# 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 a disorder 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 a disorder within the first month of life can lead to mental retardation, severe illness or death.

### How does a baby get a disorder?

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 listed 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 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 30 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 a disorder?

In Oklahoma, approximately 1 in 1,000 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's blood is tested during the first week of life; if the blood is taken less than 24 hours, another test must be performed.

- Before you leave the hospital, ask for the blue parent information sheet. It contains information needed to obtain test results. Test results are available two weeks after the blood test at 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

- Have your baby tested again if recommended by your doctor.

**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 listed disorders.

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

**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)
Biotinidase Deficiency (to be added)
Maple Syrup Urine Disease
Homocystinuria
Amino Acid Disorders
Fatty Acid Oxidation Disorders
Organic Acid Disorders

**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):

Hyperammonemia/ornithinemia
Prolinemia
Ethylmalonic encephalopathy
Nonketotic hyperglycinemia
5-oxoprolinuria (pyroglutamic aciduria)
Carbamoylphosphate synthetase
Krabbe Disease
Glucose 6 phosphate dehydrogenase deficiency
Infectious diseases, such as Human Immunodeficiency Virus (HIV) and Toxoplasmosis

**More Information**

- http://nsp.health.ok.gov
- 405.271.6617 or 1.800.766.2223
- http://genes-r-us.uthscsa.edu

**Note:** Disorders listed in pink are recommended by the *March of Dimes & the American College of Medical Genetics.*

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# Newborn Screening

Protect your baby from **hidden disease**