Having a baby is exciting, and you may have questions. Don’t be afraid to ask your doctor for more information about anything you don’t fully understand.

Florida Newborn Screening does not store specimens beyond the time necessary to conduct quality assurance activities. Residual dried bloodspot specimens are destroyed six months after testing is complete. Some abnormal samples are kept unidentified for quality assurance and method validation purposes. Florida Newborn Screening does not use residual dried bloodspot specimens for biomedical research. See Sections 383.14 and 383.145, Florida Statutes, at www.leg.state.fl.us for laws governing Florida Newborn Screening.

Why does my baby need Newborn Screening tests?

- All babies are tested because even babies who look healthy may have a rare health problem.
- If problems are found early, treatment can begin and may be able to prevent serious problems like mental retardation or death.
- It is important to remember that the newborn screening test is a screening test and not a diagnostic test. There will be false positive test results and false negative test results.
- Some disorders will detect an infants’ carrier status in the process to detect a true positive.

How will my baby be tested for the Newborn Blood Screening?

- Before you leave the hospital, several drops of blood will be taken from your baby’s heel.
- The hospital will send the blood sample to the Florida Newborn Screening Lab in Jacksonville.

How will I get the results of the test?

- Your baby’s doctor will be given the results by the hospital. Be sure to tell the hospital the correct name and phone number of your baby’s doctor so they can send the results.
- Parents are directly notified of test results if there is a problem.
- Ask about the results when you see your baby’s doctor.

Why do some babies need to have the blood screening repeated?

- Some babies need to have the screening repeated because there is a problem with the blood sample.
- All babies who leave the hospital earlier than 24 hours must have the screening repeated within 5 days of age.
- A few babies need to have the screening repeated because the first test showed a possible health problem.
- If your baby needs to have the screening repeated, get it done right away.
- Our screening tests are very sensitive. Sometimes the results look positive even if there are no problems. Get your baby retested to be sure.

What babies need to have additional testing?

- All babies with abnormal screening results need more testing.
- You will be contacted if your baby needs to have additional testing.

What if my baby is uninsured?

- Find out if Florida’s KidCare health insurance is for you. Visit www.floridakidcare.org or call 1-888-540-5437.

Your baby is precious and, as a new parent, you want to do everything you can to keep your baby safe and healthy. An important step to make sure your baby gets newborn screening tests before you both leave the hospital:

- Your baby’s blood spots are kept by the lab for only six months and then destroyed.
- Newborn Blood Screening tests your baby’s blood for different diseases and conditions. Newborn Hearing Screening checks to see if your baby has any hearing problems. Early detection and treatment of health issues can help your baby grow up healthier.
- These tests are an important beginning of a long, healthy life for your baby.

“This one small screening has changed the entire outcome of our daughter’s life.” — a new parent
Disorders found by Newborn Screening

All disorders, except for hypothyroidism, are inherited from parents. Some children who are diagnosed with one of these disorders will need close supervision by a medical specialist and their team.

Hypobetalipoproteinemia is when the body is unable to use the vitamin biotin. It can result in seizures, hearing loss, and death in severe cases. Treatment is simple and involves daily doses of biotin.

Endocrine Disorders are caused by decrease or absence of certain hormones.

CONGENITAL HYPOSPERMIA can result in mental and growth retardation.

Cystic Fibrosis is a progressive lung disease with other organ failures and long and food digestion problems. Treatment leads to decreased hospitalizations and better growth, development and lung functioning.

Galactosemia is the failure to break down the milk sugar galactose. It can lead to cataracts, low blood sugar, mental retardation and/or death. Treatment is elimination of galactose from the diet usually by substituting soy.

Amino Acid Disorders are caused by the body’s failure to breakdown certain proteins. If untreated, the baby could have poor feeding, vomiting, neurological symptoms, mental retardation, coma, and death. Treatment may involve strict dietary management of the amino acid and medication. Florida currently screens for seven amino acid disorders.

Fatty Acid Oxidation Disorders are caused by the body’s failure to breakdown fatty acids to convert to energy. If not diagnosed, fatty acid disorders may result in excessive fat buildup in the liver, heart and kidneys. If left untreated, low blood sugar, vomiting, seizures, lethargy, liver disease, developmental delay, coma, and death could occur. Treatment may include regular food intake, a special low fat diet and medicine. The child will need close supervision by a metabolic specialist and dietician.

