Facts About North Carolina Newborn Screening

Most babies are born without health conditions, but a few babies have certain health conditions that may be missed during pregnancy or early in life. Newborn screening is the best way to find and help treat serious health conditions before a baby becomes sick.

North Carolina does a blood test to check newborns for over 50 health conditions. Some of these conditions can be life-threatening early in life, and others can cause serious long-term problems if they are not treated early. Fortunately, most of these conditions have effective treatments. If they are caught soon at birth, they can be treated to prevent future problems.

How is your baby tested?
Before you leave the hospital or birthing center, a doctor or nurse will prick your baby’s heel with a needle to collect a few drops of blood. Then they’ll send the blood to the North Carolina State Laboratory of Public Health (http://slph.ncpublichealth.com/newborn) in Raleigh for testing. All babies are tested this way.

What is your role?
After you get home from the hospital, you may be contacted by your baby’s doctor to bring your baby in to get another blood sample. It’s important that you respond quickly. If you have concerns about the test results, please contact your baby’s doctor.

What is included in the test?
North Carolina tests your baby for over 50 health conditions that can be treated by your baby’s doctor (http://slph.ncpublichealth.com/newborn/ConditionsTested.asp).

Can your baby have any of these conditions even if your family has no history of them?
Most of these health conditions are passed down in families through genes (units of DNA controlling inherited traits). Sometimes a baby is the first person in the family to have the condition. This is because most rare conditions require both parents to be carriers of the gene for the baby to be affected. A person who is a carrier has a non-working gene that can be passed to their child but has another working copy of the gene that keeps them healthy. Please note that newborn screening does not identify all carriers of genetic disorders in babies or their parents.

Can you choose not to have your baby tested?
Your baby’s doctor must submit a blood sample for the regular newborn screening test unless you object. If you do not want your baby tested, then you must provide your refusal in writing, which will be added to your child’s medical record.
What is Early Check?

Early Check is a research study that offers two extra screening tests for fragile x syndrome and spinal muscular atrophy. These are rare but serious health conditions. The Early Check screening tests are free, and no appointments are needed. It’s up to parents to decide whether or not to sign up their babies. Early Check is for babies born in North Carolina and currently living in North Carolina or South Carolina. The babies must have received regular North Carolina newborn screening.

Are newborn screening and Early Check the same?

Early Check is not the same as regular North Carolina newborn screening. This table shows the differences.

<table>
<thead>
<tr>
<th>Early Check</th>
<th>Regular newborn screening</th>
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</thead>
<tbody>
<tr>
<td>Parents must give permission for their baby to be screened</td>
<td>Yes</td>
</tr>
<tr>
<td>There are treatments for babies with the health conditions, which can greatly improve their symptoms</td>
<td>Maybe*</td>
</tr>
<tr>
<td>Type of program</td>
<td>Research</td>
</tr>
<tr>
<td>Who notifies parents about the results</td>
<td>Study team</td>
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</table>

*There are no cures for these health problems, but there are resources to help babies get the best start. Researchers are looking for better treatments.

Regular newborn screening is automatic for all babies in North Carolina, but you will need to choose to join Early Check. If you choose not to enroll your baby in Early Check, your baby will still have regular newborn screening just like other babies in North Carolina.

Learn More

North Carolina State Lab Newborn Screening Program: [http://slph.ncpublichealth.com/newborn](http://slph.ncpublichealth.com/newborn)

Baby’s First Test: [http://www.babysfirsttest.org/](http://www.babysfirsttest.org/)

Early Check: [https://earlycheck.org/](https://earlycheck.org/)