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NEWBORN SCREEN BLOOD TEST

State law requires that all babies have their blood drawn and tested. This is called a Newborn Screen Blood Test, although it used to be called PKU. This test checks to see if your baby has certain diseases or conditions (see below).

Your baby may look healthy, even if he or she has one of these diseases. If your infant has one of these conditions and it is not found early, there will be serious problems. This blood test will tell whether more testing and future counseling will be needed.

HOW THE TEST IS DONE

All infants are screened before they are released from the hospital where they were born. If your baby goes home from the hospital before he or she is 48 hours old (about 2 days), the test will have to be repeated. ***It is important that the repeat test be done in the first 14 days of life.***

- The test is done with 5 drops of blood drawn from the heel of the infant and dripped on a special paper (Picture 2, page 2). All the newborn screens are sent to the Ohio Department of Health.
- When a premature or sick newborn is transferred here from another hospital, the doctors and nurses at Nationwide Children's Hospital make sure the needed newborn screens or follow-up tests are done.
- You will **not** be notified of the results unless further testing is needed.
- The baby's primary care doctor is responsible for keeping the test results in your child's medical record.

The newborn screen blood test checks for these diseases and conditions:

PKU (Phenylketonuria) – A person who has this condition (pronounced FEN-il-KEE-to-nur-EE-ah) is not able to use the amino acid *phenylalanine*. This substance will build up in the body and can cause brain damage. If the condition is not found early, the brain can be damaged soon after birth. However, a baby who is treated before 3 to 4 weeks of age can have normal development, and mental retardation can be prevented. Treatment usually involves feeding the baby a special formula and a special diet.

Galactosemia (ga-lak-to-SEE-me-uh) – A baby with this disease can't use a milk sugar called *galactose*. The unused galactose builds up and damages the brain, liver, and eyes. There will be severe and permanent damage to the brain and liver if the condition is not detected and treated at the beginning of life. A baby can have a healthy life if a special galactose-free diet is started and controlled early in life. (continued on back)

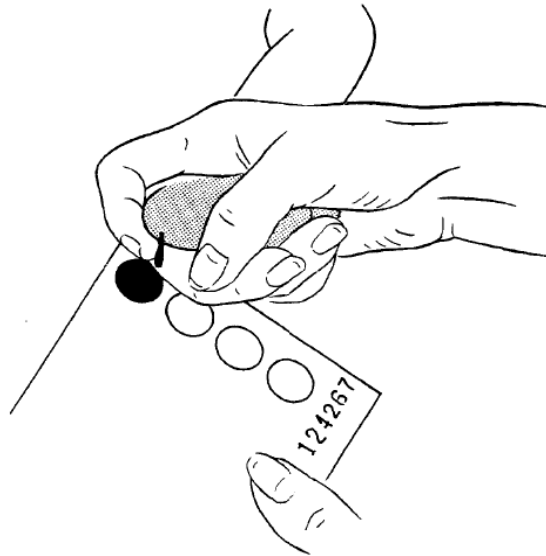


Picture 1 A baby with PKU needs to be fed a special formula.

Hypothyroidism (HI-poe-THI-royd-izm) – An infant with this condition doesn't make enough thyroid hormone for the body to function normally. When there is not enough thyroid hormone, the baby will have slow physical and mental development. Giving the baby a pill daily to replace the missing hormone can treat this condition.

Homocystinuria (HO-mo-siss-ti-NU-re-uh) – A baby with this disease does not have a liver enzyme that is needed for normal growth. The tissues, vessels, and bones become damaged. This disease progresses very slowly, so it needs to be found before any symptoms occur. The child can develop normally if the condition is found at the beginning of life. Treatment usually includes regular doctor's visits, a special diet, and/or extra vitamins.

Sickle Cell Anemia (or other disorders of the hemoglobin [HEE-moe-glo-bin] in the blood) – Babies with this disease have red blood cells that become sickle-shaped because they don't get enough oxygen. These sickle-shaped cells can clog the blood vessels, and this can cause severe pain. A baby with this disease can get infections much easier and have slower growth and development. If this is not found early, the infant can get a severe infection that could lead to death. The screening helps identify this disease so that daily doses of penicillin can be given by mouth to reduce the chances of infection. Infants diagnosed with sickle cell disease will be referred to the Sickle Cell Treatment Center at Nationwide Children's Hospital.



Picture 2 The Newborn Screen Blood Test.

If you have any questions, be sure to ask your doctor or nurse, or call_____.