



What is newborn blood spot screening?

YOUR BABY'S HEALTH IS IMPORTANT

and that's why your health care provider and the Iowa Department of Public Health work together to make sure all babies born in Iowa are as healthy as they can be.

Some of these disorders can be caused by the accumulation or lack of certain chemicals or hormones made naturally in the body. Your baby will have a blood screen shortly after birth that looks for these rare, but serious disorders.

These disorders can cause serious health problems, but early treatment can help your baby.

Why is my baby screened?

NEWBORN SCREENING FINDS PROBLEMS EARLY

All parents want a healthy baby. Screening helps assure that your baby will be as healthy as possible. Babies can look very healthy at birth and still have one of these disorders.

If a condition is not found early, poor physical and mental development, and even death, may occur.

To make sure these disorders are found quickly, Iowa law requires that all babies be screened. If found early, babies with most of these conditions can be treated and live healthy lives.

How is my baby screened?

THE SCREEN IS SAFE AND SIMPLE

A few drops of blood are taken from your baby's heel. The blood is then sent to the state University Hygienic Laboratory in Ankeny, Iowa.

The screening should be done before your baby leaves the hospital. If your baby is tested before 24 hours of age, a second test should be done as soon as possible. If your baby was born at home, then testing should be done before five days of age.

Can I refuse to have my baby screened?

You may refuse screening on behalf of your child. If after consulting with your health care provider you decide to refuse the screen, you must accept the legal responsibility for the consequences of this decision, and inform your health care provider, who must inform the Iowa Department of Public Health.

What happens to the blood specimen when testing is done?

Unless a parent or legal guardian refuses in writing or prohibits such use in writing, the blood specimen and information becomes the property of the state. The specimen may be used for research to improve the health of mothers and children as well as program evaluation.

Why does IDPH store residual newborn screening specimens

- Results or specimens may be requested by the baby's health care team for other health related testing
- Results or specimens may be requested by the baby's parent or legal guardian for health related testing
- Quality control for the newborn screening laboratory
- Develop new tests to screen for more disorders
- Public health studies and research to better understand disorders for the benefit of the general public

In other cases, all identifying information is removed from the specimen (name, address, identification numbers, etc.) so a specimen cannot be traced back to a particular baby.

To order additional copies, contact:

**University Hygienic Laboratory
(515) 725-1630**

for questions contact:

**Iowa Neonatal Metabolic Screening
Program (INMSP)
1-800-260-2065**

or

Iowa Department of Public Health
Center for Congenital and Inherited Disorders
321 East 12th Street
Des Moines, IA 50319-0075
www.idph.state.ia.us/genetics



**One simple
screening could
save your
baby's life.**



please read this information



I was told I need to repeat my baby's screening

WHAT DOES THIS MEAN?

Re-screening does NOT mean there is anything wrong with your baby. It simply means that another blood specimen must be taken.

Re-screening may be required for a number of reasons. Some of these reasons include:

Unsatisfactory specimen: There is not enough blood to complete all of the required screening tests, or the sample cannot be tested for other reasons, such as too much blood on the specimen.

Early collection: The blood sample was drawn before your baby was 24 hours old. A repeat test must be done as soon as possible to avoid missing a disorder.

Medications: Certain medications can cause an abnormal result.

Abnormal test result: An abnormal test result means your baby "might" have a disorder. Your doctor will work with you to determine if further testing is needed.

How do I get the screening results?

TALK WITH YOUR BABY'S HEALTH CARE PROVIDER

You can find out the results from your baby's health care provider or the hospital where your baby was born. Generally parents/guardians are notified by the baby's health care provider when re-screening or further testing is needed.

WHAT WILL MY BABY BE SCREENED FOR?

Disorders identified by the Iowa Neonatal Metabolic Screening Program:

Galactosemia: Babies with this disorder cannot convert galactose, a sugar present in milk, into glucose, a sugar the body uses as an energy source. Galactosemia can cause death in infancy, or blindness and mental retardation. The treatment for this condition is to eliminate milk and all other dairy products from your baby's diet. *This disorder occurs in about 1 in every 70,000 births.*

Congenital Adrenal Hyperplasia: Babies with this disorder have adrenal glands that are unable to make enough of the hormone cortisol and, in some cases, are unable to make enough of the hormone aldosterone. This disorder may affect genital development and, without treatment, severe cases may result in death. Treatment consists of replacing the deficient hormones by medication, or eliminating the source of excess hormones. *This disorder occurs in about 1 in every 16,000 births.*

Congenital Hypothyroidism: Babies with this disorder are born with a thyroid gland that does not make enough thyroid hormone. This can lead to poor growth and abnormal brain development. If it is detected in time, a baby can be treated with medication. *This disorder occurs in about 1 in every 4,000 births.*

Biotinidase Deficiency: Babies with biotinidase deficiency cannot reuse the vitamin biotin. Biotin helps maintain normal body functioning. Without treatment, this disorder can lead to seizures, developmental delay, eczema and hearing loss. Problems can be prevented with biotin treatment. *This disorder occurs in about 1 in every 60,000 births.*

Cystic Fibrosis (CF): Cystic fibrosis is the most common inherited (genetic) disorder, affecting about 30,000 children and adults in the U.S. A defective gene causes lung infections and digestive problems with malnutrition. CF can be life-shortening. *Cystic fibrosis occurs in about 1 in every 3,200 Caucasian births (1 in every 3,900 births in the U.S.).*

Hemoglobinopathies: Hemoglobinopathies are inherited red blood cell disorders. Hemoglobin is the protein in blood that carries oxygen from the lungs to the body. The most common hemoglobin disorder is sickle cell disease. When sickle-cell shaped cells block small blood vessels, less blood can reach that part of the body. *Sickle cell anemia occurs in about 1 in every 375 African Americans.*

EXPANDED SCREENING PANEL

Expanded screening is a group of up to 30 additional disorders. These disorders fall into three main types:

Amino Acid Disorders: Babies born with one of these disorders cannot process certain amino acids. These amino acids, along with other toxic substances, build up in the body and cause serious effects on health, growth and learning. Treatment may include a special diet, close monitoring and/or vitamin and amino acid supplements. An example of an amino acid disorder is Phenylketonuria (PKU). Babies with PKU cannot process a substance called phenylalanine. Left untreated, phenylalanine builds up in the bloodstream and causes brain damage and

mental retardation. If PKU is detected early, mental retardation can be prevented by feeding your baby a special diet. *PKU occurs in about 1 in every 12,000 births.*

Fatty Acid Oxidation Disorders: Babies with fatty acid disorders are unable to breakdown stored fats for energy. One example of a fatty acid disorder is Medium Chain Acyl-CoA Dehydrogenase Deficiency (MCAD). Babies born with MCAD cannot break down fat into energy because an enzyme is missing or does not work correctly. People with MCAD should not fast (go without food) for very long or they can experience low blood sugar, seizures, coma and even death. *MCAD occurs in about 1 in every 12,000 births.*

Organic Acid Disorders: Babies born with organic acid disorders have a chemical imbalance in their bodies which can be toxic. Organic acids play an important role in the breakdown of fats, sugars and protein for the body's use and storage. Muscle wasting, seizures, developmental delays and even death can occur if untreated. Treatment may include a special diet, monitoring and medications.

