

Newborn Screening Test

Why is my baby screened?

A small spot of your baby's blood can be used to get important information about his or her health. A newborn baby can look healthy but have a rare and serious disorder that you and your doctor or midwife may not know about. Newborn screening finds babies who may have one of these rare disorders. Finding and treating these disorders early prevents or reduces serious health problems. If not treated, many of these disorders can cause severe mental handicap, other health problems and sudden infant death.

In B.C., there are about 55 babies born each year (1 out of every 1000) who are found to have one of these disorders.

What will my baby be tested for?

Your baby will be tested for 24 rare but treatable metabolic disorders, endocrine (hormone) disorders, blood disorders and Cystic Fibrosis. For more information on these tests, visit Perinatal Services BC <http://www.perinatalservicesbc.ca/our-services/screening-programs/newborn-screening-program/>.

How is my baby screened?

A small blood sample is taken by a simple heel prick, usually before discharge from hospital. This will only cause a moment of discomfort for your baby. The blood sample is sent to the laboratory at BC Children's Hospital for testing. Cord blood should not be used as it could be contaminated with the mother's blood.

How soon after birth will my baby be tested?

The ideal time to collect the newborn screening blood sample is between 24 and 48 hours after birth.

If you are under the care of a midwife and your baby is not born in the hospital, your midwife will collect the blood sample during a home visit.

What if I go home with my baby less than 24 hours after birth?

A blood sample will still be taken in the hospital before leaving. Screening detects over 80% of disorders at even less than 24 hours of age. Early detection is important if your child has one of these disorders. You will get instructions on how to have the sample repeated within 2 weeks. The purpose of the second sample is to double check the few disorders that can be missed on the first (early) screen.

Can I wait and have my baby tested later?

The earlier these treatable disorders are found, the better the outcome for babies with these disorders. It is strongly advised that your baby has a blood sample taken before leaving the hospital. You will need to sign a form if you decide you do not want your baby to have a blood sample taken before hospital discharge, and plan to have the blood sample taken later. This form shows you understand the reasons for the test and the possible outcomes for your baby if tested too late or not at all.

How do I find out the results of the screening?

Your baby's screening results are reported to your baby's doctor or midwife.

What does it mean if the screen is negative?

A negative screening test result means that the chance your baby has one of the 24 disorders is very low. It is rare that the test does not pick up a disorder in a baby.

What does it mean if the screen is positive and what happens next?

A positive screen means that there might be a problem. It does not mean that your baby has one of these disorders, but it is possible. Your baby will need more tests to find out for sure.

If your baby has one of these conditions, early detection will help your baby get effective treatment as soon as possible. You will be referred to a doctor with experience in treating these disorders.

What happens to my baby's blood sample (blood spot card) when the testing is complete?

The BC Newborn Screening Program keeps your baby's blood spot card with the leftover blood for 10 years in secure storage. Occasionally, the dried blood spot samples

may be used for other purposes after the testing is finished. These include:

- Re-running a test if the first test result was not clear
- Trying to find the reason for a health problem that has developed later in a child's life or trying to find the cause of an unexplained illness or death of a child
- Checking the quality of testing done by the laboratory to make sure that results are accurate
- Developing better tests for screening of disorders

Samples may also be used for health research if the research has been approved by a Clinical Research Ethics Board. In these cases, all information that may identify the baby is removed.

If you do not wish your baby's stored blood spot card to be used for these purposes, you may fill out a form called a "Directive to Destroy Leftover Newborn Screening Blood samples" and send it to the BC Newborn Screening Program. Visit <http://www.perinatalservicesbc.ca/our-services/screening-programs/newborn-screening-program/> for details.