



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 screening 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 before your baby is two weeks old. 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 screening, 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 sample when testing is done?

Unless the person or his/her legal authorized representative specifically prohibits such use in writing, the blood specimen and information obtained during the screening process becomes property of the state, and may be used for program evaluation or research by the Iowa Department of Public Health or department-approved scientific researchers to improve the health of mothers and children. Such studies are published without identifying the person or persons from whom these results were obtained.

Why does IDPH store residual newborn screening specimens

There are a number of reasons why the residual blood spots and the results are kept, most of which benefit Iowa families.

In some cases, results or samples are requested by the family or baby's healthcare team:

- The baby's results can be repeated, if needed, without getting another blood sample from the baby
- The baby's sample is available to parents for other health-related testing
- The baby's sample is available to parents to help identify a missing or deceased child
- Storage provides a permanent record that IDPH completed the screening

In other cases, all identifying information is removed from the samples (name, address, identification numbers, etc.) so a sample cannot be traced back to a particular baby, and these samples may be used to:

- Make sure the newborn screening laboratory is doing a good job with testing (quality control)
- Develop new tests to screen for more disorders
- Do public health studies and research to develop newborn screening tests and better understand diseases for the benefit of the general public

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To order additional copies, contact the University Hygienic Laboratory at (515) 725-1630 or toll-free at 1-866-890-5965

One simple screening could save your baby's life.



{please read this information}



WHAT WILL MY BABY BE SCREENED FOR?

Disorders identified by the Iowa Neonatal Metabolic Screening Program:

Galactosemia: Babies with this disorder cannot convert glucose, a sugar present in milk, into glucose, a sugar that 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 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 4,000 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 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. *This disorder 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. *This disorder occurs in about 1 in every 12,000 births.*

Organic Acid Disorders: Babies born with organic acid disorders have a chemical imbalance in their body 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. *This disorder occurs in about 1 in every 12,000 births.*

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 sample 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 sample.

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 are notified only if re-screening or further testing is needed.

