Where can I get more information?

March of Dimes
www.marchofdimes.com

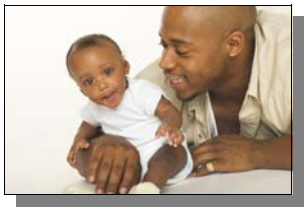
Health Care Program for Children with Special Needs
www.HCPColorado.org
(Choose "Get to know HCP," then "Screenings")

STAR-G
Screening, Technology and Research in Genetics
www.newbornscreening.info

I have questions about newborn screening

Hospital staff and your baby's doctor can answer questions you have about newborn screening. *Ask!*

Or contact:
The Health Care Program for Children with Special Needs at the Colorado Department of Public Health and Environment
Phone: (303) 692-2370
E-mail: cdphe.psdrequests@state.co.us



As new parents, what can *we* do?

As parents of a newborn baby, there are many things you can do to make sure your baby gets this important testing!

Before your baby goes home from the hospital, check with hospital staff to make sure your baby got a newborn screening test.

When your baby is one to two weeks old, your baby should see a doctor for a "well-child check-up."

> Ask the doctor for the results of your baby's first newborn screening test. In most cases, the results of your baby's newborn screening test will be normal.

If your doctor tells you that your baby's newborn screening test was **not normal**, your baby will need more testing. **Follow your doctor's instructions carefully** and be sure to get the tests your baby needs *right away*!

All babies must get a second newborn screening test when they are one to two weeks old, even if the first test was normal. Be sure the doctor tells you how to get that second test, and do it right away.

A baby's first newborn screening test is usually sent to the lab with the mother's last name. **If your baby might be known by more than one last name, include both names on the second test, so the lab will know that both tests are for the same baby.**

Check back with the doctor for the results of your baby's second newborn screening test.

Don't rely on others to *make sure* your baby gets tested!

Colorado's Newborn Screening Program

First Steps to a Healthy Start for Your Baby

Colorado Department of Public Health and Environment

The **Colorado Department of Public Health and Environment** wants to help your baby get a healthy start. Shortly after your baby is born, your baby's blood will be tested to detect rare but serious health disorders. If these disorders are not detected early in your baby's life, they can cause mental retardation or serious health problems.

What is a newborn screening test?

A newborn screening test is a simple and safe blood test which looks for disorders that are rare, but **very serious**.

Why does my baby need the test?

Newborn babies who have these disorders look healthy, but babies with some of these disorders will get very sick or die just a few days or weeks after they are born. Other disorders can cause a child to become mentally retarded.

The newborn screening test helps find babies with these disorders early, so they can get medical treatment before they get sick.

Who is tested?

State law requires that all babies born in Colorado have a newborn screening test.

Parents have the right to refuse screening. But remember, newborn screening is safe and simple and is one of the most important things you can do to protect your newborn baby's health.

Who pays for the testing?

Insurance or Medicaid pays for the test.

If you do not have insurance or Medicaid, the hospital will pay for the test.

There is no cost for the second newborn screening test.

When will my baby be tested?

Your baby will be tested **two** times.

Your newborn baby **must** be tested before your baby goes home from the hospital.

If newborn babies have to stay in the hospital for a while after they are born, they **must** be screened before they are three days old.

All babies get a **second** newborn screening test when they are one to two weeks old.

Why does my baby need to be tested twice?

Some disorders might be missed because the first newborn screening test is done so soon after birth.

The second newborn screening test is for your baby's safety. It can find a disorder that was missed on the first screen.

How is the test done?

A few drops of blood are taken from your baby's heel and put on a special paper.

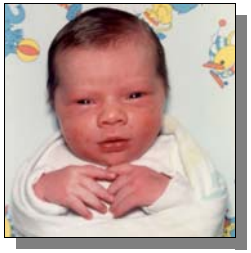
The state public health laboratory does the testing.

What will my baby be tested for?

For a complete listing of disorders that your baby will be tested for, see the brochure insert.

How do I get my baby's test results?

