



Tennessee Newborn Screening Program Information for Parents



Phone: 615-532-8462

Fax: 615-532-8555

Email: NBS.Health@tn.gov

Newborn Screening Overview

Newborn Screening is a set of tests that screens babies for serious, but treatable diseases. Newborn screening includes 3 tests called blood spot (heel stick), hearing and pulse oximetry screening.

Blood Spot Screening:

Screens for more than 65 diseases. Finding out an infant has one of the disorders soon after they are born can help keep the baby from having serious health problems, a disability or death.

How is testing performed?

Testing is performed by pricking your baby's heel and collecting a few drops of blood. The blood is placed on a special filter paper and sent to the State Laboratory in Nashville.

Hearing Screening:

Checks the baby for potential hearing loss. Identifying hearing loss early helps babies stay on track with their speech, language, and communication skills as they grow.

How is the hearing screening performed?

There are two ways to screen your baby's hearing. Both are safe and are usually done while your baby is sleeping. The first test, **Otoacoustic Emission (OAE)**, measures a tiny sound the ear makes when the baby is hearing properly. The second test, **Automated Auditory Brainstem Response (AABR)**, measures the baby's nerve response to sound. The doctor or nurse can tell you if the results are normal or abnormal immediately after the test.

Pulse Oximetry Screening:

Screens for a set of life-threatening heart defects known as critical congenital heart disease, or CCHD. If detected early, babies with CCHD can often be helped with surgery or other medical treatments.

How is the pulse oximetry screening performed?

A small strip, like a bandage, is placed around your baby's foot and/or hand. The strip has a special sensor that measures the oxygen level in your baby's blood. The doctor or nurse can tell you if the results are normal or abnormal immediately after screening.

In Tennessee, blood spot screening looks for more than 65 disorders that may affect:

- Blood cells
- Brain development
- How the body breaks down nutrients from food
- Lungs and breathing
- Hormones
- How the body fights infections

Hearing 1-3-6 Goals

1- All infants will be screened for hearing loss prior to discharge or before 1 month of age.

3- All infants who do not pass the screening will have a diagnostic audiological evaluation before 3 months of age.

6- All infants identified with hearing loss will receive appropriate early intervention services no later than 6 months of age.

Congenital Heart Disease is the most common birth defect and may be detected during either the prenatal or postnatal period. Failing to detect CCHD while in the nursery may lead to serious events. Early detection of CCHD can potentially improve the prognosis and decrease the risk of having a serious event.



Hearing Screening:

- Hearing screens should be performed once the baby is at least 12 hours old and greater than 34 weeks gestational age.

Question:

How do OAE (Otoacoustic Emission) and AABR (Automated Auditory Brainstem Response) test to see if my baby can hear?



Answer:

AABR:

- Uses earphones that produce clicks or chirps as stimuli to elicit a response from the brainstem.
- Responses are measured by electrodes/sensors on the skin.
- Results will be determined as Pass or Fail.
- Results will be available at the end of the screening.



OAE:

- Uses a probe placed in the ear that produces a sound to elicit an emission or "echo" from the cochlea (hearing organ).
- Responses are measured by a microphone in the equipment.
- Results will be determined as Pass or Fail.
- Results will be available at the end of screening.



Question:

Why are hearing screens important? What can it tell me about my baby's ability to hear?



Answer:

Hearing Screens Can:

- Identify babies that need additional hearing evaluation.
- Identify babies at a greater risk for hearing loss.
- Show that a baby hears some sounds usable for speech and language development.
- Give an opportunity for parent education regarding hearing and speech/language development.

Hearing Screens CAN NOT:

- Diagnose hearing loss.
- Identify every baby that has or will have hearing loss.
- Guarantee that hearing is normal.

Tennessee
Newborn Hearing
Screening
Program Website



MORE INFO

For a list of
audiology testing
centers in your
area



Pregnant now or in the last year?

Call your doctor if you have any of these urgent maternal warning signs!



Chest pain or rapid heartbeat



Severe swelling, redness, or pain in leg or arm



Severe nausea or vomiting



Dizziness or fainting



Overwhelming tiredness



100.4°F + fever



Vision changes



Severe belly pain that won't stop



Baby's movement slowing or stopping



Extreme swelling of hands or face



Headache that won't go away



Trouble breathing



Thoughts of harming yourself or your baby



Vaginal bleeding/fluid leaking *during* pregnancy



Heavy vaginal bleeding or discharge *after* pregnancy



These could be signs of very serious complications. If you can't reach a healthcare provider, go to the emergency room or call 911. Be sure to tell them you are pregnant or were pregnant within the last year.



