What do the results mean?

- **Negative result**—this means that a normal amount of salt was found in your baby's sweat. It is very rare for a person with a negative sweat to have CF. Your baby should get regular baby care and you will be provided with genetic counseling to plan for the risk of CF in future pregnancies.
- **Positive result**—a positive sweat test means that your baby probably has CF. The baby should have a second sweat test or a more detailed blood test for CF genes, and be seen by the CF specialist at the accredited CF center.
- **Borderline result**—sometimes the sweat test result will be in-between positive and negative. You will be asked to bring the baby back for a second sweat test or a more detailed blood test for CF genes.
- **"QNS"**—this means Quantity Not Sufficient (there was not enough sweat to measure). You will be asked to bring the baby back for another sweat test or possibly for a more detailed blood test for CF genes.

How is CF treated?

The majority of people with CF must take pancreatic enzyme supplements with every meal in order to absorb enough calories and nutrients to grow and remain healthy. They must also eat a diet high in calories and protein. In addition, people with CF must perform daily airway clearance therapy in order to help clear mucus from the lungs. Other types of treatments include antibiotics to fight lung infections and drugs to thin the mucus and improve lung function. Most importantly, people with CF should be followed regularly by a CF Care Team at an accredited CF center.

For more information, call:

Alabama Newborn Screening Division Bureau of Family Health Services RSA Tower, 201 Monroe Street Montgomery, Alabama 36104

NBS Follow-Up Coordinators 334-206-2971 or 334-206-5955 or 334-206-5729Fax: 334-206-3791

> NBS Lab Branch Manager 334-260-3475

NBS Lab 334-260-3476 Fax: 334-260-3439

http://www.adph.org/newbornscreening

Where can I get more information?

Cystic Fibrosis Foundation www.cff.org

Children's Hospital / University of Alabama at Birmingham CF Center http://cfuab.chsys.org

Children's Rehabilitation Services (CRS)/Alabama Department of Rehabilitation Services www.rehab.state.al.us



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NEWBORN screening



Cystic Fibrosis



What is Cystic Fibrosis?

Cystic Fibrosis (CF) is a genetic disease that causes thick, sticky mucus to build up in the lungs, digestive system, and other organs of the body. The mucus can lead to chronic lung infections and difficulty digesting food and nutrients causing poor growth and development.

What causes it?

CF is an inherited disease caused by a recessive gene. This means that a child must inherit two copies of a defective CF gene—one from each parent—to have the disease. More than 10 million Americans are unknowing carriers of the defective gene and most are not aware of a family history of the disease. There is a one in four chance that the child of two parent carriers will have CF. This disease affects one in every 2500 babies born in Alabama.



How is CF found?

Shortly after birth, at the same time other screening tests are completed, a few drops of blood are taken from your baby's heel. The dried blood specimen is sent to the State Laboratory, where it is tested for a substance in the blood that is typically high in newborns with CF. If this substance is present, an additional screening test on the same specimen will be done looking for a defective gene that causes CF. If there is an abnormality found, your baby's doctor and an accredited CF center will be notified.

Does an abnormal screening mean that my baby has Cystic Fibrosis?

Not necessarily. An abnormal screening test will always need to be confirmed by additional testing and medical evaluation. In many cases, a screening test is found to be abnormal, but a follow-up test is within normal limits. You will be contacted by your baby's doctor and the CF newborn screening coordinator.



Alabama Newborn Screening Program

What happens next?

The CF newborn screening coordinator will arrange an appointment for your baby at an accredited CF Center. At your appointment your baby will be given a sweat test. The sweat test is the best way of checking for CF and will measure how much salt is in your baby's sweat. Do not use any lotions or creams on your baby's arms or legs on the day of the test. Bring an extra blanket or sweater and hat to keep the baby warm during the test.

How is the test done?

The sweat test takes about an hour from start to finish. A special machine causes a small part of the baby's arm or leg to sweat. The skin may feel warm and tingly for 5 minutes while the machine is on. Your baby may cry during this part of the test, but it is not painful. A gauze or pad is placed on the skin and wrapped to collect the sweat. After 30 minutes, the gauze is removed and the sweat is tested in the lab.

When do I get the results?

The sweat tests are done in the morning and the results are ready in the early afternoon. While you are at the CF center, you will also be given information on CF genetics and be able to have most of your questions answered. After the sweat test, you and your baby will be seen in the Newborn Screening Clinic.