

## PARENT INFORMATION for Positive Initial Newborn Screening Results for Cystic Fibrosis (CF)

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 called an "IRT" were elevated and DNA testing suggests a diagnosis of cystic fibrosis (SIS-tic FY-bro-sis). To be sure these test results are your child's, a repeat dried blood spot filter paper specimen should be collected and tested. The Nebraska Newborn Screening Program recommends referral to an Accredited Cystic Fibrosis Center.

### Why should we go to an Accredited CF Center?

Cystic Fibrosis affects each person differently. The CF Centers offer an array of professional services to best meet your child's and your family's needs. For example, diagnostic testing, counseling, pulmonary, physical therapy, nutritional, gastrointestinal, pharmacy and other specialty services can be obtained through the Center. An Accredited CF Center has the experience of treating hundreds of patients with CF. The staff is informed of the latest research, developments and improvements in treatment.

### 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 disease for weeks, months or even years. CF affects each person differently.

CF causes the body to produce abnormally thick, sticky mucus, which 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.

It is important to remember that new research and treatment have greatly improved the quality and length of life for those affected. As a result, children with CF should not be limited in their future goals and plans. With early diagnosis and treatment, children with CF may have improved growth and development, and fewer hospitalizations. Regular monitoring may prevent or reduce lung infections.

### What should I do?

**The most important thing you can do is to be sure that a repeat blood test is collected and that your baby is seen at a CF Center.** The CF Center in Nebraska is located in Omaha. There is also a CF center in Denver, Colorado.

#### **Dried Blood Spot Filter Paper Test:**

Collect at \_\_\_\_\_

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

#### **CF Center appointment:**

Appointment Date: \_\_\_\_\_

Appointment 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. Also, 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

