

HOW CAN YOU HELP YOUR BABY?

- Be sure your baby is tested – look for the bandage on your baby's heel. Ask your nurse or doctor if the sample was collected before you leave the hospital. If your baby will have a different last name than the mother, tell your baby's nurse. The nurse can put both names on your baby's screening card.
- Before discharge, you may be given a special filter card for the second test. Place it in your baby's diaper bag where it will be kept clean and dry. When you go to your baby's first doctor's visit, it will be with you for the second test.
- Be sure to leave your phone number or that of a friend, relative or neighbor with your doctor and the hospital. In case your baby has an abnormal test result, they will be able to reach you quickly.
- Ask your doctor for the newborn screening test results. The results should be available 2-3 weeks after birth if all is normal.

HOW MUCH DO THE TESTS COST?

The current cost of the two screening tests is \$54. This is paid by most insurance companies and Medicaid programs. If you cannot pay the fee, discuss this with your doctor, midwife or nurse. They can arrange for your baby to be tested at no charge.

DO YOU NEED MORE INFORMATION?

Talk with your doctor, midwife, or nurse, or call your local health department, or go to the following websites:

Oregon State Public Health Laboratories -
<http://www.ohd.hr.state.or.us/nbs/welcome.htm>
Newborn Screen and Genetics Resource Center -
<http://genes-r-us.uthscsa.edu/>

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

Oregon Department of Human Services
Oregon Health & Science University
Idaho Department of Health & Welfare
Nevada State Health Division
Alaska Department of Health
and Social Services
State of Hawai'i Department of Health



Testing Your Baby For Hidden Birth Defects



Oregon

The Northwest Regional Newborn Screening Program



In compliance with the Americans with Disabilities Act (ADA), if you need this information in an alternate format, please call Oregon State Public Health Laboratories at (503) 229-5882.

<http://www.ohd.hr.state.or.us/nbs/welcome.htm>

WHAT ARE “HIDDEN” BIRTH DEFECTS?

Hidden birth defects are problems in the body’s ability to make and use hormones, proteins, sugars or blood cells. They are difficult or impossible for you or your baby’s doctor to find just by looking at your baby. These defects may be found in the blood before they can cause serious damage to a baby. Your baby’s blood is tested for about 30 of these birth defects.

WHAT IS THE NEWBORN SCREENING BLOOD TEST?

This is a special blood test. The test looks for about 30 of the hidden birth defects.

WHO SHOULD HAVE A NEWBORN SCREENING BLOOD TEST?

Every baby should have this test. It is not possible to tell if your baby has one of these defects just by looking at or examining your baby. These defects can cause brain damage or death if not found and treated soon after birth. Babies who have these birth defects will seem normal, but will slowly get very sick in many cases if not found and treated.

IS THE BLOOD TEST SAFE FOR MY BABY?

Yes. Your baby’s heel will be pricked. A few drops of blood are collected on a special filter paper. There is a small risk of infection when the skin is broken. This risk is low. Hospital personnel take precautions to keep your baby safe. Over a million newborns have been screened in Oregon since 1961. To our knowledge, not one newborn has had a problem from the heel prick.

WHEN SHOULD THE TEST BE DONE?

If your baby is born in a hospital or birthing center, the first test should be done before your baby comes home. This will be when your baby is 1-2 days old. If your baby was born at home, the first sample should be collected when your baby is between 2-3 days of age. The second sample should be collected between 2-4 weeks of age. This is usually done at the first visit to the primary health care provider after discharge or birth.

WHO WILL MAKE SURE THAT MY BABY HAS A NEWBORN SCREENING SAMPLE COLLECTED?

The doctor, midwife or nurse who delivered your baby should make sure the sample is collected for testing.

WHERE CAN THE SAMPLE BE COLLECTED?

The sample can be collected at any hospital, birthing center, clinic, public health department or medical laboratory.

CAN I SAY NO TO THE TEST?

Yes. Oregon law says that parents may refuse the test for religious reasons. If you do not want your baby tested, you need to sign a special form. This form states the importance of the test and that the hospital and your doctor will not be held responsible if your baby is damaged or dies because these disorders were not identified and treated early.

WHAT BIRTH DEFECTS ARE SCREENED FOR?

All newborns are screened for the following birth defects:

- Endocrine (hormone) defects: congenital hypothyroidism and congenital adrenal hyperplasia

- Hemoglobinopathies (blood): sickle cell disease and 3 other defects
- Biochemical (metabolism) defects:
 - Amino acid (protein) defects: phenylketonuria, maple syrup urine disease and 5 other amino acid defects.
 - Carbohydrates (sugars): galactosemia
 - Fatty acid defects: medium chain acyl-CoA dehydrogenase deficiency (MCADD) and 7 other defects
 - Organic acid defects: At least 6 defects
 - Biotinidase deficiency

WHAT IF MY BABY’S TEST IS ABNORMAL?

Your doctor will call you to bring your baby back for more testing. An abnormal newborn screening result does not mean that your baby has a defect. Rather, further testing must be done. If your baby is affected, it is important that treatment begin as soon as possible.

HOW ARE THESE BIRTH DEFECTS TREATED?

Each defect is different. Some are treated with a special diet and others with drug therapy. If treated early, many infants grow up to lead a normal healthy life. In a few cases, the defects may not be completely treatable. The early diagnosis and treatment of the defect will allow your baby the best chance of normal growth and development.