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# *Family Teaching Toolbox*

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## FAMILY TEACHING TOOLBOX

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# A PARENT'S GUIDE TO NEWBORN SCREENING



Figure 1. This newborn will get her screening test done before she leaves the hospital.



Figure 2. You can help your baby feel more comfortable during the test by wrapping your baby in a blanket or giving him or her something to suck on, such as the breast or a pacifier.



Figure 3. After the heel is warmed, a small lancet is used to draw blood. A blood drop is then placed on special filter paper.

## What is newborn screening?

Your baby is being tested to look for serious problems with metabolism. In the past, this test was called the “PKU test.” Newborn screening includes more diseases than just PKU. Each state tests for different diseases. Ask your health care provider to give you a list of the diseases your state screens for. A complete list is available on the Web at: <http://genes-r-us.uthscsa.edu/resources/newborn/state.htm>

## Why does my baby need screening?

Babies born with metabolic problems can look healthy soon after they are born. But if they are not treated early, they may develop serious problems. Some of the problems may include mental retardation or even death. Every baby born in the United States is screened, even if they are healthy, so that a problem can be found before the baby gets sick.

## How is the screening test done?

A small amount of blood is taken from your baby's heel. The blood is placed on special filter paper, dried, and is sent to your state's laboratory for testing.

## When is the test done?

The blood is drawn before your baby leaves the hospital. The test is completed within 5 to 10 days. Results should be given to your primary care provider at that time. Some states require a repeat test done at 2 weeks of age. You may be given a form to bring to your healthcare provider for the repeat testing.

## How will I get the results?

Your baby's healthcare provider will be notified of the results by your state's lab. Ask your health care provider if the results are normal. You may want a copy of the test results for your own health records. If the results are not normal, other testing will need to be done.

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Figure 4. Each of the circles on the special filter paper must be filled with a drop of blood.



Figure 5. After the circles are filled, the test is done and a bandage is placed over the heel.



Figure 6. After the test is done, you can hold your baby and provide comfort. You will need to check on the test results at your next visit to the clinic.

## What disorders are screened for?

Every state screens for PKU, also known as hyperphenylalaninemia. In this disease, there is an enzyme missing which is needed to break down protein. Proteins are found in many food products, including breast milk and formula. Most results are normal. Babies who have this disease need special formulas to avoid brain damage.

Galactosemia is another disease all infants are screened for. The body cannot break down the milk sugar called galactose. Treatment consists of using special formulas to prevent liver damage, cataracts, or in some cases death.

Every state also tests for congenital hypothyroidism. This is a disease where the body does not make enough thyroid hormone. Thyroid hormones are important for brain growth and many other functions. Early screening and treatment are needed to prevent permanent brain damage.

## What is supplemental screening?

Supplemental screening is extra testing that can be done at the same time as the screening test in the hospital. This test requires a second blood sample on special filter paper. It is done to look for other diseases that your state may not routinely screen for.

## Does my baby need this additional screening test?

If there is a family history of metabolic problems or sudden death in an infant, you may want to consider testing your baby. Ask your baby's healthcare provider if he or she recommends this additional testing.

## Where can I get more information?

It is important that you understand what testing was done for your baby and why. Do not be afraid to ask questions. It may help to write your questions below:

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To read more about newborn screening please visit the following Web sites, or call these sources for more free information.

### **March of Dimes Birth Defects Foundation**

1275 Mamaroneck Avenue  
White Plains, NY 10605  
888-MODIMES or (914) 428-7100  
<http://www.modimes.org>

### **Save Babies Through Screening Foundation**

4 Manor View Circle  
Malvern, PA 19355-1622  
1-888-454-3383  
<http://www.savebabies.org>