

## CF Facts\*

- ☞ Cystic Fibrosis (CF) is the most common fatal genetic disease in the U.S.
  - ☞ CF affects approx. 30,000 people in the U.S., many of whom are children.
  - ☞ Most individuals are diagnosed by the age of 3, however 8% of all newly diagnosed cases are age 18 or older.
  - ☞ One in 29 Americans (more than 10 million) are symptomless carriers.
  - ☞ An individual must inherit two defective copies of a CF gene - one from each parent - to have cystic fibrosis.
  - ☞ The most common symptoms of CF are: salty-tasting skin; persistent coughing, wheezing or pneumonia; excessive appetite but poor weight gain; and bulky, foul-smelling stools.
- CF causes the body to produce an abnormally thick, sticky mucus which clogs the lungs leading to fatal lung infections.

\*Facts about CF, The Cystic Fibrosis Foundation, Bethesda, Maryland.

## NCFAC

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## ***About NCFAC***

The National Cystic Fibrosis Awareness Committee is a nonprofit organization made up of individuals with CF, their families and friends. Membership is spread throughout the U.S. with associates spread throughout the world.

We are a volunteer organization. Our goal is threefold: to raise public awareness of CF; to educate about CF; and to support those affected by CF. We are not a fundraising organization, however we strongly support those organizations who are devoted to finding a cure for Cystic Fibrosis.

We believe we can make a difference. We feel that individuals with CF need to feel included and empowered whenever they can. One way of doing so is by being more proactive in reaching out to help spread the word about CF and supporting others who are travelling a similar path.

## **Questions?**

We welcome anyone who wants to join our cause and spread the word. Should you have any questions about NCFAC, you may contact the individuals listed or contact us at our website.

## **Our Mission**

The National Cystic Fibrosis Awareness Committee exists to serve as an instrument for advancing the public's awareness of the genetic disease, Cystic Fibrosis (CF).

Our well-defined mission is to bring CF, the most common fatal genetic disease, to the forefront by:

- ◆ Establishing and promoting an annual Cystic Fibrosis Awareness Week in the United States;
- ◆ Holding various campaigns and promotions in which to educate the public and heighten awareness of CF;
- ◆ Showing support for those who suffer from the disease and their loved ones.

Our objective is a personal one. The Committee, as patients with Cystic Fibrosis and their family members, holds to the hope that through heightened awareness, the quality of life for people with this disease will be improved and lives even lengthened. We believe this aim will be realized through the efforts of us as individuals and communities throughout the nation.

## **Awareness**

Raising awareness of CF is crucial to the future of individuals with the disease. An increased knowledge and understanding of the disease in schools, the workplace and social situations will greatly improve their quality of life. In addition, awareness brings about earlier diagnosis which is imperative for optimal treatment.



## **Education**

Education will relieve some of the misconceptions and ignorance that exists about CF. Educational materials, medical information, as well as information on daily care should be easily accessible for patients as well as the general public.



## **Support**

There is a vast need for various avenues of support for CF patients and their families. Increasing support to the CF community can prevent the disease from emotionally and financially crippling them. Services should be made available to direct individuals to the support they need as well as receiving emotional support from others in the CF community.