

Information for Parents and Caregivers about Newborn Screening

A simple blood test could save your baby's life

∞ Why is my baby tested?

A simple, quick blood test gives important facts about your baby's health. A newborn baby can look healthy, but have a rare and serious disorder that you or your doctor or midwife may not know about. The newborn screening test identifies those babies who may have one of a number of rare disorders. If not treated, these disorders can cause mental handicap, blindness, liver problems, brain damage or even death.

∞ Why is it important to find these disorders early?

When these disorders are found and treated early, illness from these disorders can usually be prevented.

∞ Which disorders are included in the Newborn Screening Test?

In British Columbia, all babies are tested for Hypothyroidism, Phenylketonuria (PKU), Galactosemia and Medium Chain Acyl-CoA dehydrogenase deficiency (MCAD). Read the other side for more details about these disorders and their treatment.

∞ How will my baby be tested?

A few drops of blood are taken from the heel of your baby's foot. The same blood sample is used for all tests.

∞ When is the best time to test my baby?

Hypothyroidism and Galactosemia can be detected by the blood test any time after birth. The earlier these treatable disorders are found, the better the outcome will be for your baby. The blood test for PKU and MCAD may not give true results if done less than 24 hours after birth.

∞ How soon after birth will my baby be tested?

Your baby is tested between 24 and 48 hours after birth. The test is usually done before your baby leaves the hospital.

∞ **What if I go home before my baby is 24 hours old?**

If your baby goes home before 24 hours old, your doctor/midwife will arrange for your baby to have the blood test after you go home. The test must be done before the baby is 7 days old.

∞ **What does a positive blood test mean?**

If the test comes back positive, your doctor/midwife will call you so more in-depth testing can be done. You will be referred to a doctor who specializes in these disorders.

Newborn Screening in British Columbia includes tests for the following disorders:

∞ **Hypothyroidism**

A baby born with hypothyroidism cannot make enough thyroid hormone. Thyroid hormone keeps a baby's body growing strong and healthy. Without it, delayed growth and brain damage occur. By finding this disorder early and treating it with thyroid hormone, these children have normal growth and intelligence. One baby in 3,500 is born with hypothyroidism.

∞ **Phenylketonuria or PKU**

A baby with PKU is missing an enzyme that is needed for her or his body to use the essential amino acid phenylalanine, found in certain foods. Without treatment, phenylalanine builds up in the baby's blood and causes mental handicap. If PKU is found early, the baby is fed a special diet that is low in phenylalanine. Most children with PKU who are treated early have normal intelligence. One baby in 15,000 is born with PKU.

∞ **Medium Chain Acyl-CoA Dehydrogenase Deficiency (MCAD)**

A baby born with MCAD may have problems using fats stored in their body for energy. The baby is healthy when eating well. If the baby has a cold or the flu he or she may not be able to use the stored fatty acids as energy. There is a risk of sudden unexpected death which can be prevented by using a special diet and not fasting. One baby in 20,000 is born with MCAD.

∞ **Galactosemia**

If a baby has this condition, her or his body cannot use galactose, a sugar found in milk. If galactosemia is not treated, it can cause damage to the baby's eyes, liver, and brain. These problems are prevented with a special diet. One baby in 60,000 is born with galactosemia.