Newborn Screening Quick Facts

- All babies born in Tennessee should have a newborn screening completed 24-36 hours after birth.
- After the blood spot is collected, it will be sent to the State Laboratory in Nashville for testing. Your baby's doctor will receive and review the results with you.
- Hospitals, Birthing Facilities and Midwives will complete the 3 newborn screening tests.
- The Goal of Newborn Screening is Early Testing for Early Treatment.
- A full list of disorders screened on the newborn screening can be found on our website: www.tn.gov/newbornscreening
- All blood samples are kept for one year, after testing is completed, to give time for the baby's doctor to ask for more tests.
 - After one year, blood samples with normal results and the form with identifying information are destroyed.
 - Blood samples that have a confirmed diagnosis are kept indefinitely; however the form with identifying information is destroyed.
 - If a blood sample is needed to help check the quality of the lab work or the test process, that sample may be kept for longer than a year, but the form with information that identifies your baby is separated and destroyed to make sure the source of the sample cannot be identified.
- The Newborn Screening Lab is open and performs testing 7 days a week.
- The State of Tennessee provides a courier for newborn screening dried blood spot specimens from the hospital to the State Laboratory.

Can I refuse screening for my baby?

Babies can be exempt from testing on their parent's religious beliefs. If you believe the tests are against your religious beliefs or practices, you must sign a refusal form. The refusal form will be sent to the Department of Health. You can get the form at the hospital or online at: https://www.tn.gov/content/dam/tn/health/program-areas/newborn-screening/PH-3686%20Refusal_Form%2006-17-21.pdf



My baby seems very healthy. Does my baby still need these tests?

YES! Most babies with one of these disorders will not have any obvious signs of illness at birth. The screening tests can detect these health conditions before problems begin. By testing every infant between 24-36 hours after birth, a baby who has one of these disorders will be identified early and doctors can start a treatment plan.



What To Expect After The Screening Is Complete And You Are Ready To Go Home: Next Steps

Screening Results:

Your baby's **hearing** and **CCHD (pulse oximetry)** screening results will be ready the same day your baby is screened. Before you leave the hospital, ask your baby's nurse or doctor to review the results with you. The **blood spot screening** takes a few days to complete, but your baby's doctor will contact you as soon as possible if the test shows your baby may have a problem. The first time you take your baby for a well-child doctor visit is also a good time to talk to your baby's doctor about the test results.

Next Steps if one of the Newborn Screenings is abnormal:

Question:
What happens if one of the test results is "Abnormal"?



Answer:

If the **blood spot screening** suggests that your baby may have a health problem, the Newborn Screening Follow-up Program will alert your baby's doctor about what to do next. Additional testing may need to be completed. You will be asked to bring your baby to the doctor's office as soon as possible. **It is important to get your baby to the doctor as soon as possible. Your baby will also be referred to a specialist doctor that treats these health problems.** The specialist doctor will help find out if your baby has a health problem. If your baby does have one of the health problems, the specialist doctor will work with your baby's doctor to start treatment. Starting medical treatment early may help lower, and often prevent, the serious problems caused by these diseases.

If your baby needs more testing or treatment after the **CCHD (pulse oximetry) screening**, the hospital will tell you what to do before you leave the hospital. Your baby may need to go to a different hospital to receive additional testing or follow-up with a heart doctor once you are discharged from the hospital.

If your baby needs more testing or treatment after the **hearing screening**, the hospital will tell you before you take your baby home. An outpatient appointment will need to be made for repeat hearing screen or diagnostic testing. Your provider will need to make a referral to an audiology center.

Question:
If a repeat screen is needed, does that mean my child is sick or cannot hear?



Answer:

Not necessarily. Repeat testing may be needed to find out if your child has a health problem that needs more tests or treatment. It is important to get the repeat test as soon as possible.

If one of my children has a disorder, will my future children have it too?

They might. Families who have a child with one of these health problems should speak to the specialist to get information about what their chances are that future children may have the same health problem.



What conditions are screened for in Tennessee?

Tennessee's newborn screening program tests for more than 65 health conditions. For the most up to date list of these health conditions, please visit the Tennessee Department of Health Newborn Screening Program website: www.tn.gov/newbornscreening



Why are Newborn Screenings done?

Babies with these diseases may seem completely healthy and normal at birth. If not treated, babies can get very sick and develop serious health problems. Some health problems have to be treated early to prevent possible death.



Is there anything else I need to do?

A B C D

Ask ✓

- Hospital staff or your midwife if the newborn screening was done.

Be Sure ✓

- The hospital or midwife and your baby's healthcare provider have the right phone number and address to reach you.
- The hospital or midwife has the correct doctor listed for your baby.

Check ✓

- With your baby's doctor or midwife about the newborn screening results for the blood spot, hearing and CCHD screening.

Directions ✓

- Follow instructions from your baby's doctor if more tests or medical appointments are needed.

