

Educational Material Provided

Every baby born in the State of Tennessee is tested for rare, treatable disorders. The Newborn Screening Program provides the parents/guardian with an educational pamphlet to inform them about the testing and also addresses some of the most common questions about newborn screening.

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

On ____/____/____

I, _____ was provided with a pamphlet about newborn screening.

Parent or Guardian

Witness: _____ Date: ____/____/____

Facility staff:

Remove proof of documentation that educational material was provided and place in patient record.

Tennessee



Newborn



Screening



Program



Department of
Health



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NEWBORN SCREENING BASICS

What is newborn screening?

Newborn screening is a set of tests that check babies for serious, rare diseases. Most of these diseases can be cured or treated if found soon after the baby is born. Newborn screening includes three tests called blood spot, hearing and pulse oximetry.

- **Blood spot screening** checks for more than 50 rare but treatable diseases. Finding out a baby has any of these diseases soon after it is born can help keep the baby from having serious health problems, a disability and even from dying.
- **Hearing screening** checks for hearing loss. Identifying hearing loss early helps babies stay on track with their speech, language and communication skills as they grow.
- **Pulse oximetry screening** checks 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.

Why are newborn screenings done?

Babies with these diseases may seem completely normal at birth. However, if the health problems aren't treated, babies can get very sick and develop serious health problems. Some health problems have to be found and treated early to prevent possible death of the baby.

Who is screened?

The law requires that every baby born in Tennessee be tested.

How are babies tested?

- **Blood spot screening:** The hospital or birthing facility gets a drop of blood by pricking your baby's heel. The blood is placed on a special filter paper and sent to the State Laboratory.
- **Hearing screening:** There are two ways to screen your baby's hearing. Both are safe and are usually done when your baby is asleep. The first test measures a tiny sound the ear makes when the baby is hearing properly; this test is called an Otoacoustic Emissions (OAE) test. The second test measures the baby's nerve response to sound. This is called an Auditory Brainstem Response (ABR) test.
- **Pulse oximetry:** 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.

Hospital Staff:

Review the following information with parents if the specimen was collected <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 specimen collected prior to 24 hours of age must be rescreened. Your baby's specimen was collected when he or she was less than 24 hours old and will need to be repeated when your baby is between 24-48 hours of age. Take your baby to your pediatrician or local health department to have the specimen recollected.

FOR MORE INFORMATION

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

Tennessee Department of Health Newborn Screening Program

<https://www.tn.gov/health/health-program-areas/newborn-screening.html>

Baby's First Test

<http://www.babysfirsttest.org/>

Save Babies Through Screening Foundation

<http://www.savebabies.org/>

NewSTEPS

<http://newsteps.org>

Centers for Disease Control and Prevention

<http://www.cdc.gov/newbornscreening/>

Where are newborn screenings done?

All screenings are performed in the hospital or birthing facility. The blood sample is sent to the State Laboratory in Nashville for testing. Your baby's doctor can give you the results of the blood sample test. The hearing screening results and CCHD results are available right after the screening is done. Your baby's doctor or nurse can discuss the results with you. Most of the time, parents are only told about the hearing and CCHD test results if the baby needs a repeat screening; this means if the tests are fine and no problems were found, you may not get a call or

other notice about the results of these tests. You can ask about the result when you take your baby to the doctor for a regular checkup.

When are newborn screenings done?

Screenings are done before you take your baby home from the hospital. If your baby is not born in a hospital, the tests are done between 24-48 hours after your baby's birth.

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

YES! Most babies with the health problems these tests look for won't show any obvious signs of disease at birth. The screening tests can detect these health conditions before problems develop. By testing every baby between 24-48 hours after its birth, a baby who has one of these diseases will be identified and doctors can start a treatment plan.

What health problems are screened for in Tennessee?

Tennessee's newborn screening program tests for more than 50 health problems. For the most up-to-date list of these health problems, visit the Tennessee Department of Health's newborn screening program website at <https://www.tn.gov/health/health-program-areas/newborn-screening/newborn-screening/newborn-genetic-screening/for-parents.html>.

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.

What happens to my baby's blood spot after the screening at the lab?

Blood samples are kept for one year to give time for the baby's doctor to ask for more tests. After one year, both the blood sample and the form with information that identifies your baby are destroyed.

If a blood sample is needed for helping check the quality of the lab work



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or the test process, that sample may be kept for longer than one year if the form with information that identifies your baby has been separated from the sample and destroyed, to make sure the source of the sample cannot be identified.

Can I refuse screening for my baby?

Babies can be exempt from testing based on their parent's religious beliefs. If you believe the tests are against your religious beliefs or practices, you must sign a written statement. The statement will be sent to the Department of Health. You can get this form from the hospital or birthing facility where you have your baby, or find it online at https://www.tn.gov/content/dam/tn/health/program-areas/newborn-screening/Refusal_form_8-2017.docx.

What is the Tennessee Birth Defects Registry?

The Tennessee Birth Defects Registry is not part of the Newborn Screening Program; however, it is operated by the Tennessee Department of Health.

The Tennessee Birth Defects Registry, or TBDR, was created in June 2000 to provide annual information on birth defects. The TBDR gets information from birth and death certificates. This information is collected and kept secure by the Tennessee Department of Health. TBDR does a report on birth defects every year. No information that identifies any baby or person is contained in the report.

AFTER THE TEST

When will I get my baby's results?

Your baby's hearing and pulse oximetry test results will be ready the day your baby is screened. Be sure to ask your baby's health care provider to discuss the test results with you.

The blood spot test takes a few days, but your baby's health care provider 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 health care provider about the test results.

What happens if one of the test results is "abnormal"?

If any of the tests from the blood drops show a possible health problem, the follow-up program will contact your baby's doctor or the health department right away to ask for another blood sample. You will be asked to bring your baby in to the doctor as soon as possible. It's very important

to get your baby to the doctor as soon as you can. Your baby will be referred to a doctor who specializes in the health problem to confirm if it does have that problem, and to get treatment if it does. You should make sure the hospital where your baby is born has the right name, address and phone number for you in case your baby needs more tests. Remember, it is very important to get these tests quickly after your baby is born.

If your baby needs more testing or treatment after the hearing screening, the hospital will tell you before you take your baby home. You will get a letter to remind you to have your baby's hearing tested again.

If your baby needs more testing or treatment after the CCHD testing, the hospital will tell you what to do before you leave the hospital.

If a repeat screen is necessary, does that mean that my baby is sick or cannot hear?

Not necessarily. Repeat testing may be needed to find out if your child has a health problem that needs more tests or treatment.

There are several reasons your baby may need to repeat the hearing test. If your baby's doctor thinks the baby is at risk for hearing loss, the doctor will need to check on the baby's hearing until he or she is three years old. You and the baby's doctor will get reminder letters about the hearing tests that your baby needs.

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

They might. Families who have a child with one of these health problems should get information about their chance that any other children they may have will have the same health problem. You can get that information from the Tennessee Genetics Network. Find out about this program and how to get in touch with them at <https://www.tn.gov/health/health-program-areas/newborn-screening/newborn-screening/newborn-genetic-screening/additional-resources.html>.

If my baby has one of the health problems, can it be cured?

It cannot be cured, just as you can't permanently change eye color or how tall the baby will be. However, starting medical treatment early may help lower, and often prevent, the serious problems caused by the disease.