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Maine Newborn Bloodspot Screening Program

“My Baby Had a Positive Cystic Fibrosis (CF)

Newborn Screening Result”-two CF gene changes

****Your baby has a form of Cystic Fibrosis and will need to see a special lung doctor to see how CF will affect him/her and what the next steps are****

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 your baby has two gene changes that cause CF and will need to see a doctor that specializes in CF to determine how your baby will be affected by this condition. Results from CF newborn screening may show that your baby may need to have other tests. One of those tests is called a sweat test.

What is a sweat test?

The sweat test is a way of checking how your baby might be affected by 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.

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>.

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 **three** possible results for your baby:

1. **Positive:** This helps the doctor understand what specific symptoms of CF your baby might show. Your baby will most likely have this result.
2. **Indeterminate:** Sometimes the test result is between positive and negative. You may be asked to bring the baby back for another sweat test. Some babies with CF may have indeterminate results even if they have two CF genes.
3. **"QNS":** This means Quantity Not Sufficient (there was not enough sweat collected). You may be asked to bring the baby back another day to try again.

Where do I go to have the Sweat Test done?

For infants being seen at MMC: Your baby will see a specialist at the CF center in Portland after the Sweat Test which is located;

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

The appointment with the specialist will be directly after the sweat test located across the street at;

The CF Center, 887 Congress ST, Suite 320

For infants being seen at EMMC: Your baby will be seen by a specialist around the same time as the sweat test. You will be notified by the CF clinic where and when these appointments are. Your baby will have the Sweat test at;

Eastern Maine Medical Center, 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.

What if I need to change my appointment?

It is very important that your baby have these first appointments. However, if you are unable to make the appointment or will be late, please call the CF Clinic at 662-5522 opt 3 for MMC, and 973-7520 for EMMC.

BEST Resources for More Information about Cystic Fibrosis

You can call the CF Center Team at the CF Center MMC (662-5522 opt 3), 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

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

<https://www.cff.org/What-is-CF/Testing/Newborn-Screening-for-CF/>

Hope for the future: <https://www.cff.org/For-Caregivers/CF-Infant-Care/>

www.mainepublichealth.gov/bloodspot