

PARENT INFORMATION for Positive Repeat newborn screening results for Cystic Fibrosis (CF)

The results of your baby's repeat screening test continue to be elevated and DNA testing suggests a diagnosis of cystic fibrosis. 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 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.

It is important to remember that new research and treatment has 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, 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 is seen at an Accredited CF Center.

The CF Center in Nebraska is located in Omaha. There is also a CF center in Denver, Colorado.

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. You may want to visit the Cystic Fibrosis Foundation's web site at www.cff.org.

