

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

If your baby has an abnormal heel stick screen, this means that your baby's heel stick screen had a result that requires another heel stick sample to confirm. There are several reasons why a baby's heel stick 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.*

If your baby has an abnormal heel stick, ask your baby's doctor or PCP to order another heel stick 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 heel stick.

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 your baby has a permanent hearing loss. When a baby does not pass a hearing screening, it means that the baby needs more testing. There can be simple reasons for this, but without further testing, we cannot be sure how your baby hears.

If your baby did not pass his/her hearing screen, your baby's birthing facility and/or PCP should help you make an appointment with an audiologist. The audiologist will be one who is skilled at testing infants. He or she will give your baby a complete diagnostic audiological (hearing) evaluation. This 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 critical congenital heart disease (also called CCHD).

If a baby does not pass the pulse oximetry screen, that means that 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 & 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 PCP about your child's newborn screening results during your child's next visit to the PCP's office.

For more information, please contact us at **(888) 815-0006** or visit the ISDH Newborn Screening Program website at **www.nbs.in.gov**.



NEWBORN SCREENING

in Indiana

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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 45 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 mental retardation 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 47 conditions. There are three different tests that are done as part of Indiana's newborn screen:

- A blood test, called a **heel stick** (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, 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 a child's parent(s) or legal guardian(s) may object to newborn screening is due to his/her/their religious beliefs.

What conditions are included on Indiana's newborn screen?

- **Critical congenital heart disease:** (also called CCHD) CCHD occurs when a baby's heart does not develop properly. In Indiana, there are 7 different heart defects that can be identified with pulse oximetry newborn screening. All of these defects require some type of treatment (usually surgery) soon after birth.
- **Cystic fibrosis (also called CF):** Cystic fibrosis is a condition that most commonly causes frequent respiratory infections & digestive problems (such as failure to gain weight).
- **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 & develop.

- **Hearing loss**
- **Metabolic conditions:** A person with a metabolic condition is not able to break down fats or proteins from food.
- **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.

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

First, it is important for parents/guardians to know that an invalid heel stick screen does NOT mean there is anything wrong with your baby! Sometimes, a baby's heel stick may need to be repeated because it is invalid (meaning that the heel stick screen cannot be done). There are several reasons why a baby may need to have a second heel stick. For example:

- Some heel stick 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 heel stick.

If your baby has an invalid heel stick screen, ask your baby's doctor or primary care provider (also called PCP) to order another heel stick 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 heel stick.

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