

PARENT INFORMATION for
INITIAL INCONCLUSIVE Newborn Screening Results for
Cystic Fibrosis (CF)
(Repeat screen 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 are identified as inconclusive on screening. Most are later found not to have the disorder. A new blood sample needs to be collected from your baby to find out if your baby has this disorder or not. The Nebraska Newborn Screening Program recommends that the new test be done at about 2 weeks of age. Keep in mind that the new test could show that your baby does not have cystic fibrosis.

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 visible signs of the 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 has a repeat blood test collected as directed by your baby's doctor.

Repeat Dried Blood Spot Test

Collect at _____

Date: _____

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. Also you may want to visit the Cystic Fibrosis Foundation's web site at www.cff.org or www.cff.org/AboutCF/Testing/NewbornScreening

Department of Health & Human Services

