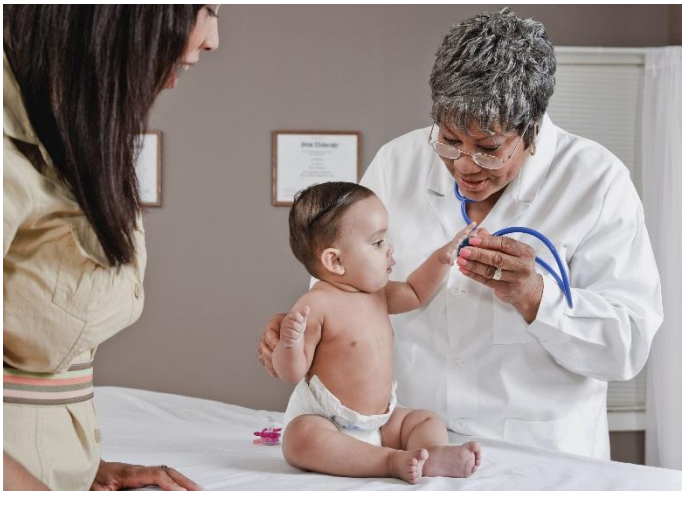
Newborn Screening FAQ

What are the legal requirements for newborn screening?

The legal requirements for newborn screening are that every baby in Georgia must be tested, prior to discharge from the hospital and regardless of the baby's age or feeding status. If the baby is tested and discharged before 24 hours of birth, the baby must be tested again, prior to one week of age. The only legal reason for not having newborn screening tests performed is if the parents object to such testing in writing for religious reasons.

What is my role as a parent?

Make sure you give your correct address and phone number to the hospital or provider where your baby was born. If you do not have a telephone, give the phone number of someone who knows how to reach you. If possible, give the name and phone number of the doctor who will take care of your baby after leaving the hospital and have them put this doctor's information on your baby's screening card.



Make sure your baby's doctor also has your correct address and phone number. Again, give another contact number if you do not have a telephone. It is important that your baby's doctor be able to contact you quickly if a re-test is needed. If you are asked to bring your baby for re-testing, do so as soon as you can. If your child does have a condition, quick action is very important.

But my baby looks healthy. Are the tests still necessary?

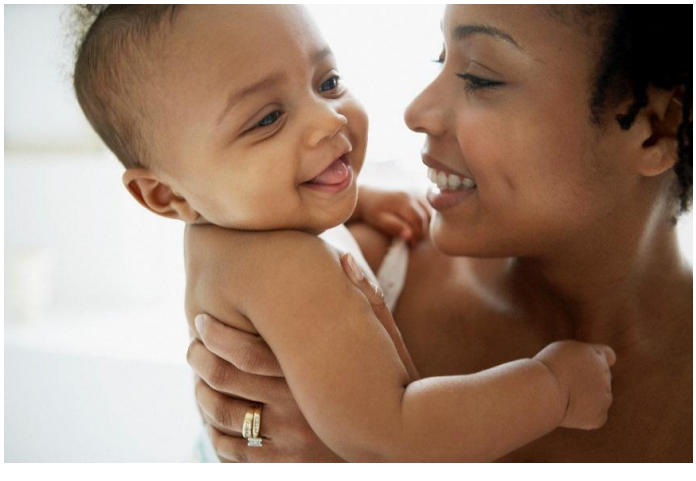
YES! Most infants with a condition found by newborn screening show no signs of the condition right after birth, and if a condition is present, it can usually be identified before the baby becomes sick or permanent damage is done. If an infant has a condition and there is a need for special care, your baby's doctor can be informed.

Do I have to give permission for my baby to be tested?

No. The law says that all babies born in Georgia must be tested. You may refuse testing only if it is against your religion. If you do not want to have the tests done, you will be asked to sign a statement that says you do not want to have your baby tested because of religious reasons. This statement will go in your baby's medical record.

Do I have to pay for this test?

A fee of $80.40 is currently billed to hospitals for specimens submitted for screening. Hospitals, medical offices, and local health departments may also charge a small fee to perform and send the test. If you had a homebirth, you may be required to pay for the initial newborn screen. However, all residents of Georgia have access to services, regardless of income. If you are told that your child cannot have this test because you cannot pay the fee, please call the Newborn Screening Program at (404) 657-4143.



Will I be told the tests results?

Your baby's doctor should be able to tell you these test results. Results are mailed to the hospital of birth and to the doctor listed on the screening card, which may or may not be your baby's current doctor. If you are seeing a different doctor than the one listed on the screening card in the hospital, the colored parent slip given to you after your baby's test was done can be given to your baby's doctor as a reminder to check your baby's results at the first health check–up.

If a re-test is requested, does it mean my baby has a condition?

No. There are several reasons why a repeat test may be needed. Before your baby goes home from the hospital, the hospital has to (by Georgia law) do the first test. The hospital also has to tell you if a second test must be done before one week of age. If the first test is done incorrectly or is unsatisfactory for testing, a second test is needed. Having to re-test for these two reasons does not mean that something is wrong with your baby. It simply means that another sample is needed so that the tests can be interpreted correctly.

