



**NEWBORN SCREENING
OFFICE OF HEALTH PROMOTION**
535 W. Jefferson St., 2nd Floor
Springfield, IL 62761
Phone: 217-785-8101
Fax: 217-557-5396

Cystic Fibrosis (CF) Information for Parents and Families

What is Cystic Fibrosis? Cystic fibrosis, or CF, affects breathing and how foods are digested within the body. CF causes the body to make thick, sticky mucus that clogs breathing airways in the lungs, and also can prevent the pancreas from making special chemicals (enzymes) that help the body break down and absorb foods. In people with CF, the sweat glands also make very salty sweat.

What causes CF? CF is inherited when both parents carry an abnormal CF gene and both parents pass the CF gene to their child. A person who has one abnormal CF gene is called a “carrier.” Carriers usually do not have any health problems caused by CF. When two carrier parents have children together, with each pregnancy there is a one in four chance of having a baby with two abnormal CF genes, a baby who will develop CF.

What problems can CF cause? CF is different for each child. While babies born with CF usually appear healthy at birth, signs of CF that may appear later include, wheezing, lung infections, thick mucus and greasy, smelly stools. Babies with CF may have trouble gaining weight and grow more slowly. Kids with CF can benefit from visits to a CF specialist to see the care team of doctors, nutritionists and nurses there. Babies and children with CF will need more frequent checkups with the CF doctor than kids who do not have CF.

What is the treatment for CF? Although CF cannot be cured, many treatments are available to help people with CF. Kids with CF need healthy high calorie diets and vitamins to help them grow. Some people with CF will need to take digestive enzymes to help them absorb nutrients from foods they eat. Special breathing exercises, treatments and medications also can help people with CF breathe better and prevent infections.

People with CF should have a primary care doctor, and a doctor who specializes in CF. The CF team can give kids and adults with CF the special medical care they need. The health care team can help families learn about CF, and how best to manage the life long treatment needed by people with CF.

Where can I find a CF specialist? The Illinois Department of Public Health Newborn Screening Program can provide a listing of CF specialists. Please call 217-785-8101, or TTY 800-547-0466, for hearing impaired use only, to talk with the Newborn Screening Program staff. The Cystic Fibrosis Foundation Web site, <http://www.cff.org>, also provides contact information for area chapters.