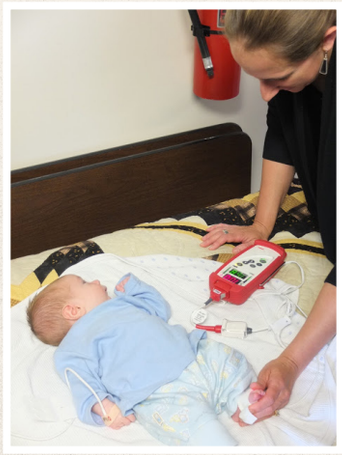
Quick Facts

- Newborn screening helps us find babies with certain serious health conditions so they can begin treatment right away.
- The three tests included in newborn screening can identify certain heart problems, hearing loss, and rare but treatable genetic conditions.
- Babies with these conditions appear healthy at birth and may not show symptoms for a few weeks or months.
- The tests and machines used in screening are safe and do not harm the baby.
- Newborn screening is performed in the first few days after birth. If a positive result is detected, specific follow-up testing will determine for certain if the baby has a problem.
- Newborn screening is important for all babies born at home, in hospitals, or birthing centers.

Our Recommendations

The Clinic for Special Children recommends that all babies have newborn screening.

Please contact your midwife or doctor with any questions.



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What Parents Need to Know

Newborn Screening

Clinic *for* Special Children

Metabolic
(Heel Prick)

Why should I test?

Most infants look fine when born but could have a serious health problem. **Finding** and **treating** an illness **quickly** reduces or prevents problems with growth, eating, and quality of life.

How is the test conducted?

Around 24 hours after birth, the baby's medical provider will take a few drops of blood from the heel of the baby's foot. The blood is placed on a small card, and the card is sent to a laboratory to be screened for many different metabolic and genetic conditions.

Parents will be contacted if the results are positive or unclear and the baby needs a follow-up test.

What is my baby tested for?

Babies born in Pennsylvania are all tested for 10 conditions, including spinal muscular atrophy (SMA), maple syrup urine disease (MSUD) and phenylketonuria (PKU). These are known as **mandatory** tests. SMA and MSUD are more common in Mennonite babies; PKU is found in both Amish and Mennonite.

Testing for other conditions found in the Plain community, such as Glutaric Aciduria Type 1 (GA1) and Severe Combined Immunodeficiency (SCID) can also be tested as a part of the **supplementary** panel. No additional blood is needed for this testing, but the additional testing has a small fee.

Hearing

Why should I test?

It is very hard to determine if young babies have hearing loss; they can appear to have normal hearing even when they are unable to hear properly.

The test detects different degrees of hearing loss. Some forms of hearing loss are genetic and found in babies of Plain descent.

With early treatment, a child with hearing loss has the best chance to build normal language skills.

How is the test conducted?

The hearing test is painless, safe, and noninvasive. The baby will be sleeping when the test is performed. A baby may be retested or referred to a doctor if results are not normal.

Pulse-Oximetry

Why should I test?

Pulse-oximetry can find serious heart problems or other health issues that are not apparent by newborn physical exam.

The test is noninvasive, painless, and quick: small sensors are placed on the right hand and either foot of the baby for about a minute. This test checks for low oxygen levels in blood that can indicate a heart problem or other health concern such as infection or lung concerns.

When should I test?

Pulse-oximetry is ideally performed 24 to 48 hours after birth. A positive screening test does not always mean the baby has a heart problem, but follow-up testing may be needed to determine this for certain.

Where are tests performed?

This test is routinely performed in hospitals and birthing centers, as well as by many midwives following at-home deliveries. There may be a fee associated with testing.