Newborn screening could save your BABY'S life

Newborn Screening In Hawaii

What?

Newborn metabolic screening is a special blood test that can find rare genetic disorders that could cause serious health and development problems, and even death, if not treated early.

Who?

Every baby born in the State of Hawaii should be offered newborn screening. State law requires hospitals, attending physicians, and midwives to collect a screening specimen on every baby born in the State of Hawaii. You may refuse to have your baby tested if it is against your religious beliefs. Parents and guardians of the baby who refuse the test must sign a refusal form.

When?

If your baby is born in a hospital, the newborn screening blood test should be done before your baby leaves the hospital, usually at 1-2 days of age. If your baby is tested before 24 hours of age, a second test should be done as soon as possible before your baby is 7 days of age.

If your baby is born at home, your baby should be tested before 7 days of age, preferably between 1-3 days of age.

How?

A few drops of blood from your baby's heel are put on a special filter paper. This filter paper is allowed to dry and is then sent to the Washington Newborn Screening Laboratory. Your baby's blood is tested for 35 disorders which can cause serious health problems if not treated early.

For More Information About Newborn Metabolic Screening

Tel: (808) 733-9069
or go to our websites at:

- health.hawaii.gov/genetics/programs/nbshome/
- www.newbornscreening.info

Disorders identified by newborn screening

- Congenital Hypothyroidism
- Phenylketonuria (PKU)
- Cystic Fibrosis (CF)
- Galactosemia
- Biotinidase Deficiency
- Congenital Adrenal Hyperplasia
- Hemoglobinopathies
- Amino Acid (Protein) Disorders
- Organic Acid Disorders
- Fatty Acid Oxidation Disorders
- Urea Cycle Disorders
- Severe Combined Immunodeficiency
- Lysosomal Storage Disorder

For a detailed list of disorders on the Hawaii newborn screening panel, visit the program website.

Is the blood test safe for my baby?

Yes, the blood test is safe. Your baby will experience no additional physical discomfort beyond the heelstick normally done for newborn screening. The risk of infection is very low.

What about test results?

Ask your baby's doctor for the test results. If your baby needs more testing, it is important to act quickly. If needed, treatment should be started as soon as possible.

How much does this test cost?

The current cost of the newborn screening test for 35 disorders is $99.00. Most health insurance plans pay for the newborn screening test. If you do not have insurance or cannot afford the cost of the test, please call the Hawaii Newborn Metabolic Screening Program at (808) 733-9069 and we can help you.

What happens if my baby's test results are positive or unusual?

Your baby's doctor will be contacted by the Newborn Metabolic Screening Program if there are any positive or unusual test results. He/she will contact you about the test results.

A positive or unusual result does not always mean that a disorder is present. This screening test finds babies who may be at risk for a disorder. More tests are needed to find out if your baby really has a disorder. If you are asked to have your baby tested again, please do it as soon as possible.

There is also a chance that these rare disorders could be missed by this test since it is only a screening test.

How are these disorders treated?

Each disorder is different. Some disorders are treated with special diets and other disorders are treated with medications. If treated early, infants may grow up to lead a healthy and normal life. In a few cases, the disorder may not be completely treatable. The early diagnosis and treatment of the disorder will allow your baby the best chance of normal growth and development.

What if I move?

It is important to let your doctor know if you have a new address or phone number. This information is important if your baby needs further testing or treatment.