



Why does my baby need to be screened?

Does my baby really need newborn blood spot screening?

- Newborn blood spot screening is the best way to find out if your baby has a treatable condition that you, your doctor or your midwife might not know about.
- Your baby may look and act healthy, but could still have a treatable condition.
- Your baby may have a treatable condition even if there's no family history of one.

What are the main steps of newborn blood spot screening?

- Newborn blood spot screening has 3 steps:
 - collecting a few blood drops from a heel poke
 - testing the blood spots for certain treatable conditions
 - helping your baby get more testing and treatment if they need it

What conditions does newborn blood spot screening look for?

- Newborn blood spot screening looks for treatable conditions that include:
 - metabolic conditions cause problems with how the body uses food to grow and develop
 - endocrine conditions cause problems with how the body makes hormones
 - cystic fibrosis, a condition that affects the lungs and digestive system
 - sickle cell disease, a condition that affects the blood and causes damage to heart, lungs, and kidneys
 - severe combined immunodeficiency, a condition that has serious effects on the immune system

When should the newborn blood spot screen happen?

- 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. That's so your baby can be treated right away to prevent health problems.

Where does the newborn blood spot screen happen?

- it's best if the newborn blood spot screen happens at the hospital before your baby goes home
- If the screen doesn't happen at the hospital, it will happen at a home visit, a clinic visit, or a lab in your community.

How is my baby's blood collected during the newborn blood spot 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.)
 - 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 keeping them warm, comforting them, and holding them close against your skin.
- Breastfeeding your baby during and after the heel poke often helps.

What are metabolic conditions and how are they treated?

- In metabolic conditions, the body can't break down some substances in food like fats, proteins, or sugars. Your baby needs these things to be healthy, to grow, and to develop.
- The substances build up in the body and may cause serious health problems.
- The treatment for metabolic conditions is often special diets or nutritional supplements.



Alberta's Newborn Metabolic Screening Program

Newborn blood spot screening helps your doctor or midwife find conditions that can be treated early to prevent health problems, improve your baby's health and maybe even save your baby's life.

What is Alberta's Newborn Metabolic Screening Program?

- Alberta's Newborn Metabolic Screening (NMS) Program is about health care providers working together with parents or guardians to screen for certain treatable conditions.
- Timely screening helps find conditions that can be treated early, when the treatment can help your baby the most.
- Alberta's NMS Program makes sure all screened babies who may have one of the treatable conditions get more testing and early treatment.





What are endocrine conditions and how are they treated?

- In endocrine conditions, the body can't make the right amount of hormones.
- Not having the right amount of hormones may cause problems with growing and developing.
- The treatment for endocrine conditions is giving hormones the body can't make itself.

What is cystic fibrosis and how is it treated?

- Cystic fibrosis is a condition that causes thick, sticky mucus to build up in the lungs, digestive tract and other areas of the body.
- This causes problems with how your baby breathes and digests food.
- The treatment for cystic fibrosis is medicine and physical therapy.

What is sickle cell disease and how is it treated?

- Sickle cell disease is a condition that causes red blood cells to have a crescent moon or sickle shape.
- Red blood cells with the sickle shape get trapped in blood vessels. This causes pain, damages tissue, and causes red blood cells to break down too early.
- The treatment for sickle cell disease is antibiotics, immunizations, and care for fevers.
- Newborn blood spot screening will detect babies who carry the sickle cell trait but who don't have sickle cell disease.

What is severe combined immunodeficiency and how is it treated?

- Severe combined immunodeficiency causes serious problems with the immune system, so the body can't fight off germs.
- When the immune system doesn't work well, a person can get serious, life-threatening infections.
- The treatment for severe combined immunodeficiency is giving antibiotics before an infection happens and keeping the person away from any germs (isolation) to prevent infections.

How is my baby's privacy protected within Alberta's NMS Program?

- Health information is collected, used and shared (disclosed) by following the laws of Alberta's *Health Information Act*.
- Your baby's health information is protected in a secure, private and confidential place as required by the *Health Information Act*.

What happens after the newborn blood spot screen is done?

- After the newborn blood spot screen is done, the card goes to the Newborn Metabolic Screening Lab in Edmonton for testing.
- The results become part of your baby's health record. Your baby's doctor or midwife and birth hospital will get the results.

How will I find out my baby's newborn blood spot screen results?

- Your doctor or midwife will have the results by the time your baby is two weeks old.
- You can talk to your doctor or midwife about your baby's results.
- If your doctor or midwife does not contact you about your baby's blood spot screen results, it means the results are normal.

- Your public health nurse, doctor or midwife will contact you if your baby needs to have the screen done again.
- Your doctor, midwife or a specialist will contact you if your baby needs more tests.

What will the newborn blood spot screen results show?

- Newborn blood spot screen results show
 - if your baby's screen is normal
 - if your baby needs to have the screen done again
 - if your baby needs more testing to find out if they have one of the treatable conditions

What does a normal newborn blood spot screen result mean?

- A normal newborn blood spot screen means it is **very unlikely** your baby has one of the treatable conditions.
- Your baby does not need the screen done again.

What does it mean if my baby needs to have the newborn blood spot 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 treatable conditions.
- Your public health nurse or midwife will arrange for another screening to happen as soon as possible.

What does it mean if my baby needs more tests?

- If your baby needs to have more tests, it doesn't mean that they have one of the treatable conditions. It means your baby has a higher chance of having one of the treatable conditions, and your baby needs more tests to find out for sure.
- If your baby needs more tests, a specialist will contact you to explain what will happen.
- If the tests show that your baby does have a treatable condition, they'll get the support they need to live a healthy life. They may also need a change in diet and may need to take special medicine.

What else can I do to take care of my baby?

- Screening only looks for certain treatable conditions. It doesn't check for any other health problems. So it's important that your baby sees a doctor, midwife, or public health nurse regularly.
- If you're worried about the way your baby is growing or if you think your baby isn't well, contact your doctor, midwife, public health nurse or Health Link.
- And always be sure to take good care of yourself, so you can care for your baby.

What if I have more questions about newborn blood spot screening and Alberta's NMS Program?

- Talk to your public health nurse, doctor or midwife for more information.
- Visit: www.ahs.ca/newbornscreening
- If you need health advice or information call Health Link 24/7 by dialing 811

