



# INCLUSIVE 4-H



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## Youth and Cystic Fibrosis

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### What is Cystic Fibrosis?

Cystic fibrosis is a genetic disease that causes the body to produce thick mucus, which then clogs the lungs. This disease can lead to potentially deadly lung infections. The mucus also obstructs the pancreas, thus blocking digestive enzymes from reaching the intestines. Malnutrition can eventually result.

### What Causes Cystic Fibrosis?

Cystic fibrosis is a recessive genetic disease. One can be a carrier of the disease without actually having the disease. In order to have cystic fibrosis, a person needs to inherit a recessive cystic fibrosis gene from each parent. If only a recessive gene from one parent is inherited, offspring will not have the disease, but that person will still be a cystic fibrosis carrier. Most people do not know they are cystic fibrosis carriers and only find out if a family member or child has the disease. Genetic testing can be performed to find out if one is a carrier.

### What are the Symptoms of Cystic Fibrosis?

Symptoms of cystic fibrosis are present in most cases before the age of 3 years. However, some cases are not diagnosed until adulthood. Because of many different gene mutations, cystic fibrosis is characterized by a variety of symptoms. These include:

1. Wheezing,
2. Shortness of breath,
3. Salty-tasting skin,
4. Persistent coughing with or without phlegm,
5. Excessive appetite but poor weight gain,
6. Risky pregnancies in women because of reduced lung capacity and nutritional deficiencies,
7. Greasy, bulky stools,
8. Sterility in men,
9. Cystic fibrosis-related diabetes,
10. Cystic fibrosis-related osteoporosis,
11. A median death rate in the early 30s.

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## **What is the Treatment for Cystic Fibrosis?**

Treatment includes the necessary daily clearing of mucus. Vigorous clapping on the back and chest will often loosen the mucus. Other treatments include aerosolized antibiotics and mucus-thinning drugs. Antibiotics may be prescribed if lung infections occur. Special diets high in calories will be needed to ensure adequate nutrition, weight maintenance, and growth. Teenagers with cystic fibrosis may need to consume as much as 5000 calories per day. Nutritional supplements may be needed in the form of energy supplements, vitamin supplements, and pancreatic enzyme supplements to aid digestion. Some people with cystic fibrosis have had success using a feeding tube at night and then having normal diets during the day. Moderate exercise can be important in strengthening the lungs.

## **Important Issues for Extension Educators and 4-H Leaders to Consider:**

1. Have contact information for parents or guardians and the member's doctor in accessible places. An example of this would be behind the child's nametag and in the medical forms box in the main office at 4-H events. This form should include information such as what kinds of medications the child is taking, allergies, if any adaptive devices are used, and other health conditions.
2. Visit with the member and his or her family about the member's cystic fibrosis. Find out about the specifics of the condition. Questions that can be asked include: "What special diet needs do you have?" and "What are your exercise limitations?"
3. Exercise can be very beneficial to children with cystic fibrosis, but care should be taken that they do not over exercise.
4. Lung infections and colds can create serious and even life-threatening consequences to those with cystic fibrosis. Care should be taken to minimally expose people with the disease to those with lung infections. Hand washing and sanitation should be emphasized.
5. Let anyone preparing meals know about the child's dietary needs so that they can meet those needs.
6. Find out what needs the child has with the clearing of mucus. If on a trip that lasts more than a day, make sure there is someone who can competently assist with this process.

## **For More Information Contact:**

### **The Cystic Fibrosis Foundation**

6931 Arlington Road

Bethesda, MD 20814

Phone: (800) 344-4823

Web site: [www.cff.org](http://www.cff.org)

(Web site active as of May 5, 2005)

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