

What does the testing look for?

The newborn testing looks for 30 plus rare disorders that can cause health problems in babies and children.

Disorders screened:

When the body is not able to break down (metabolize) certain substances in food like fats, proteins or sugars, they can accumulate in the body and cause serious health problems.

- Organic Acid Disorders
- Fatty Acid Oxidation Defects
- Amino Acid Disorders

Others like:

- Congenital hypothyroidism
- Cystic fibrosis

Want to learn more?

For more information about newborn screening in Saskatchewan, speak to your health care provider, or visit <https://www.saskhealthauthority.ca/Services-Locations/RRPL/Pages/Screening-and-Reference-Services.aspx>

Please note that you have the right to refuse newborn screening. If this is your wish, ask your health care provider for a refusal form.



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saskhealthauthority.ca

NEWBORN SCREENING

A healthy start leads to a healthier life



Healthy People, Healthy Saskatchewan

Getting the best start

As a new or expecting parent, you place great importance on your baby's health. To ensure that your baby gets the best start in life and stays healthy, your newborn — and every other newborn in Saskatchewan — will be screened for at least 30 plus rare disorders.

Although most babies with these disorders look healthy at birth, they may be at risk of having serious health problems — including developmental disabilities, recurrent sickness and even death — if their disorder is not detected and treated. Early identification is the key to effective treatment.

Early detection leads to early treatment

Individually, these disorders are very rare. As a group, they will affect about eight to 12 out of approximately 16,000 babies born each year in Saskatchewan. By testing newborns within the first days of their lives, many disorders can be treated early, reducing the chance of serious health problems later in life.

This brochure will provide you with information about newborn screening in Saskatchewan and answer questions that you may have about the newborn screening test.

A small test producing big benefits

In order to perform the screening tests, a small sample of blood is taken from your baby by pricking the heel. The blood is collected on a special paper card and then sent to Roy Romanow Provincial Laboratory (RRPL) for testing. Blood samples can be taken any time between one day (24 hours) and seven days after your baby is born. The best time to collect the blood sample is when your baby is between two days (48 hours) and three days (72 hours) old. If your baby is tested before one day (24 hours) of age, your baby's health care provider should **repeat** the test within five days, at the baby's first check-up.

Screening results: high risk and low risk

A screening test only shows where there is a high or low risk that your baby has a disorder. It is important to understand that the test does not make a diagnosis of a disorder, but only identifies babies who need further testing.

Once RRPL has received and analyzed your baby's blood sample, one of the following will occur:

1. Your baby screens negative for all the disorders

RRPL will send a report by mail to your hospital and/or health care provider. It will be filed in your baby's medical records.

More than 99 per cent of babies screened will receive a "screen negative" result. This means there is a very low risk that your baby has one of these rare disorders. On very rare occasions, the newborn screening test may miss a baby with one of these disorders.

2. RRPL may need another blood sample

It may be that the first sample was not taken properly, there wasn't enough blood to complete the testing, or there was some other problem with the sample. In this case, your baby's health care provider will contact you and arrange for another blood sample to be taken as soon as possible.

3. Your baby screens positive for one of the conditions

A screen positive **does not necessarily mean** that your baby has a disorder, but only that further testing is needed. Your baby's health care provider will contact you right away to make arrangements for follow-up at a hospital where specialists can do further testing. If a diagnosis of a disorder is made, the hospital will provide your baby with treatment and your family with counselling and advice.

RRPL also issues a report by mail to your hospital and/or health care provider, which will be filed in your baby's medical records. It is important to remember that less than one per cent of babies tested will receive a "screen positive" result.