

PARENT INFORMATION for positive newborn screening 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 suggest a diagnosis of cystic fibrosis (SIS-tic FY-bro-sis). 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 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. CF is not contagious. Children who have cystic fibrosis are born with the disorder. They may 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.

These problems 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 your baby is seen at a CF Center or by the doctors from the 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. You can contact the Nebraska Newborn Screening Program at (402) 471-6558. You may want to visit the Cystic Fibrosis Foundation's website at www.cff.org.

