

What does it mean if my baby has an abnormal heelstick screen?

There are several reasons why a baby's heelstick screen can be abnormal. It is important for parents or guardians to know that an abnormal result does not always mean that your baby has one of the conditions on the newborn screen list.

If your baby has an abnormal heelstick screen, this means that the results require additional tests. Ask your baby's healthcare provider to discuss with you your next steps for diagnosis and care. If a repeat heelstick is needed take your baby back to his/her birthing facility as soon as possible. You should not have to pay for the second heelstick.

What does it mean if my baby does not pass the hearing screen?

If your baby does not pass his/her hearing screen, it does **NOT** necessarily mean that he/she has hearing loss. There are several reasons why a baby may not pass his/her hearing screen. For example, some babies are crying or moving around during the hearing screen. Some babies have fluid in their ears.

If your baby does not pass his/her newborn hearing screen, your baby's birthing facility or healthcare provider should help you make an appointment with an audiologist (a healthcare professional who specializes in hearing). The audiologist will give your baby a complete diagnostic audiological (hearing) evaluation. This evaluation is done to determine how well your baby is hearing and look for possible causes of hearing loss.

What does it mean if my baby does not pass the pulse oximetry screen?

Pulse oximetry newborn screening (also called "pulse ox") is a test that measures how much oxygen a baby has in his/her blood. Babies who have low oxygen levels (meaning there is not much oxygen in the baby's blood) may have one of the 7 critical congenital heart disease (also called CCHD) conditions.

If a baby does not pass the pulse oximetry screen, then the level of oxygen in the baby's blood was low or that there was a difference of more than 3% between the pulse oximetry results in the baby's hand and foot. *It is important for parents to know that there are several reasons why a baby does not pass the pulse oximetry screen.*

Your baby's doctor will perform a thorough physical examination to figure out why your baby did not pass his/her pulse ox newborn screen. Your baby may also receive an echocardiogram (an ultrasound of the heart) to look for CCHD.

How will I find out about my baby's newborn screening results?

Please ask your child's healthcare provider about his/her newborn screening results during your next visit with your healthcare provider.

For more information, please contact us at ISDHNBS@isdh.IN.gov or visit the ISDH Newborn Screening Program website at www.nbs.in.gov.



Indiana State
Department of Health

Genomics & Newborn
Screening Program



NEWBORN SCREENING

in Indiana

{Information Parents Need to Know}



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What is newborn screening?

Newborn screening is used to describe a special set of tests that help identify babies who are at risk for certain conditions. A newborn baby may look healthy, but he/she can have a serious condition that cannot be seen.

Newborn screening is important because it saves lives! In Indiana, every baby who has newborn screening is checked for 49 genetic (meaning inherited, or passed, from parent to child) conditions. Through newborn screening, babies who have these conditions can get treatment shortly after birth, which can prevent serious health problems, including developmental delay or death.

How is newborn screening done in Indiana?

According to Indiana's newborn screening law, every baby born in Indiana must be tested (or screened) for a total of 49 conditions. There are three different tests that are done as part of Indiana's newborn screen:

- A blood test, called a **heelstick** (a small amount of blood is taken from the baby's heel)
- A **hearing screen** to identify possible hearing loss
- A **pulse oximetry screen**, which checks babies for critical congenital heart disease (also called CCHD)

If a baby is born at a hospital or birth center, newborn screening must be done before the baby leaves the hospital. Babies born at home must have newborn screening within one week of birth.

Can a baby's parent(s) or legal guardian(s) refuse (or say no) to newborn screening?

In Indiana, newborn screening is mandated (or required) by state law. The only legal reason that any of the three newborn screens may be refused is due to religious beliefs. Please ask your healthcare provider for a religious waiver if desired.

What conditions are included on Indiana's newborn screen?

- **Critical congenital heart disease:**
Also called CCHD, critical congenital heart disease occurs when a baby's heart does not develop properly. In Indiana, we target 7 different heart defects using pulse oximetry newborn screening. All of these defects require some type of treatment (usually surgery) soon after birth.
- **Endocrine conditions:**
A person with an endocrine condition is not able to produce enough of a certain hormone. Hormones are proteins that tell our bodies how to grow and develop.
- **Severe Combined Immunodeficiency:**
Severe Combined Immunodeficiency (SCID) is a condition present in a baby at birth where the body doesn't have an immune system that works well. The body is not able to fight infections without a good immune system.
- **Spinal Muscular Atrophy:**
Spinal Muscular Atrophy (SMA) is a disorder that affects the nervous system. SMA damages the nerve cells that control the muscles. Because of this, a child with SMA cannot move or breathe normally and will get weaker over time.
- **Metabolic conditions:**
A person with a metabolic condition is not able to break down fats or proteins from food.
- **Hearing loss**
Simple tests can be used to screen a baby's hearing immediately after birth. It is important to find hearing loss early so a baby has the best chance possible to learn to communicate.
- **Sickle cell anemia & other hemoglobinopathies:**
Hemoglobinopathies are conditions where a person has abnormal hemoglobin. A person's blood cells use hemoglobin to carry oxygen from the lungs to other parts of the body.
- **Cystic fibrosis (CF):**
Cystic fibrosis is a condition that most commonly causes frequent respiratory infections and digestive problems (such as failure to gain weight).

What does it mean if my baby has an invalid heelstick screen?

First, it is important for parents/guardians to know that an invalid heelstick screen does NOT mean there is anything wrong with your baby! Sometimes, a baby's heelstick may need to be repeated because of poor sampling that prevents test completion. There are several reasons why a baby may need to have a second heelstick. For example:

- Some heelstick samples don't have enough blood to test for all of the conditions.
- Some samples are drawn too early, which means that the test results may not be accurate (or correct).
- Some babies have a result that needs to be confirmed with a second heelstick.

If your baby has an invalid heelstick screen, ask your baby's doctor or healthcare provider to order another heelstick at the birthing facility where your baby was born. Take your baby back to his/her birthing facility as soon as possible. You should not have to pay for the second heelstick.

