

# Cystic Fibrosis Foundation

- Cystic fibrosis (CF) is a life shortening genetic disease that affects the systems of the body where mucus exists (lungs, digestive system, sinuses and reproductive organs). Persons living with CF have abnormally thick, sticky mucus that causes recurring lung infections and progressive lung deterioration. CF can also impair digestion, causing an infant to suffer from “failure to thrive”, where nutrients from food consumed are unable to be broken down and the child will grow slowly, be frail and small.
- Currently there is no cure for cystic fibrosis, but there is great hope as much has been learned about the cause and progression of CF.
- One in every 31 Americans carries the defective, recessive CF gene. Both parents must pass the defective gene to their offspring in order for a child to be born with CF. If both parents are carriers, the odds are 1 in 4 that a child will be born with cystic fibrosis, 1 in 2 that he will be a carrier of CF.
- Cystic Fibrosis Foundation (CFF) was founded 50 years ago by a group of friends and family of children born with CF. At the time, the average age of a person with cystic fibrosis was 5. Most children did not live long enough to enter Kindergarten. Today, one half of all individuals affected by cystic fibrosis live into the early 30’s.
- The mission of the Cystic Fibrosis Foundation is to control and/or find a cure for cystic fibrosis and improve the quality of life for those born with the disease.
- In 1989, CFF supported researchers found the defective gene responsible for cystic fibrosis. When their quest started in 1980, they were told it was impossible, because no gene, for any genetic disorder, had been identified or discovered. It took CF researchers nine years to find the CF gene. Once found, other genetic diseases were able to find their gene – the first was found only nine days later. Today, all genetic diseases know where their gene is and genetic testing is routinely available for families at risk of genetic abnormalities. Many states, including Florida, require all pregnant women to have genetic screening for several genetic diseases, including cystic fibrosis.
- In the early 90’s several new drugs were brought to market as a result of CFF supported research. These drugs are making a difference and adding to the quality of life for those living with CF.
- Currently there are 20 drugs and therapies in the developmental pipeline that could further control or cure cystic fibrosis. The cost of bringing any one drug to market can run into the \$100 millions. CFF researchers are convinced a cure can be found for this disease, it is just a matter of time and money.
- Cystic Fibrosis Foundation is recognized routinely for their operating efficiency. In December 2003 issue of *Smart Money Magazine*, the magazine of the *Wall Street Journal*, CFF was listed as the top charity in the medical research category in terms of efficiency. This recognition insures that money raised for CFF will be used wisely.
- Advancements made by CF researchers have translated into better screening and treatments for many genetic diseases, not just cystic fibrosis. So too, will be the case when the cure is found.