BC NEWBORN SCREENING PROGRAM

Why is my baby screened?

A blood test can be used to get important information about his or her health. A newborn baby can look healthy but have a rare disorder that you and your doctor or midwife may not be able to detect with regular postpartum care. Newborn screening detects these babies who may have one of a number of 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 mental developmental, growth problems, health problems and sudden infant death.

How is my baby screened?

Your baby's heel is pricked and a few drops of blood are put onto a special card. You baby may cry and fuss a little but taking the test does not harms your baby. You can hold your baby or breastfeed while the test is being done. The blood sample is sent to the newborn screening laboratory at BC Children's Hospital for testing. The same blood sample is used to screen for all disorders.

How soon after birth will my baby be screened?

The blood is usually taken between 24-48 hours after birth. This is usually done before your baby leaves the hospital, however, if you have an early discharge or a home birth it may be done by your midwife at home.

Can the baby be tested later?

The earlier these treatable disorders are found, the better the outcome for babies with these disorders. If you decide to make an informed refusal you will be asked to sign a form that you understand the reasons for the test and the possible outcome if the baby is not tested and treated. As there is no risk to the baby and is it strongly recommended to have the test done.

How do I find out the results of the screening?

Your baby's screening results are reported to the hospital where the baby was born and your baby's midwife or doctor. Your midwife will advise you of the results.

What does it mean if the test is negative?

A negative screen means that the chance of 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 tells that there might be a problem. It does not mean that the baby has one of these disorders, but that it is possible. More tests are needed.

Will screening for these disorders find anything else?

Screening for sickle cell disease and cystic fibrosis may also tell if your baby is a carrier for one of these disorders. Babies who are carriers are healthy and no more likely to get sick than any other baby. If your baby is a carrier, you will be provided with more information to find out what this means for your baby, yourself and your family.

Which disorders are included in the Newborn Screening?

In British Columbia babies are screened for 19 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. Serious ingoing health problems can be prevented with early treatment.

Endocrine Disorders: Babies with endocrine disorders of either the thyroid or adrenal glands make too little of certain hormones to t replace the ones their bodies cannot make. Replacement of thyroid hormone prevents growth problems and mental handicap. Replacement of adrenal gland hormones can prevent serious health problems such as shock or unexpected death.

Blood Disorders: Blood disorder happen when the part of the red blood cell that carries the 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 is an inherited life-limiting disorder. It causes thick mucous to build up in the lungs, digestive system (and pancreas) and other organs. Most people with CF get chest infections. They also have problems digesting their food and as a result, they may not gain weight as well as they should. Early treatment can be started with medicines and physical therapy that help babies with cystic fibrosis digest food and keep lings clear of mucous. CF affects about 1 in every 3,600 babies in BC.

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

Babies who have any of these disorders will need treatment from a doctor who specializes in the disorder. Babies are referred to a specialist right away. Treatment can start in a few days.

For more information: www.newbornscreeningbc.ca