

About facts



Every baby born in Oklahoma is required to have a blood test in the first week of life.

The test requires a small amount of blood to be collected from your baby's heel.

The blood test helps to find out if your baby might have any of the disorders listed on the back of this pamphlet.

The *Oklahoma State Department of Health* performs the test. The results are sent to the doctor listed on the lab form that is sent with your baby's blood sample. Blood test results will inform the doctor if more testing is needed.

If your baby is found to have a disorder, **immediate** care and treatment by a special medical doctor is needed.

What happens if a baby with a disorder does not get screened?

Babies with these disorders often appear healthy at birth. This makes it difficult for doctors to know the baby has the disorder without a blood test. Failure to treat a baby who has one of these disorders within the first month of life can lead to mental retardation, severe illness or death.

How does a baby get one of these disorders?

Except for congenital hypothyroidism, a baby **inherits** the disorder from both parents. Usually the parents have **no** family history of the disorder and are healthy. Most cases of congenital hypothyroidism are not inherited.

Will the screening test identify all these disorders?

Newborn screening tests are very accurate, but no screening test is perfect. It is uncommon for the screening test not to identify a baby with a disorder. It is important for your baby to have regular health check-ups by a doctor. If you become concerned about your baby's health you should talk with your baby's doctor.

How are the test results reported?

Results are reported to the birth hospital and the physician listed on the lab form. To ensure results are reported quickly to the right person, you should make sure the hospital staff writes the following information correctly on the lab form:

Your Address

Your Phone Number

The Planned Health Care Provider

(This is the baby's doctor you plan to use the first year of life; however, if your baby is sick or premature list the baby's doctor at the hospital.)

Will my baby need more testing?

A repeat test is needed if:

- Screen result is abnormal
- Testing could not be done on the blood specimen
- Test was collected before your baby was 24 hours of age
- Your baby's doctor desires a repeat test
- Your baby is premature or sick at birth
- Your baby had a blood transfusion before the test was collected

Does an abnormal screening test mean my baby has a disorder?

No, often test results are abnormal for other reasons and your baby may not have a disorder. In Oklahoma, approximately **1 in 31** infants will have an **abnormal** screen that requires further testing. Sometimes the blood test finds your baby is a "**carrier**" of a disorder. Carriers **do not** need treatment or any special medical care.

How often are babies found to have these disorders?

In Oklahoma, approximately **1 in 893** infants will be identified with a disorder through screening.

Will this test detect all childhood disorders?

No, the test only screens for the disorders listed on the back of this pamphlet.

Your Role

Make sure your baby has the test in the **first week of life**.

Before you leave the hospital, ask for the **blue parent information sheet**.

If your baby was **less than 24 hours of age** at the time of testing, make sure another test is performed within your baby's first week of life.

Two weeks after the blood test, obtain your baby's test results using the **blue parent information sheet**. Ask for the results during your baby's first doctor visit or by calling the *Oklahoma State Department of Health*, Newborn Screening Program, at: 405.271.6617 or 1.800.766.2223

Tell your baby's doctor:

- If your baby was on soy or lactose-free formula at the time of testing.
- If anyone in your family has any of the disorders.

Make sure your baby is tested again if recommended by your doctor.

Oklahoma

The Oklahoma State Board of Health requires all newborns to be screened for:

- Phenylketonuria (PKU)
- Congenital Hypothyroidism
- Classic Galactosemia
- Sickle Cell Disease
- Cystic Fibrosis
- Congenital Adrenal Hyperplasia
- *Medium-chain acyl coenzyme A dehydrogenase deficiency (MCAD)

United States

In the United States, these disorders are offered by a limited number of newborn screening programs (Not currently offered by the Oklahoma program):

- Biotinidase Deficiency
- Maple Syrup Urine Disease
- Homocystinuria
- Amino Acid Disorders
- Fatty Acid Oxidation Disorders
- Organic Acid Disorders
- Glucose 6 phosphate dehydrogenase deficiency
- Infectious diseases, such as Human Immunodeficiency Virus (HIV) and Toxoplasmosis

- www.health.ok.gov/program/gp
- 405.271.6617 or 1.800.766.2223
- genes-r-us.uthscsa.edu

Note: disorders listed in pink are recommended by the *March of Dimes*

*This disorder is being added in 2006.

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Designed by Sara C. Ramsey

Newborn Screening

On baby's first doctor visit, ask for the screening result!

