

Newborn screening could save your



Newborn Screening Tests Hawai'i

Why?

A special blood test can find rare disorders that can cause serious health, developmental problems and even death, if not treated early.

Who?

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 religion. Parents, guardians, or other persons having custody or control of the child, 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 before your baby is 2 weeks old.

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 test filter paper. This filter paper is allowed

to dry and is then sent to the Oregon newborn screening testing laboratory. Your baby's blood is then tested for 32 disorders which can cause serious health problems, if not treated early.

What about test results?

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

For more information

Call the Hawai'i Newborn Metabolic Screening Program at (808) 733-9069; TDD (808) 733-9055; or go to the following Web sites:

- www.hawaiigenetics.org
- www.newbornscreening.info
- <http://genes-r-us.uthscsa.edu>
- www.oregon.gov/DHS/ph/nbs/index.shtml

Disorders identified by newborn screening

- Congenital Hypothyroidism
- Phenylketonuria (PKU)
- Cystic Fibrosis (CF)
- Galactosemia
- Biotinidase Deficiency
- Congenital Adrenal Hyperplasia
- Hemoglobinopathies
- Amino Acid Disorders
- Organic Acid Disorders
- Fatty Acid Disorders
- Urea Cycle Disorders

You can get this publication in an alternate format for individuals with disabilities by contacting: (503) 229-5882.



Description of disorders

Endocrine (hormone) disorders:

- Congenital hypothyroidism in which the thyroid gland cannot make enough thyroid hormone for normal body and brain growth.
- Congenital adrenal hyperplasia in which the adrenal glands are unable to produce normal amounts of certain hormones.

Hemoglobin (blood) disorders:

- Sickle cell disease and other hemoglobinopathies in which abnormal hemoglobin in the red blood cells may cause anemia.



Cystic Fibrosis (CF)

- CF is a severe multi-organ disorder, primarily affecting the lungs and pancreas. CF causes the body to produce abnormally thick mucus which clogs the lungs and leads to life threatening lung infections.

Biochemical (metabolic) disorders:

- Biotinidase deficiency in which the body is unable to use biotin, a B-vitamin.
- Galactosemia in which the body cannot break down a sugar (galactose) found in milk.
- Amino acid (protein) disorders: a group of hereditary disorders caused by enzymatic defects, which result in the toxic accumulation of certain amino acids in the blood.
- Fatty acid oxidation disorders: a group of hereditary disorders caused by defects in enzymes which are involved in the breakdown of fats to energy.
- Organic acid disorders: a group of hereditary disorders caused by enzymatic defects which result in a toxic accumulation of certain organic acids in the blood.
- Urea cycle disorders: a group of hereditary disorders, caused by enzymatic defects which result in a toxic accumulation of ammonia in the blood.

Get the facts

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.

HOW MUCH DOES THIS TEST COST?

The current cost of the newborn screening test is \$55.00. 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 Hawai'i Newborn Metabolic Screening Program at (808) 733-9069.

WHAT HAPPENS IF MY BABY'S TEST RESULTS ARE POSITIVE OR UNUSUAL?

Your baby's doctor will be contacted if there are any positive or unusual test results, and will talk to you about the test results. A positive or unusual result does not always mean that a disorder is present. This is a screening test which finds those 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 normal, healthy life. In a few cases, the disorders 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?

Let your doctor know if you have a new address or phone number. This information is important if your baby needs further follow-up.

THE NORTHWEST REGIONAL NEWBORN SCREENING PROGRAM IS A COLLABORATIVE PROJECT INVOLVING:

- Oregon Department of Human Services
- Oregon Health & Science University
- Alaska Department of Health and Social Services
- Idaho Department of Health & Welfare
- New Mexico Department of Health
- Nevada State Health Division
- Hawaii Department of Health