Newborn Screening
Free health checks for your baby

Your newborn baby's blood test



The Newborn Metabolic Screening Programme

All babies are checked at birth to see that all is well. Some of your baby's health checks are called 'screening'.





The Newborn Metabolic Screening Programme

The Newborn Metabolic Screening Programme detects rare but life-threatening disorders with a blood test done at 24 hours old or as soon as possible after this. Since 1969, almost all babies in New Zealand have had this screening. Early diagnosis means that treatment can start quickly, before the baby becomes sick. These disorders are hard to find without screening.

Why screen for these disorders?

Screening saves lives. Each year, about 60 New Zealand babies are found to have a disorder through screening. Although these disorders cannot be cured, early treatment with medication or a special diet can help your baby stay well and prevent severe disability or even death.

These disorders can occur in any family, even when there is no family history of disorders. Screening is an important way of identifying babies who are more likely than other babies to have a disorder.



Who is newborn screening for?

Newborn screening is offered free for babies born in New Zealand. Your midwife or doctor will talk with you during pregnancy about screening for your baby.

Health New Zealand | Te Whatu Ora strongly recommends screening for your baby.

How is the blood sample collected?

The blood sample is collected from your baby's heel onto a blood spot card. The blood spot card is sent to the laboratory for testing. For the most accurate test results, the sample should be collected when your baby is 24 hours old or as soon as possible after this.





It is your decision to have your baby screened. When your baby has screening, you also decide whether the leftover blood spots are stored or returned to you after screening.

Test results

Your midwife or doctor will receive your baby's results and tell you what they are. This will be within 10 days if the results are normal. If any result is abnormal, the laboratory will notify your midwife or doctor as soon as possible.

Why is another blood sample sometimes needed?

Another blood sample may need to be taken if the first test result is not clear. If another sample is needed from your baby, your midwife or doctor will tell you why.

It is important that the new sample is taken as soon as possible so that your baby completes screening.

