



Maine Newborn Screening Program

11 State House Station
 Augusta, Maine 04333-0011
 Tel: 207-287-5357 or 1-800-698-3624
 TTY: 1-800-606-0215
 Fax: 207-287-4743

Caring..Responsive..Well-Managed..We Are DHHS

My Baby Had a Positive Cystic Fibrosis (CF) Newborn Screening Result

****The most important thing to know is that **most** babies who screen positive for Cystic Fibrosis DO NOT have Cystic Fibrosis****

What is CF Newborn Screening?

Before you took your newborn baby home from the hospital, a blood specimen was taken from his or her heel for Maine's Newborn Screening Program. Newborn screening is done to identify a baby that **may** have certain conditions that should be detected early in life. CF newborn screening tests help to find babies who might have cystic fibrosis.

What is CF?

Cystic fibrosis is a serious condition that causes breathing and digestive problems and needs special medical care. When CF is diagnosed early, the baby can start treatment early, which will benefit his/her health.

What is a positive screening test?

A positive **screen** means that **another test must be done** to determine if the baby has the condition. Most babies with a positive screening test DO NOT have Cystic Fibrosis. Results from CF newborn screening show that your baby is one of the babies who need to have another test. This test is called a sweat test.

I had a negative CF test when I was pregnant. Does my baby still need a sweat test?

Yes. Any baby whose newborn screening result is positive should have a sweat test.

What is a sweat test?

The sweat test is the best way of checking for Cystic Fibrosis. The test is simple that tells how much salt is in your baby's sweat. Babies with CF have more salt in their sweat than other babies. The sweat test needs to be done when your baby weighs at least 5 pounds or is at least 2 weeks old. Younger and smaller babies may not make enough sweat to do the test.

How is the sweat test is done?

The sweat test is an easy and painless test. It takes about an hour to collect your baby's sweat from a small spot on the baby's arm or leg. The baby's arm or leg is washed with water. Then a round, gel patch is placed on the arm. This patch has medicine that causes sweating. An electrode attached to a special machine is placed over the gel patch. This will cause a small part of the baby's arm or leg to sweat. This may feel like a tingle or itch but it does not hurt. After a period of time, the electrodes and patch are removed. A piece of special paper is then placed on the skin to absorb the sweat. The special paper is removed after 30-40 minutes and is weighed. The salt in the sweat sample is tested in the lab. Generally, the results are available the next morning.

There is a video showing a sweat test that can be viewed on the internet at

<http://www.youtube.com/cysticfibrosisusa>.

When your baby has the sweat test you will meet with a genetic counselor. You will learn how CF is inherited and what this means to your baby and your family.

How do I prepare for the test?

There are a few things you can do to prepare for the test.

- You should bring very warm clothes for your baby so that he/she will sweat easily.
- Do not apply creams or lotions to the baby's skin on the morning of the test.
- Your baby should not be given any steroid preparations by mouth when the test is scheduled. Any other medications can be continued.
- Your baby can still have the test if he or she is having a minor illness such as a cold.

What do the sweat test results mean?

There are **four** possible results:

1. **Negative:** This means your baby had a normal amount of salt in the sweat. This means that your baby does **NOT** have CF. Your baby should get regular baby care.
2. **Positive:** This means that your baby probably has CF. The baby may have a second sweat test and a check-up with a special doctor.
3. **Borderline:** Sometimes the test result is between positive and negative. You will be asked to bring the baby back for another sweat test, and maybe a check up or blood test.
4. **"QNS":** This means Quantity Not Sufficient (there was not enough sweat collected). You will be asked to bring the baby back another day to try again.

Where do I go to have the Sweat Test done?

Your baby's doctor will make your appointment at the closest sweat test laboratory. There are three special sweat test laboratories in Maine.

Maine Medical Center is located at 22 Bramhall Street, Portland. The sweat testing is done at the laboratory on the ground floor, main building.

Central Maine Medical Center is located at 300 Main Street, Lewiston. The sweat testing is done at the laboratory on the ground floor by the cafeteria.

Eastern Maine Medical Center is located at 489 State Street, Bangor. The sweat testing laboratory is between Webber East and Webber West at Eastern Maine Medical Center. You should enter through the doors facing the registration desk, take a left and go through the double doors. Follow the sign for the laboratory.

If your sweat test needs to be rescheduled, you or your doctor should contact the Genetics Center at the number below to help coordinate this test and genetic counseling.

BEST Resources for More Information about Cystic Fibrosis

You can call the CF Center Team at the Genetics Center at EMMC (973-7559) or MMC (662-1622), Monday through Friday, 8am-5pm.

Not all information on the internet is up to date and accurate. We suggest the following web sites:

Cystic Fibrosis Foundation at: www.cff.org

March of Dimes at: <http://www.marchofdimes.com>

Maine Newborn Screening Program at: www.maine.gov/dhhs/boh/cshn/bloodspot_screening

The Genetic Alliance at: www.geneticalliance.org

Sweat test video at: www.youtube.com/cysticfibrosisusa