

Newborn Screening:

A healthy start leads to a healthier life

Getting the best start

As a new or expecting parent, your baby's health is important to you. To ensure that your baby gets the best start in life and stays healthy, your newborn – and every other newborn in Ontario – will be screened for at least 27 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 50 out of approximately 130,000 babies born each year in Ontario. By testing newborns within the first days of their lives, disorders can be treated early, reducing the chance of serious health problems later in life.

This fact sheet will provide you with information about The Ontario Newborn Screening Program, which will be rolled out in 2006 and answer questions that you may have about the newborn screening test.

A small test, producing big benefits

In order to perform the screening test, 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 the Newborn Screening Program Laboratory for testing. Blood samples can be taken anytime 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 checkup.

Screening results: high risk and low risk

A screening test only shows whether 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 the Newborn Screening Program Laboratory has received and analyzed your baby's blood sample, one of the following will occur:

1. Your baby screens negative for all the disorders. The Newborn Screening Laboratory 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% 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. The Newborn Screening Laboratory 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 counseling and advice.

The Newborn Screening Laboratory 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 1% of babies tested will receive a "screen positive" result.

What does the testing look for?

The testing done for the Ontario Newborn Screening Program looks for at least 27 rare disorders that can cause health problems in babies and children.

These disorders are:

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

Endocrine disorders: The endocrine system, which is responsible for producing hormones, can sometimes produce too much or too little of some hormones, leading to sickness or developmental disabilities.

Blood disorders: Oxygen is carried through the body in the hemoglobin found in red blood cells. If hemoglobin is not formed or not working properly, red blood cells break down, leading to health problems including severe anemia and serious infections.

Want to learn more?

For more information about the Ontario Newborn Screening Program, speak to your doctor or midwife. Call 1-866-532-3161 (TTY 1-800-387-5559) or visit www.health.gov.on.ca/newbornscreening