

# **PARENT INFORMATION for INITIAL INCONCLUSIVE Newborn Screening Test Results for Cystic Fibrosis (CF) (referral recommended)**

When your baby was born a small sample of blood was taken from your baby's heel to test for certain conditions. These conditions usually cannot be found simply by looking at your baby, so that is why the blood test is so important.

The results of your baby's screening test were "**inconclusive**" for a disorder called Cystic Fibrosis (SIS-tic FY-bro-sis). It is important to remember this is only a screening test.

## **What does an "inconclusive" screen mean?**

A small percent of all babies screened will be identified as "inconclusive" on the screening test. The Nebraska Newborn Screening Program recommends referral to an Accredited Cystic Fibrosis Center to explain the meaning of these results. It is recommended that these babies have a "sweat test" at an Accredited CF center to find out if these babies have CF or not. The sweat test is considered the best way to diagnose CF. Keep in mind that the new test could show that your baby does not have cystic fibrosis. Your baby's doctor can provide more information about the sweat test.

## **What exactly is Cystic Fibrosis?**

It is an inherited disorder. The genes that cause CF are inherited from both parents. CF affects about 30,000 Americans and is not contagious. Children who have cystic fibrosis are born with the disorder, but often do not show signs of disease for weeks, months or even years. CF affects each person differently.

CF causes the body to produce abnormally thick, sticky mucus that can clog the lungs, pancreas and other organs. This can lead to lung and digestive problems, which are treatable. A baby with CF will need special

medical care and a good diet. With early diagnosis and treatment, children with CF may have improved growth and development, fewer hospitalizations and regular monitoring may prevent or reduce lung infections.

## **What should I do?**

**The most important thing you can do is to be sure that your baby goes to the CF center for sweat testing.** The CF center in Nebraska is located in Omaha. There is also a CF center in Denver, CO.

This could be a false alarm, but if it turns out your baby has cystic fibrosis new research and treatment have greatly improved the quality and length of life for those affected.

### **CF Center Appointment:**

Date: \_\_\_\_\_ Time: \_\_\_\_\_

Phone # of CF center: \_\_\_\_\_

Address of CF center: \_\_\_\_\_  
\_\_\_\_\_

You may have already done this, but now is also a good time to be sure your baby is covered by your health insurance provider.

For more information talk with your baby's doctor or you can contact the Nebraska Newborn Screening Program at (402) 471-6558. You may want to visit the Cystic Fibrosis Foundation's web site at [www.cff.org](http://www.cff.org) or [www.cff.org/AboutCF/Testing/NewbornScreening](http://www.cff.org/AboutCF/Testing/NewbornScreening)

Department of Health & Human Services

