



Paul R. LePage, Governor

Mary C. Mayhew, Commissioner

Department of Health and Human Services
Maine Center for Disease Control and Prevention
286 Water Street
11 State House Station
Augusta, Maine 04333-0011
Tel.: (207) 287-8016; Fax: (207) 287-9058
TTY Users: Dial 711 (Maine Relay)

Direct Line Tel. (207)287-5351 Fax. (207)287-4743

Maine Newborn Bloodspot Screening Program

“My Baby Had a Positive Cystic Fibrosis (CF)

Newborn Screening Result”-one CF gene change

****The most important thing to know is that **most** babies who screen positive with only one gene change for Cystic Fibrosis DO NOT have Cystic Fibrosis****

What is a positive 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. A positive **screen** means that **another test must be done** to determine if the baby has the condition. This test is called a sweat test. Most babies with a positive screening test DO NOT have Cystic Fibrosis. There is a video designed to help put parents minds at ease about newborn screening for cystic fibrosis. It’s good to know that most babies with an abnormal screening do not have CF.

https://www.youtube.com/watch?v=lyOJ-107n_Y&feature=em-share_video_user

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 sweat test?

The sweat test is the best way of checking for Cystic Fibrosis. The test is simple and 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.

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. Not all CF tests look for the same gene changes.

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. A special machine 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. The test takes about 1 hour. 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.

What if I need to change the appointment?"

For appointments at MMC or CMMC: Please call the Genetic Counselors at Maine Medical Pediatric Specialty Care at 207-662-5522 option 8, and ask to speak to a genetic counselor to change the sweat test appointment.

For appointments at EMMC: Please call the CF clinic at 973-7520 to speak to the genetic counselor about changing the appointment.

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. **Indeterminate or 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. If your baby has the same result on a repeat sweat test, DNA testing may be done to look for other genes that cause CF?)

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?

The genetic counselor 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.

BEST Resources for More Information about Cystic Fibrosis

You can call the CF Center Team at the Genetics Center at 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.mainepublichealth.gov/bloodspot

The Genetic Alliance at: www.geneticalliance.org

Newborn Screening for CF video at: https://www.youtube.com/watch?v=lyOJ-107n_Y&feature=em-share_video_user

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

www.mainepublichealth.gov/bloodspot