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Newborn Screening Information

What is the Newborn Screening test?

- The newborn screening test is a blood test that looks for disorders that are very rare but serious.

How is the test done?

- The blood test is done by making a small prick on the baby's heel. A few drops of blood are placed on a special paper and sent in for testing. (see below for comfort measures)

Why would I want the Newborn Screening test?

- There is a family history of metabolic or genetic disorders from the maternal or paternal side of the family. Or if the maternal or paternal family history isn't known.
- Newborn babies with these conditions may look healthy in the first few days. By the time symptoms start to become obvious, there could be various levels of damage done already. Babies with these disorders can become mentally retarded, very sick, or even die if treatment isn't started early.
- Although there is no cure for these disorders, babies that get treatment early can prevent/reduce serious problems and even death. Early treatment can help most babies with these conditions grow, develop normally, and live healthy lives.

What does the law say?

- State law requires that all babies born in Colorado be tested. Parents do have the right to refuse both or one of the newborn screenings. Colorado requires that all babies should be tested because it is felt that the potential for prevention outweighs all other issues.

When is the test done?

- The first test is done before the baby is 3 days old. There are also some diseases that could cause severe illness by one week of age if not treated right away.
- The second test is more accurate and it screens for some conditions that the first test wouldn't have detected yet. This test should be done between 8-14 days old.

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What happens if the test comes back positive?

- If a test comes back positive, then the person that performed the test will be notified immediately. You will then be referred to a specialist to have more tests done. A positive test does not guarantee that your baby has one of these conditions. It just means that more tests are needed. Otherwise, the results take about two weeks to come back to your midwife or care provider.

How is the test paid for?

- Insurance and Medicaid will pay for this test. You can also pay for it in cash. Talk to your midwife about which option is best for you.

What can I do to comfort my baby during the heel prick?

- Tell the baby what is happening, what procedures are being done, and why. It may be the reassuring tone of your voice or something deeper that helps babies during a procedure, but regardless of why it helps, it is respectful to tell any human what is happening to them and why.
- Nursing the baby is often a good way to help the baby to relax and be distracted during the procedure
- If you are feeling anxious about it, then have your partner hold the baby

What's the controversy? Why wouldn't I want to do the test?

- The controversy doesn't come from the fact that early diagnosis of a sick baby can reduce a bad outcome. The controversy is more about what is done with the blood sample and for how long the blood samples are stored after the tests are done. Some people are concerned about the potential of collecting DNA data from these cards and screening our newest citizens for genetic mutations. The American Academy of Pediatrics states, "Analysis of DNA mutations is not a primary screening method for any of the disorders for which newborn screening is performed today." Another concern is about the potential for long term storage of the tests that could lead to government raids on people with certain genetic mutations.

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- There is some evidence that the blood spot tests are used to improve the quality of the test and research additional diseases that the test can detect. This concerns some because it is often done without any prior consent given.
- In Colorado, you can contact the health department to have your samples returned to you after the testing is complete.

Do you perform the test or do I have to go to my doctor?

- Yes, as your midwife can perform the test. I prefer to do the test between 24-48 hours after birth. Then again at the 8-10 day visit. The Health Department is also an option as a testing site.

In conclusion, the test is a simple procedure that is minimally invasive. Finding out if your child has one of these VERY rare conditions can help you provide the best quality of life your child can have.

Additional Resources:

Children with Special Health Care Needs Unit www.HCPColorado.org

March of Dimes www.marchofdimes.org

Genetics Home Reference: http://ghr.nlm.nih.gov/nbs

STAR-G Screening, Technology, and Research in Genetics www.newbornscreening.info

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