Tear Here

Notes/Questions

MORE INFO

To learn more about newborn screening or locate your local health department for appropriate follow-up, contact your baby's doctor or visit one of the websites below:

- **Tennessee Department of Health Newborn Screening Program:**
www.tn.gov/newbornscreening
- **Tennessee Local Health Departments:**
 - <https://www.tn.gov/health/health-programareas/localdepartments.html>
- **Baby's First Test:**
www.babysfirsttest.org
- **Save Babies through Screening Foundation**
www.savebabies.org
- **Centers for Disease Control and Prevention**
www.cdc.gov/newbornscreening



Hospital staff should review the following information with parents if the specimen was collected less than 24 hours of age and the baby is being discharged home.

To be sure the screening results are accurate; babies who go home and have had a newborn screening blood spot specimen collected prior to 24 hours of age must be rescreened. Your baby's specimen was collected when they were less than 24 hours old and will need to be repeated as soon as possible after your baby is at least 24 hours old. Take your baby to the doctor or local health department to have the specimen recollected.

What if we have no family history of these conditions?

Most babies with these health problems are born to families with no history of the problems and/or who already have other healthy children.



Pulse Oximetry Screening:

- The pulse oximetry screening for critical congenital heart disease is performed when the baby is at least 24 to 36 hours old.

Question:
What does the pulse oximetry sensor look like when they perform the test?



Answer:

The pulse oximetry sensor is a small strip like a bandage that is placed around your baby's foot or hand. The sensor measures the oxygen level in your baby's blood.



Question:
How does critical congenital heart disease affect an infant?



Answer:

Sometimes when an infant is born, parts of the fetal (before birth) blood-pumping system can continue to work hiding the signs and symptoms of CCHD. This makes it possible for an infant with CCHD to appear healthy and be discharged home without knowing they have a heart defect. Signs and symptoms are related to the type and severity of the heart defect. An infant may show shortness of breath, turn a grayish-blue color, have poor feeding habits, cold hands and feet, or be unusually sleepy or inactive.

Question:
What causes Congenital Heart Defects?



Answer:

Despite much research, in the majority of the cases heart defects occur without any known cause. However, since genetic and hormonal factors play a role in the development of the heart in the fetus, some defects may arise due to genetic "syndromes". During pregnancy other health and environmental factors may contribute as well: maternal obesity, gestational diabetes, German measles, systemic lupus erythematosus, cigarette smoking, certain medications and alcohol and opioid use.



Hearing Screening:

Question:
What does it mean if my baby does not pass the hearing screening?

Answer: It does not necessarily mean that your baby has hearing loss. A baby can fail the hearing screening for several reasons. It does mean more testing is needed. Additional testing is the only way to find out how your baby hears. It is important to have follow-up testing done as soon as possible. Your baby should have an appointment with an audiologist (hearing specialist) for this testing.



Question:
Can my baby pass the hearing screening and still have hearing loss?

Answer: Yes, some babies hear well enough to pass the hearing screening but have some hearing loss or lose hearing later due to illness, injury, some medicines, or a family history of hearing loss. Babies who have certain risk factors for hearing loss may need testing when they are older to make sure their hearing has not changed. Your baby's doctor will help you know if your baby needs more testing. Watch for signs of hearing loss and talk with your baby's doctor if you are worried.



Your Baby's Hearing Checklist

Birth to 3 months

- Quiets to familiar voice
- Startles to loud sounds

3 to 6 months

- Enjoys toys that make sound
- Responds by cooing
- Watches speaker's face

6 to 9 months

- Turns head towards voices
- Babbles (bababa)

9 to 12 months

- Follows simple directions
- Responds to own name
- Imitates sounds

12-18 months

- Says 10-20 words
- Understands "yes-no" questions

18 to 24 months

- Says more than 50 words
- Uses 2-word phrases

Your Baby's Pulse Oximetry Results

Date: _____

O2 Sat %: _____

Results: Pass or Fail

Next Steps:

- No additional Follow-up is required.

- Baby did not pass the Pulse Oximetry Screening for CCHD. Hospital staff will discuss next steps.



Your Baby's Hearing Screening Results

Date: _____

Type of screen: AABR OAE

Results: **Right Ear** **Left Ear**

Pass

Fail

Could not test

Next Steps:

- No other hearing testing is needed for your baby unless you have concerns.

- No other hearing testing is needed at this time, but your baby has a risk factor for hearing loss. Talk with your baby's doctor about when to have more testing.

- More hearing testing is needed as soon as possible. Ask your baby's doctor to help you schedule an appointment.

Facility Staff, after education is provided to family:

- Have parent/guardian sign
- Staff sign as witness
- Remove signed acknowledgment form as proof of documentation that educational material was provided and place in patient record.

Acknowledgement of Received Educational Materials

By signing below, you indicate that you were provided with the pamphlet by your baby's birthing facility or provider.

On ___/___/___ at ___:___

I, _____, **(Parent/Guardian)**
was provided with a pamphlet about newborn screening.

Witness: _____

Date and Time ___/___/___ ___:___

