks old. You can ask them about your baby's results.

A healthcare provider will contact you if your baby needs to have the screen done again or if your baby needs more tests.

#### What does a normal screen result mean?

A normal newborn blood spot screen means it's **very unlikely** that your baby has one of the conditions that was tested for.

#### What if my baby needs the screen done again?

Sometimes the newborn blood spot screen has to be done again to get clear results. This doesn't always mean that your baby has one of the conditions.

The screen may have to be done again if any of the following happen:

- There was a problem with the blood spot card, like missing information on the card, too little blood on the card, or blood not being put on the card correctly.
- There was a borderline screen result. This means the result did not give a clear answer and another screen is needed to get a clear result.
- Your baby was born too small (less than 2,000 grams) or too early (before 37 weeks) to properly detect some conditions. Another screen done after a few weeks will help make sure test result is clear.

When your baby needs to have the newborn blood spot screen done again, your public health nurse or midwife will arrange for another screen as soon as possible. The screen can happen at a home visit, a clinic visit, a lab in your community, or the hospital if you haven't brought your baby home yet.

#### What if my baby needs more tests?

Sometimes a baby needs to have more tests. This doesn't mean that they have one of the treatable conditions they were screened for. It means they'll need more tests to find out if they have the condition or not.

Testing is important because even though your baby looks and acts healthy, they could still have one of the treatable conditions. 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.

If your baby needs more tests, a specialist will contact you to explain what will happen next.

#### What if I have more questions?

- Talk to your public health nurse, doctor or midwife if you have any questions about your baby's health or newborn blood spot screening.
- Call Health Link at 811 to talk to a registered nurse 24 hours a day.
- Visit <u>ahs.ca/assets/info/hp/nms/if-hp-nms-additional-info.pdf</u>
  or scan this QR Code.



