

# NEWBORN SCREENING BC

## Blood spot card screening | Parent information sheet

### A simple blood test could save your baby's life



#### 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 a number of these rare disorders. When these disorders are found and treated early, the chances of serious health problems are prevented or reduced later in life. If not treated, these disorders can cause severe developmental delay, health problems and sudden infant death.

In British Columbia there are about 60 babies born each year (1 out of every 750) who are found to have one of these rare disorders.

#### How is my baby screened?

Your baby's heel is pricked and a few drops of blood are taken and put onto a special card. Your baby may cry, but taking the blood sample does not harm your baby. You can help comfort your baby by holding and breastfeeding her or him while the blood is being taken. The blood sample is sent to the laboratory at BC Children's Hospital for testing. The same blood sample is used to screen for all the disorders described on page 2.

#### How soon after birth will my baby be screened?

The blood sample is usually taken between 24 and 48 hours after birth. This will be done before your baby leaves the hospital, or by your midwife at home if you have a home birth.

#### What if my baby goes home before 24 hrs of age?

A blood sample will still be taken in the hospital before leaving. Over 80% of these disorders can be screened using this blood sample. You will be given 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 not leave the hospital without a blood sample being taken. If you decide you do not want your baby to have a blood sample taken before he or she leaves the hospital, you will be asked to sign a form to show you understand the reasons for the test and the possible outcome for your baby if your baby is not tested and has one of these disorders. If your baby is under the care of a Registered Midwife, the midwife may review options with you to have the blood sample drawn at home.

#### 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 screen means that the chance that your baby has one of these disorders is very low. Very rarely, the test may miss a baby with one of these disorders.

#### 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. More tests are needed to find out for sure.

## Which disorders are included in Newborn Blood Spot Card Screening?

In British Columbia, babies are screened for more than 25 rare but treatable disorders. These include:

### Metabolic disorders

These occur when the body is not able to break down (metabolize) certain substances in food like fats, proteins or sugars. These substances can build up in the body and cause serious health problems. These problems can usually be prevented with early treatment.

### Endocrine disorders

Babies with endocrine disorders of either the thyroid or adrenal glands make too little of certain hormones. Babies with these disorders can receive hormones to replace the ones their bodies cannot make. Replacement of thyroid hormone prevents growth problems and intellectual disability/developmental delay. Replacement of adrenal gland hormones can prevent serious health problems such as shock or unexpected death. Endocrine disorders are the most commonly identified group of conditions on the newborn blood spot screening panel.

### Blood disorders

Blood disorders such as sickle cell disease happen when the part of the red blood cell that carries oxygen (hemoglobin) throughout the body is changed. Hemoglobin is important because it picks up oxygen in the lungs and carries it to the other parts of the body. Serious health problems can be prevented through medicines and special treatments.

### Cystic Fibrosis

Cystic fibrosis (CF) is an inherited disorder that causes thick mucus to build up in the lungs and may affect the digestive system. Most people with CF get frequent chest infections and may have problems digesting food which can result in slow weight gain. Treatment is provided to help with growth and reduce the risk of lung infections.

### Spinal Muscular Atrophy (SMA)

SMA affects the nerves that control muscle movement. Babies and children with SMA may have difficulty with swallowing, crawling, sitting, or walking. Treatment can slow or even stop some of these problems.

### Severe Combined Immunodeficiency (SCID)

SCID affects a baby's immune system and makes it hard to fight against infections or germs. Early treatment can greatly improve overall health.

## What if the results show that my baby has one of the disorders after all the tests are done?

Your baby will need treatment from a doctor who specializes in the disorder. You will be referred to a specialist right away. Treatment can start in a few days.

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

Your baby's card with the leftover blood will be kept 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

- (1) re-running a test if the first test result was not clear;
- (2) 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;
- (3) checking the quality of testing done by the laboratory to make sure that results are accurate; and
- (4) 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. See website for details.

## If you need more information:

Talk to your doctor or midwife. Visit the Newborn Screening website at [www.newbornscreeningbc.ca](http://www.newbornscreeningbc.ca).

### We are committed to protecting the privacy of personal information:

Newborn Screening BC collects, uses and discloses personal information only as authorized under section 26 (c) of the BC Freedom of Information and Protection of Privacy Act and other legislation. We take all reasonable steps to make sure personal information is treated confidentially, is used only for the intended purpose and securely stored. For questions regarding collection, use or disclosure of your baby's personal information, please contact the Medical Director, Newborn Screening at 604-875-2148 or business address:

**BC Children's Hospital Newborn Screening Laboratory,  
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