

How can parents or guardians help?

You need to make sure your baby has had their newborn screen blood specimen and hearing screen before they leave the hospital. You should make sure that your baby's doctor has the correct address and phone number information to contact you regarding the results.

Kentucky is in the process of expanding its newborn screening program. It is expected that beginning January 1, 2006 Kentucky will test for the full panel of 28 disorders recommended by the American College of Medical Genetics, but until this date parents can seek additional screening for their newborn by asking your birthing or delivery hospital or by contacting one of the laboratories listed below:

Baylor Medical Laboratory
Toll Free 1-800-422-9567

Pediatrics
Toll free 1-866-463-6436

University of Colorado
303-724-3826



Kentucky Newborn Screening Program

Department for Public Health

275 East Main St. HS 2W C

Frankfort, KY 40621

Phone 502-564-3756 Ext 3761

Toll Free 800-462-6122 Ext 3761

Fax 502-564-1510

Website

<http://chfs.ky.gov/dph/ach/newbornscreening>

Newborn Hearing Website

<http://chfs.ky.gov/ccshcn/CCSHCNunhs>

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Health & Family Services Cabinet

Your Baby's Newborn Screening



The Newborn Screening Program for the State of Kentucky



Health & Family Services Cabinet

Questions and Answers about Newborn Screening

What is Newborn Screening?

A screening includes a blood spot and hearing check performed on all newborns. This helps doctors to possibly detect inherited conditions. Early diagnosis and treatment may prevent serious health problems, and gives your baby the best chance to grow and develop normally.

What is Newborn Hearing Screening?

Babies have their hearing checked soon after birth. The screening is safe and does not hurt.



Your baby may “pass” the hearing screen or could be “referred” for more testing.

If your baby is “referred” for more testing you will get a letter from the Universal Newborn Hearing Screening Program. For help call toll free voice or TTY 877-757-4327

When is Newborn Screening done?

Your baby should be screened before leaving the hospital. Before your baby leaves the hospital, the heel is pricked and a few drops of blood are collected.

Is Newborn Screening required?

Kentucky law requires that newborn screening be done before the baby leaves the hospital but after 24 hours of age, and after they are fed. For babies who are not born in a hospital they are required to be tested at 48 hours of age.

How will I get the results?

Your baby’s doctor will receive a report with the screening results. You have the right to ask your doctor or nurse to explain the screening process to you and to provide the results to you. Results usually take about one week.

Repeating the Newborn Blood Screen

The newborn screen is most accurate if your baby’s blood is taken after the first 24 hours of life. If your baby’s heel stick was done prior to 24 hours of life or before they had been fed, a second blood sample needs to be taken.



Which blood disorders are screened?

- Phenylketonuria (PKU)
- Galactosemia
- Congenital Hypothyroidism
- Sickle Cell and Red Blood Cell Disorders

Phenylketonuria (PKU)

Infants with PKU lack an enzyme which is needed by the body to break down phenylalanine, a component of protein in foods. A special diet can prevent mental retardation and other effects of PKU.

Galactosemia

Galactosemia is caused by a lack of an enzyme that the body needs to process galactose, a natural sugar found in milk (breast and cow’s milk). Serious liver and brain damage, and even death may occur if the disorder is not detected and treated early in life.



Congenital Hypothyroidism

Hypothyroidism is caused by inadequate production of thyroid hormone that permits proper body and brain growth. If detected early and hormone therapy is started, normal growth and development can take place.

Sickle Cell and other Red Blood Cell Disorders

Healthy red blood cells are shaped like a donut. In red blood cell diseases, these blood cells may take on a variety of shapes. These cells become trapped in blood vessels causing pain, discomfort or life threatening infection.