



**NEWBORN SCREENING
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Cystic Fibrosis (CF)

Information For Parents and Families

My Baby had a Positive CF Newborn Screening Test

What is CF newborn screening? CF newborn screening tests help to find babies who might have cystic fibrosis. Most babies with positive newborn screening tests do not have CF. Babies who are found to have CF early can be treated early.

What does my baby's abnormal CF newborn screen mean? It means that your baby needs a special test so you can know if your baby has CF. The special test is called a *sweat test*.

Where do I get a sweat test for my baby? We recommend that CF specialists with expertise in sweat testing babies arrange for the sweat test. At a CF center, staff members know how to do the test on young babies. In addition, there will be support staff at the center who may be able to provide you with genetic counseling about your baby's CF newborn screening test or who will be able to help if the sweat test result is not clear.

I had a negative CF blood test when I was pregnant. Does my baby still need a sweat test? Yes. Any baby whose newborn screening result is positive for CF should have a sweat test.

How is the sweat test done? The sweat test is simple and should not hurt your baby. If you yourself were to have a sweat test, your skin might feel warm and tingly for about five minutes during the test. Before the test, the technician will apply a chemical that causes sweating to a small area on your baby's arm or leg. Then, an electrode is attached, and the area is stimulated to cause sweating. Your baby's sweat is collected on a piece of gauze or filter paper, or in a plastic coil. The collected sweat is sent to the CF lab and tested. It takes about one hour from start to finish.

Do I need to do anything to prepare my baby for the sweat test? Do not use any lotions or creams on your baby's arms or legs on the day of the test. Any regular medications may be continued and will have no effect on the test results. Because clinic rooms may be chilly, bring an extra blanket or sweater and hat to keep your baby warm during the test.

How will I know the results of the sweat test? That depends on the CF specialist and the center where the sweat test is done. Some CF specialists may phone the sweat test results to your baby's doctor at the end of the day, and your doctor will notify you. At some centers you may have a genetic counseling appointment before you leave and sometimes the genetic counselor will report the results to you. You can ask ahead of time so that you will know what to expect.

When I have the results of the sweat test, will I know if my baby has CF? Most of the time the results of your baby's sweat test will clearly tell you if your baby has CF or not. Sometimes, the sweat test will have to be repeated.

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If you have questions about your baby's newborn screening test or how to reach a CF specialist, you may call the Newborn Screening Program at 217-785-8101, or talk with your baby's doctor. Additional information about CF is provided at <http://www.cff.org>, the Cystic Fibrosis Foundation Web site.