

CYSTIC FIBROSIS (CF) NEWBORN SCREENING FACT SHEET FOR PARENTS AND FAMILIES

FROM THE
GEORGIA CYSTIC
FIBROSIS CENTERS

1. WHY DOES MY BABY NEED A TEST FOR CYSTIC FIBROSIS?

After your baby was born, a small amount of blood was taken from his or her foot for newborn screening. Your baby's test showed that your baby might have cystic fibrosis (CF).

WHAT IS CYSTIC FIBROSIS (CF)?

CF is a genetic disease that causes thick, sticky mucus to build up. This mucus can lead to problems with breathing and lung infections. CF can also make it harder for the body to break down food.

Children with CF can develop:

- Poor weight gain
- Greasy or oily bowel movements
- Poor growth
- Coughing and wheezing
- Lung infections

Children of all races and ethnicities can have CF.

2. WHAT TEST DOES MY BABY NEED?

A sweat test is the best way to find out if your baby has CF. This test measures the salt level in your baby's sweat, which is typically high in children with CF. The sweat test should be done at a CF care center. The two centers in Georgia are at Children's Hospital of Atlanta and Children's Hospital of Georgia (in Augusta). The test should be scheduled as soon as possible (by one month of age at the latest) so that treatment can be started, if needed, to keep your baby healthy.

WHAT CAN I EXPECT DURING THE TEST?

On the day of the sweat test, do not use any lotions or creams on your baby's arms or legs. Feed your baby their usual amount at their usual times.

During the test, a small gel patch is applied to the arms or legs to make the baby sweat. The skin may feel tingly, but it is not painful. It usually takes about an hour to collect the sweat but may sometimes take longer. The sweat is sent then to the lab for testing.

3. WHAT DO THE RESULTS MEAN?

Results of the sweat test are usually available to your doctor on the same day. There are four possible results:

Negative result: This means that a normal amount of salt was found in the baby's sweat. It is very rare for a person to have CF if the sweat test result is negative.

Positive result: A positive sweat test means that the baby probably has CF. An appointment should be made as soon as possible at a CF care center.

Intermediate result: Sometimes the sweat test result will be in between positive and negative. Most babies with this result will not have CF, but some will – so it is important for the baby to be seen as soon as possible at a CF care center for further testing.

Not enough sweat: Sometimes babies do not sweat enough for the test to be completed. If this happens, the baby will need to come back for another sweat test or further genetic testing.

4. FAQ: My baby has no CF symptoms. No one in my family has CF. I had a negative CF blood test when I was pregnant. DOES MY BABY STILL NEED A SWEAT TEST?

Yes. Any baby with an positive newborn screen result for CF should be tested for CF. Some babies with CF do not have any symptoms when they are born. It is important to start treatment early to keep babies healthy. Many babies with CF do not have other family members with CF. Screening tests done during pregnancy only look for the most common mutations in the CF gene. There are hundreds of CF mutations that are not included on these screening tests, so you or your partner may have a mutation that did not show up on prenatal testing.

WHERE DO I GO FOR MORE INFORMATION?

Use your phone's camera to scan the QR code below:



**CYSTIC FIBROSIS
FOUNDATION**

<https://www.cff.org/>