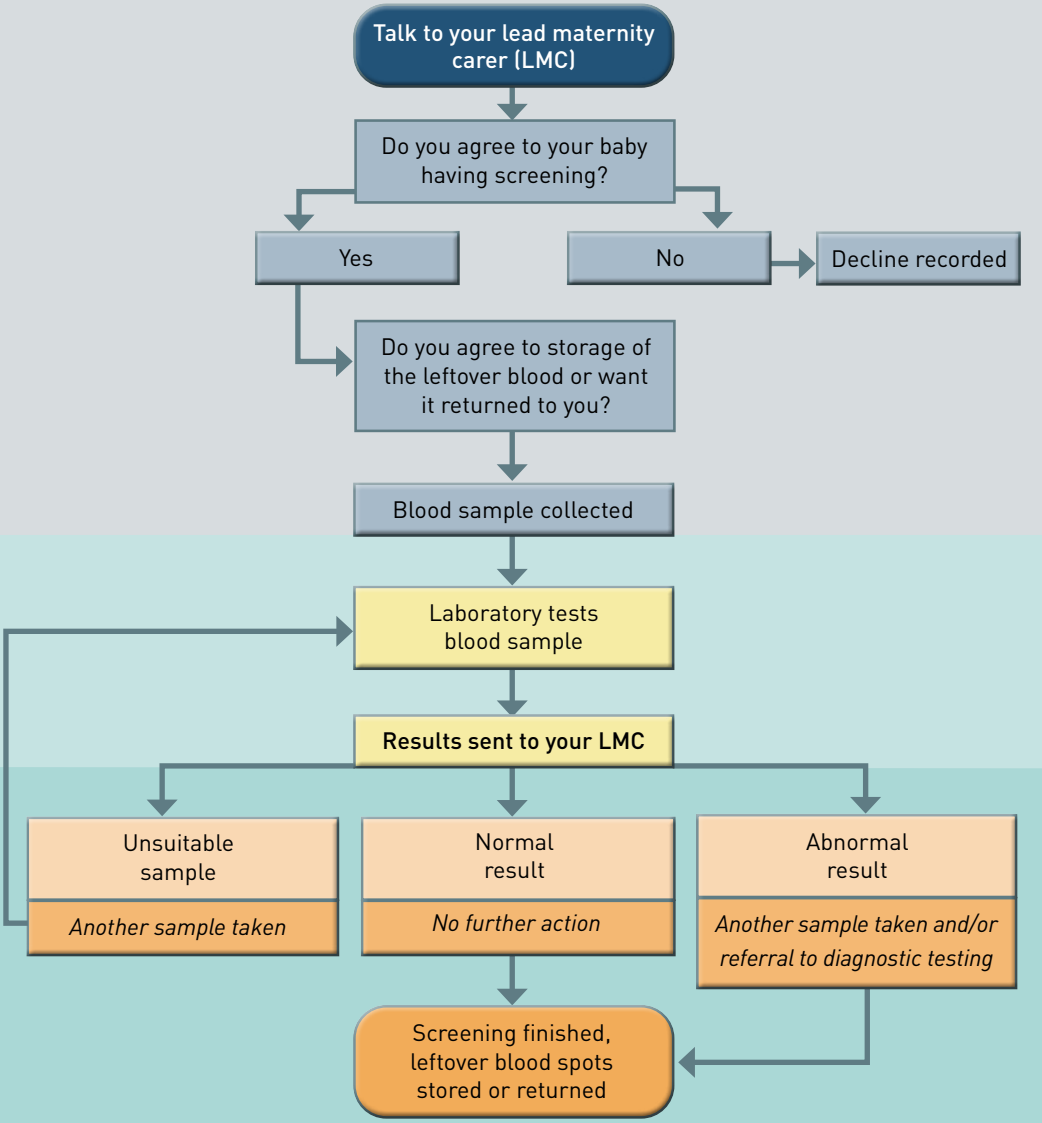


What if my baby has an abnormal result?

If your baby has an abnormal screening result, a further sample and/or referral to a specialist may be required. The specialist will examine your baby and order diagnostic testing to confirm whether your baby has a disorder or not. It is important to complete the diagnostic testing as soon as possible so that if your baby has a disorder, treatment can start straight away.

Screening identifies almost all babies with the disorders tested for. There is a small chance that some babies may be missed or a screening result will be abnormal for a baby who does not have a disorder.

The newborn metabolic screening process



What if my baby hasn't been screened?

If your baby is more than three days old and you don't think he or she has been screened, talk to your midwife or doctor.

Storage and use of leftover blood spots

Any blood left over after screening is either securely stored or returned to you. Blood is stored to assist with maintaining a high-quality screening programme and for other uses.

What can the stored blood spots be used for?



The stored blood spots may be used:

- for repeat testing. If your baby has a disorder but did not have an abnormal test result, the blood sample can be tested again to see why this happened.
- to improve the screening programme, such as by making sure that testing equipment produces accurate results.
- to develop tests for new disorders approved to be screened for in New Zealand but are not yet part of routine screening. If any results are abnormal, you will be contacted by a paediatrician and supported to access further care if needed.
- for research approved by an ethics committee and Health New Zealand | Te Whatu Ora.
- to investigate a death or illness in your family.
- to monitor the screening programme for quality assurance purposes.

The stored blood spots will not be used for anything else without written consent from the parents or guardians or from another lawful authority, such as if ordered by a court. More information is available at healthnz.govt.nz/heel-prick-test

How do I get leftover blood spots returned to me?

You can ask your midwife or doctor to arrange for the leftover blood spots to be returned to you by sending a signed request with the blood spot card. Alternatively, leftover blood spots can be requested at any time using the form 'Return of Newborn Metabolic Screening Samples' available at info.health.nz/pregnancy-children/pregnancy-newborn-screening/heel-prick-test



What information is collected and how is it used?

