

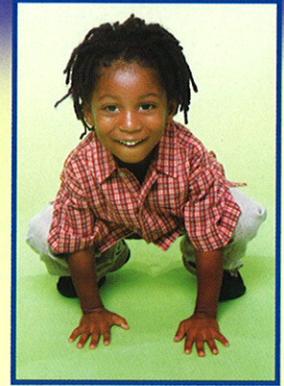
Cystic Fibrosis

What You Should Know



What is cystic fibrosis

Cystic fibrosis (CF) is a **life-long** illness that is usually diagnosed within the first few years of life. Patients with CF have problems with **breathing** and **digestion**. Some males with CF will be **infertile** (unable to have their own biological children). Cystic fibrosis does not affect a person's appearance or intelligence. More than 30,000 children and young adults in the United States currently have CF.



What causes cystic fibrosis?

Cystic fibrosis is a **genetic condition**. **Genes** are packages of information that tell your body how to grow and develop. Genes always come in pairs. Everyone has two copies of each gene, including the gene that can cause CF. One copy comes from your mother and the other copy comes from your father.

Some genes do not work properly because a change is present in that gene. If a person has a change in **both copies** of the gene for CF, he or she will develop cystic fibrosis. If a person has **one** changed copy of a CF gene, the person is a **carrier** for CF. Carriers will not develop CF, but they have a higher chance to have a child with CF.

How is CF treated?

Although there is no cure for CF, good medical care does make a difference. There is a wide range of treatments available. These may include antibiotics and dietary vitamins. If your child has cystic fibrosis, your child's doctor(s) will talk about treatments with you.

When is testing done for CF?

The newborn screening lab will use the same blood sample that is collected for the newborn test (or heelstick). The screen for cystic fibrosis is done in two parts:

1. The lab will measure the level of a protein called **immunoreactive trypsinogen (IRT)** in the blood.
2. A **DNA test** will be done **only** for children who have a high level of IRT in their blood. In Indiana, the DNA test will look for 46 of the most common gene changes that cause CF.



What does a positive newborn screen mean?



A change in your baby's DNA does not mean that your child has cystic fibrosis. In order to determine if your child has CF, a sweat test must be performed. Your doctor will let you know if a sweat test is needed and which one of the nationally-accredited CF laboratories you should use.

Resources

Nationally accredited cystic fibrosis centers

Deaconess Hospital
4011 Gateway Blvd.
Newburgh, IN 47630

Lutheran Hospital
7950 W. Jefferson Blvd.
Fort Wayne, IN 46804

Riley Hospital for Children
702 Barnhill Dr. ROC 4270
Indianapolis, IN 46202

St. Joseph Regional
Medical Center
720 E. Cedar St. Suite 440
South Bend, IN 46670

For more information about cystic fibrosis

Cystic Fibrosis Foundation
6931 Arlington Road
Bethesda, MD 20814
(800) FIGHT-CF
(800-344-4823)
www.cff.org

Indiana State Department of Health
Cystic Fibrosis Program Coordinator
2 North Meridian Street, 7B
Indianapolis, IN 46204
(317) 233-1292
<http://www.in.gov/isdh/programs/nbs>

Indiana State Department of Health
Newborn Screening Program
(888) 815-0006

Indiana State Department of Health
Family Helpline
(800) 433-0746



Indiana State
Department of Health