What is Early Check?
When babies are born in North Carolina, they get a heel prick to test for certain health conditions. This is called regular newborn screening. Early Check is a research study that offers two extra 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 babies currently living in North Carolina or South Carolina. The babies must have received regular North Carolina newborn screening.

What are the benefits of taking part in Early Check?
- **Knowledge is power.** Participating in Early Check can help you know whether your baby has a rare health condition. In the rare case that your baby has a condition, the sooner you know, the better.
- **The process is free and painless.** The extra tests don’t require any extra blood to be drawn from your baby. They use blood that is already taken through a regular heel prick after birth. You can sign up without a doctor.
- **You can make a difference.** Right now, there is no cure for the health conditions that Early Check tests for. By taking part in Early Check, you’ll help us find treatments for rare health conditions and improve the lives of babies everywhere.

How is the screening done?
A small amount of blood is taken from a baby’s heel as part of regular newborn screening shortly after birth in the hospital or birthing center. We use that same blood to do the Early Check screening.

Does it cost money to participate?
No. There are no charges to you or your insurance plan for taking part in Early Check. The costs are covered by the study.

Also, Early Check will provide **for free:**
- A second test for any baby with a screening test that’s not normal
- Genetic counseling for parents if the second test confirms the diagnosis of a health condition
- A review of the baby’s development
- Help finding doctors and support services

Early Check does not pay for:
- Any other tests, office visits, treatments, and other long-term care needs for the baby

You signed up for Early Check. What’s next?
That’s it! There’s nothing else you need to do. The Early Check team has your information and will conduct the 2 extra tests using the blood sample drawn from your baby after birth. After the tests, Early Check will contact you with the results. Most parents get their baby’s Early Check results before the baby is 2 months old. Early Check looks for rare health conditions, so **most parents get a normal test result for their baby.**
Is Early Check the same as regular newborn screening?

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

<table>
<thead>
<tr>
<th></th>
<th>Early Check</th>
<th>Regular newborn screening</th>
</tr>
</thead>
<tbody>
<tr>
<td>Parents must give permission for their babies to be screened</td>
<td>Yes</td>
<td>No</td>
</tr>
<tr>
<td>There are treatments for babies with the health conditions that can greatly improve their symptoms</td>
<td>Maybe*</td>
<td>Yes</td>
</tr>
<tr>
<td>Type of program</td>
<td>Research</td>
<td>Public Health</td>
</tr>
<tr>
<td>Who notifies parents about the results</td>
<td>Study team</td>
<td>Baby’s doctor</td>
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*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.

While regular newborn screening is automatic for all babies in North Carolina, you will need to choose to take part in 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.

Who has access to your baby’s blood sample?

The North Carolina State Lab (http://slph.ncpublichealth.com/) conducts tests on your baby’s blood sample as part of regular newborn screening. Once that testing is completed, and if you agree, the Early Check team will test the same blood at the same location. Your baby’s blood sample will be kept for 5 years in the screening computer database. If you have questions about the storage of your baby’s blood sample, call the North Carolina State Lab: 919-733-3937.

How is your information protected?

The Early Check team works hard to protect your information. We protect the privacy and security of parents’ and babies’ information by keeping it in a special area on a secure and private network that it is held to high security. It is never possible to guarantee that a system is completely secure, but we have many strong tools in place to protect your information.

What if you don’t want to take part in Early Check?

Early Check will only use your baby’s blood sample if you agree. It is your choice. If you decide not to take part in Early Check, your baby will still have regular North Carolina newborn screening and follow up. Your baby’s doctor will still receive the results of regular newborn screening.

Can you withdraw from Early Check?

Yes, you can change your mind and withdraw from Early Check at any time. But if the baby’s Early Check screening test has already been done, we’ll still contact you if the screening test is not normal. If you would like to withdraw from Early Check, contact us immediately by calling 866-881-2715.

Will you be contacted for any other reasons?

If you take part in Early Check, we might contact you to see if you’re interested in participating in future research studies.

What if you still have questions?

If you have questions before or after signing up for Early Check, please email or call us:

Email: support@earlycheck.org
Phone (toll-free): 866-881-2715

Note: This FAQ list does not take the place of talking with your doctor. If you have questions or concerns about whether Early Check is right for you, talk to your doctor before signing up.