As part of the newborn metabolic screening programme, basic information about your baby is collected and stored. This includes your baby's name and address, sex, ethnicity and weight, and where and when your baby was born. Your name is also recorded. The programme holds this information securely and confidentially.

The information is used to:

- interpret screening results
- make sure that results can be given to your midwife or doctor
- check that babies have been screened
- monitor the screening programme.

Health New Zealand | Te Whatu Ora collects information for monitoring and evaluation of the screening programme. Your decisions about screening will be recorded in your maternity and Well Child Tamariki Ora notes. If you choose not to have your baby screened, you will also be asked if this information can be sent to the screening programme.

What are my rights?

The Code of Health and Disability Services Consumers' Rights protects your rights. You can read more about these rights at hdc.org.nz

The Health Information Privacy Code protects your privacy. You can read about the code at privacy.org.nz



What disorders are babies screened for?

Babies are screened for over 20 treatable disorders. A full list of the disorders is available at info.health.nz/pregnancy-children/pregnancy-newborn-screening

Amino acid disorders, for example, phenylketonuria (PKU)

Caused by a missing enzyme. Without these enzymes, amino acids (such as phenylalanine) rise to harmful levels

Can lead to brain damage and life-threatening complications

Treated by special diet

Occurs in about 5 babies every year

Fatty acid oxidation disorders, for example, medium chain acyl-Co A dehydrogenase (MCAD) deficiency

Caused by a missing enzyme. Without these enzymes, the body cannot break down fats to make energy

Can lead to life-threatening complications

Treated by ensuring regular feeding (a special diet is needed in some disorders)

Occurs in about 5 babies every year

Congenital hypothyroidism

Caused by not enough thyroid hormone

Can lead to slowed growth and developmental delay

Treated by thyroxine

Occurs in about 20 babies every year

Cystic fibrosis (CF)

Caused by a defective gene and its protein product, leading to thick, sticky mucus

Can lead to poor growth, chest infections and shortened life

Treated by high-calorie diet, medicines and physiotherapy to keep the lungs healthy

Occurs in about 8 babies every year

Congenital adrenal hyperplasia (CAH)

Caused by lack of an enzyme in the adrenal gland

Can lead to life-threatening complications

Treated by steroid medication

Occurs in about 3 babies every year

Spinal muscular atrophy (SMA)

Caused by a defective gene leading to loss of motor nerves

Can lead to life-threatening complications including muscle weakness, difficulties in breathing and swallowing

Treated by specific medicines to preserve muscle and nerve function

Occurs in about 6 babies every year

Biotinidase deficiency

Caused by lack of an enzyme, leading to a deficiency of biotin

Can lead to life-threatening complications

Treated by taking vitamin H (biotin)

Occurs in about 1 baby every 3 years

Galactosaemia

Caused by an enzyme defect that prevents normal use of milk sugar

Can lead to jaundice, cataracts and life-threatening illness

Treated by special diet including replacement of milk-containing foods

Occurs in about 1 baby every 2 years

Severe combined immune deficiency (SCID)

Caused by lack of cells that are essential for immunity

Can lead to life-threatening complications

Treated by antibiotics, isolation precautions and bone marrow transplant

Occurs in about 1 baby every year

The Newborn Metabolic Screening Programme is committed to the highest possible standards. To maintain the quality of the programme, disorders screened for are reviewed and the programme is closely monitored. Further details are available at info.health.nz/pregnancy-children/pregnancy-newborn-screening

More information

It is important that you have enough information to help you decide about newborn screening.

If you would like more information

- ask your midwife or doctor
- check healthnz.govt.nz/heel-prick-test for:
  - a video about newborn screening
  - information on any new disorders being introduced to the screening programme

The Newborn Metabolic Screening Programme is overseen by Health New Zealand | Te Whatu Ora.

This resource is available at healthed.govt.nz or the Authorised Provider from your local health district.

Health New Zealand
Te Whatu Ora

New Zealand Government
Te Kāwanatanga o Aotearoa

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