# Newborn Screening and Hearing Test



# What is newborn screening?

Newborn screening is a test that checks for diseases your baby is born with (inherited diseases) that can be found from a sample of blood. The newborn screening test is done in the first few days after birth. All hospitals and health care providers are required by law to offer this test for every baby born in the United States. Every state's newborn screening test checks for at least 29 inherited diseases. Some states test for up to 25 more diseases. Most of these diseases affect the body's ability to grow normally. The goal of newborn testing is to find babies with these diseases before they have any problems so that treatment can help the baby's long-term health.

# Why does my baby need newborn screening?

Sometimes babies look normal but may have a disease that cannot be seen at birth. Some of these diseases can make your baby very sick, and a few can cause death, but most of them are rare. These diseases can cause physical and mental problems if they are not found and treated early in life. Treating these problems early is very important for preventing the serious long-term effects these diseases can cause.

# How and when is newborn screening done?

The baby's heel is pricked, and a few drops of blood are taken within a few days of birth. It is best if the test is done at least 24 hours after the baby is born. Some tests are not as good at finding a disease if they are done too soon. The tests are best if the baby has had breast milk or formula a few times before the test is done, because the test measures how the baby handles food. Your baby should have the test again within 1 to 2 weeks if the test was done in the first 24 hours after birth. Some states routinely test babies twice.

### How will I know the results of my baby's newborn screening?

Your baby's health care provider and/or the hospital or birth center where your baby was born will receive a copy of the test results. You may ask for a copy of the results. The state health department should contact you if your baby's results are not normal. It can take up to 1 to 2 weeks to get the results.

# What happens if my baby's newborn screening test result is abnormal?

If your baby's test result is abnormal, it does not mean that your baby has 1 of the diseases. The initial test is a screening test that looks for signs that your baby might have a disease. It is not used to say for sure a disease is present. Your baby will need more tests if the newborn screening result is abnormal. The additional tests will determine whether your baby has 1 of the diseases and needs early treatment. If these test results are positive, you will see a specialist who cares for children with that disease. Remember that most of the diseases can be treated with medicine or changes in diet that usually can prevent most of the physical and mental problems these diseases can cause.

### What does it mean if my baby's newborn screening test result is normal?

This test looks only for specific diseases. If the test result is normal, it does not mean that your baby does not have any health problems. A normal newborn screening test result means that your baby does not have 1 of the diseases that this screening test is looking for. Very rarely the newborn screening test result is wrong. If you have concerns about your baby's health at any time, you should talk to you baby's health care provider.

# Can I get my baby tested for additional diseases that my state does not have in the newborn screening?

Some laboratories offer newborn screening tests for up to 60 diseases. If the state you give birth in offers testing only for the core 29 diseases, you can have your baby tested for these additional diseases for a low cost. Your health care provider and/or baby's health care provider can give you more information about these tests. You might want to consider having your baby tested for the additional diseases if:

- you or the baby's father has a family history of an inherited disease.
- you previously gave birth to a baby with 1 of the diseases.
- a baby in your family died of a possible metabolic disease.
- you believe that your baby may be at risk for 1 of the diseases for another reason.

# Why does my baby need a hearing test?

Most states are required by law to offer a hearing test for every baby during the first few days after birth. This helps determine whether your baby can hear well. The test is easy and painless. If your baby does not pass this test, a full hearing test will be done before your baby is 3 months old. Early diagnosis and treatment of hearing loss can prevent delays in your baby's ability to talk and learn words.

### For More Information

# **Save Babies Through Screening Foundation**

The Expecting Families section contains general newborn screening information as well as descriptions of diseases detected.

http://www.savebabies.org

# March of Dimes: A Parent's Guide to Newborn Screening

A video describing the importance of newborn screening http://www.youtube.com/watch?v=yqQRio1-P6c

# National Newborn Screening & Genetic Resource Center

General information about newborn screening, what tests that each state offers, and where to get additional testing.

http://genes-r-us.uthscsa.edu/parentpage.htm

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