Organic Acidemias are a group of metabolic disorders that lead to a buildup of organic acids in blood and urine. Most of these disorders can be severe and can be present within the first week of life. The baby can develop poor feeding, liver and kidney problems, mental retardation, and possibly death. Treatment involves a strict diet that must be followed for life and medication. Florida currently screens for ten fatty acid oxidation disorders.

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Hemoglobinopathies are disorders of the red blood cells. The baby can develop heart failure, infections, pneumonia, joint pains and stroke. Sickle cell anemia causes clogged blood vessels resulting in severe pain and other severe health problems. Family education, immunizations, genetic counseling and prompt treatment of acute illness improves the outcome for the child. Florida currently screens for three hemoglobinopathies.

Scurvy, Combined Inborn Errors of Metabolism (CIEO) is a group of inherited disorders that affect the immune system. At birth, these infants appear healthy while the mother’s immune system continues to protect them from infection for the first few weeks of life. If left untreated, these infants become extremely vulnerable to infections that will develop into a life-threatening illness. Early diagnoses and treatment will provide a better outcome.

Critical Congenital Heart Disease (CCHD) Screening

Babies born with critical congenital heart disease have an abnormality in the structure of the heart which is present at birth. Some babies can look and act healthy at first, and are sent home before the heart defect is detected. These babies are at risk for developing serious complications. Pulse oximetry is a non-invasive, painless test used to detect oxygen levels in the baby’s blood. Pulse oximetry screening can identify some, but not all babies with CCHD before they have symptoms or signs. Once early diagnosis is made, babies receive specialized care and treatment, leading to a longer, healthier life. The test is performed using a machine called a pulse oximeter with sensors placed on the baby’s skin. Screening is done when a baby is at least 24 hours of age or as late as possible if the baby is to be discharged from the hospital before first or she is 24 hours old.

Possible physical symptoms of CCHD:

• Cardiomegaly (heart enlarging)
• Troubled breathing
• Fasting heart
• Weak pulse
• Yellow or blue skin color
• Poor feeding
• Very sleepy

Why should my baby’s heart be tested?

• We test all babies to find the ones who may not be able to hear.
• If we find hearing loss early, there are many ways we can help your baby.
• Make sure your baby’s hearing is tested before you leave the hospital.

What should I know about the newborn hearing test?

• The test is safe and painless and can be done in about 10 minutes.
• The test results are available before you leave the hospital.
• If your baby is not referred for a follow up test, make sure he or she is tested again as soon as possible.

Can a newborn baby pass the hearing test and still have hearing loss?

• Yes, some babies will hear well enough to pass the first test, but lose their hearing later because of: some illnesses; some medicines; some injuries; and family history of hearing loss.
• Yes, you are worried about how your baby hears or talks, call your baby’s doctor right away and ask about getting a hearing test.

Newborn Hearing Screening

Hearing loss is a defect in the way a newborn hears. Treatment may involve the use of hearing aids or other listening devices and early intervention services.

Each year in the U.S., as many as 2 to 3 babies out of each 1,000, born, are deaf or hard of hearing.

Watch for signs of hearing loss as your baby grows. Use this list as a guide to things babies with normal hearing should be able to do for their age.

BIRTH–3 MONTHS

Jumps or blinks to loud sounds

Wakes up to loud sounds

Quiets or smiles when spoken to

Makes vowel sounds like “ahhh,” “ahhhh”

3–6 MONTHS

Looks for sounds with eyes

Starts babbling “babba,” “mamma,” “gagra”

Responds to your voice

Enjoys toys that make noise

Uses a variety of sounds, squeals, chuckles

6–9 MONTHS

Turns head toward loud sounds

Responds to his or her name

Begins to imitate speech sounds

Understands “no-no” or “bye-bye”

What if I have questions?

Ask your baby’s doctor if you have any questions or concerns. Visit www.floridahealth.gov/programs-and-services/children-health/newborn-screening/cchd-disorder.

What about my newborn’s eyes?

What if my hearing is tested?

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• If we find hearing loss early, there are many ways we can help your baby.
• Make sure your baby’s hearing is tested before you leave the hospital.

Why do some babies need another test?

• Some babies may need another test because of: fluid in the ear; previous positive results; baby was moving a lot or baby has hearing loss.
• Most babies who need another test have normal hearing. Some will have hearing loss.

Can a newborn baby pass the hearing test and still have hearing loss?

• Yes, some babies will hear well enough to pass the first test, but lose their hearing later because of: some illnesses; some medicines; some injuries; and family history of hearing loss.
• If your baby does not pass the hearing test makes sure he or she is tested again as soon as possible.

Can a newborn baby pass the hearing test and still have hearing loss?

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