The state public health laboratory will give the results to the hospital or your baby's doctor. Your baby's doctor will tell you the results of your baby's newborn screening test.



It takes about two weeks for your doctor to get the results.

What does it mean if my baby's test is not normal?

If your baby's newborn screening test result is **not normal**, it means **your baby needs more testing**.

Many **healthy** babies have newborn screening results that are **not normal**.

Your doctor will tell you how to get the testing your baby needs. Your baby might need to see a specialist. Get any additional testing your baby needs right away!

If my baby has one of these disorders, is there a cure?

There are no cures for these disorders, but if these disorders are found and these babies get treatment early, the serious problems caused by these disorders can be prevented or reduced.

If babies with these disorders get early and continuous treatment, most can grow and develop normally and live healthy lives.

Complete Listing of Disorders Tested for in the Colorado Newborn Screening Program

Amino Acid Disorders

- Arginase deficiency
- Argininosuccinic acidemia
- Citrullinemia
- Homocystinuria
- Hypermethioninemia
- Maple syrup urine disease
- Phenylketonuria (PKU)
- Tyrosinemias

Endocrine Disorders

- Congenital adrenal hyperplasia
- Congenital hypothyroidism

Fatty Acid Oxidation Disorders

- Carnitine acylcarnitine translocase deficiency
- Carnitine palmitoyltransferase II deficiency
- Carnitine palmitoyltransferase deficiency 1a
- Carnitine uptake defect
- Long-chain L-3-hydroxyacyl-CoA dehydrogenase deficiency
- Medium-chain acyl-CoA dehydrogenase deficiency
- Short-chain acyl-CoA dehydrogenase deficiency
- Trifunctional protein deficiency
- Very long-chain acyl-CoA dehydrogenase deficiency

Hemoglobinopathies

- Beta-thalassemia
- Sickle cell anemia
- Hemoglobin SC disease

Organic Acid Disorders

- 3-Hydroxy-3-Methylglutaryl-CoA Lyase deficiency
- 3-Methylcrotonyl-CoA carboxylase deficiency
- 3-Methylglutaconic aciduria (3-MGA)
- Beta-ketothiolase deficiency
- Biotinidase deficiency
- Glutaric acidemia type I
- Glutaric acidemia type II
- Isovaleric acidemia
- Malonic acidemia
- Methylmalonic acidemias
- Multiple carboxylase deficiency
- Propionic acidemia

Others

- Cystic fibrosis (CF)
- Galactosemia
- Hearing (not a metabolic/bloodspot screen)

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Amino Acid Disorders

Babies with these disorders cannot process certain amino acids (building blocks of protein) because of a missing enzyme.

These amino acids, along with harmful substances, build up in the body and can cause health problems.

Treatment often includes a special diet and sometimes medication.

Endocrine Disorders

Congenital Hypothyroidism

Babies with this disorder cannot make enough thyroid hormone.

Without early treatment, children can become mentally retarded.

Congenital Adrenal Hyperplasia

The adrenal glands do not produce normal amounts of hormones.

Without early treatment, babies can have a life-threatening illness and can become disabled and some may die.

Organic Acid Disorders

Babies with organic acid disorders are missing an enzyme in their body and cannot break down protein properly.

This causes harmful substances to build up in the body and can cause serious health problems even within the first few days of life.

Some babies require a special diet, while others just need medication.

Cystic Fibrosis

Cystic fibrosis is a genetic condition that causes mucus to build up in the lungs and other organs leading to chronic poor growth and lung infections.

Early treatment can improve growth and minimize or delay complications.

Fatty Acid Disorders

Babies with fatty acid oxidation disorders cannot break down fats for energy.

Fats are an important energy source for the brain and muscles when glucose levels are low.

Some babies will need a special diet, whereas other babies will just need to avoid fasting.

Galactosemia

Babies with this disorder cannot break down a sugar found in milk.

Babies need soy formula to avoid health problems.

Hemoglobinopathies

These are inherited diseases that cause the red blood cells to become stiff and distorted in shape.

If not properly managed, the baby experiences pain, increased infections and has an increased risk of stroke or death.

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