Finally, if the first screen was abnormal for one of the conditions, a second screening test or a confirmatory test may be required. However, having an abnormal screen does not mean that your baby has a problem. The screening test does not confirm whether or not your child has a condition.

Instead, it finds those few babies, out of all those tested, who may need confirmatory testing. The confirmatory test will help verify whether or not your child has a condition.

Where can I go to have a re-test blood spot done?

Your baby's doctor may be able to do repeat tests at his or her office; if not, your local hospital, lab, or county health department should be able to do the test. The Sickle Cell Foundation of GA and the Hemoglobin Follow-up Program at Children's Healthcare of Atlanta will also collect repeat tests for abnormal hemoglobin results.

What happens if a newborn has an abnormal lab test result?

If the baby has an abnormal lab result that requires further action, the healthcare provider of the infant will be notified by the appropriate follow-up program. The parent(s) or guardian will also be contacted, if re-testing or some other action is needed.

If my child has one of the conditions, can it be treated?

There is treatment available for each of these conditions. The treatment may be a medication, special diet (or both), surgery, hearing aids, and/or special therapy. For more information on the type of treatment that is available for each condition, ask your doctor or contact one of the Georgia NBS follow-up providers.

Hearing FAQs

Why Screen for Hearing?

The newborn hearing screen is a test for hearing loss. All babies should be screened for hearing loss before 1 month of age. The screening is typically done before the baby leaves the birthing facility.

Why is the newborn hearing test important?

The most crucial period for language development is during the first year of life. Without newborn screening, hearing loss is typically not identified until two years of age. Screening for all newborns prior to discharge from the hospital, or birthing center, is essential for the earliest possible identification of hearing loss; and consequently, for language development, communication, educational, and reading potential to be maximized.

More than half of babies born with hearing problems are otherwise healthy and have no family history of hearing loss. If your baby has hearing loss, you can still help your baby develop language skills. The sooner you act, the better the outcome. Screening for hearing loss as early as possible is important to your baby because:

- Early screening allows for early treatment, if hearing loss is detected.
- Early treatment can provide earlier sound stimulation for your baby's brain.

Where are services located?

All birthing facilities in Georgia are regularly screening newborns for hearing loss, prior to hospital discharge.

What does the Newborn Hearing Program do?

As part of the Newborn Screening Program and Children 1st Program, the Early Hearing Detection and Intervention (EHDI or "Hearing") Program maintains and supports a comprehensive, coordinated, statewide screening and referral system.

EHDI includes:

- Initial screening for hearing loss in the birthing hospital;

- Referral of newborns who do not pass the initial hospital screening;
- Referral of newborns who do not pass the rescreening;
- Referral for diagnostic audiological evaluation and;
- Linkage to appropriate intervention for those babies diagnosed with hearing loss.

Technical assistance and training about implementing and maintaining a quality newborn hearing screening program is provided to hospitals, primary care physicians, audiologists, early interventionists, and public health staff.

CCHD FAQs

What is CCHD?

Critical Congenital Heart Disease (CCHD) can cause significant disability or death if undetected and requires intervention in infancy. CCHD is not always detected prenatally or upon exam in the nursery. As a result, some infants with CCHD are discharged from the nursery to home, where they quickly deteriorate.

CCHD was added to the Georgia newborn screening panel in 2014. The CCHD screen can detect 14 common congenital heart defects in newborns. Early detection and intervention for CCHD can help prevent disability and save lives.

CCHD screening is performed by medical staff at the birth hospital or birthing center before discharge. Pulse oximetry is a non-invasive test that is performed to measure the amount of oxygen in the infant's blood. An algorithm process is used to determine if further action is needed, such as a repeat screen or referral to a specialist. If the screen is failed, the medical provider will determine the next course of action, including whether or not immediate action is required.

Why screen for CCHD?

CCHD is a group of life-threatening heart defects that can cause severe disability or death. Intervention needs to occur within the first months of life, ideally within the first few days. Therefore, early detection through screening is imperative to decrease the risk of adverse outcomes. Screening is especially important to detect CCHD since affected infants can appear healthy. Screening can also detect other health issues that are not CCHD, but still need evaluation and treatment.

What is pulse oximetry?

Pulse oximetry is a test that is used to measure the amount of oxygen in the blood. It is a non-invasive test that is performed by placing one probe on the right hand for one measurement and either foot for a second measurement.

It does not harm the infant and is a relatively short test. This test can help determine whether or not an infant needs further intervention for CCHD.

What tests are included in the baby's heart screen?

CCHD screening using pulse oximetry can detect 14 common congenital heart defects. There are 7 primary targets and 7 secondary targets.

Primary Targets:

- Hypoplastic left heart syndrome
- Pulmonary atresia (with intact septum)
- Tetralogy of Fallot
- Tricuspid atresia
- Total anomalous pulmonary venous connection
- Truncus arteriosus
- Transposition of the great arteries

Secondary Targets:

- Single ventricle
- Coarctation
- Interrupted aortic arch
- Ebstein Anomaly
- Double-outlet right ventricle
- Aortic atresia
- Hypoplasia of aortic arch