



## 65 Roses: Symbols of Love and Hope



Rosebuds symbolize beauty, youth and a heart innocent of love. Red rosebuds mean pure and lovely, and white rosebuds signify girlhood or too young to love. Roses have a very special meaning to the Cystic Fibrosis Foundation.

65 Roses® is what some children with CF call their disease because the words are much easier for them to pronounce. Mary G. Weiss became a volunteer for the Cystic Fibrosis Foundation in 1965 after learning that her three little boys had CF. Her duty was to call every civic club, social and service organization seeking financial support for CF research. Mary's 4-year old son, Richard, listened closely to his mother as she made each call. After several calls, Richard came into the room and told his Mom, "I know what you are working for." Mary was dumbstruck because Richard did not know what she was doing, nor did he know that he had cystic fibrosis. With some trepidation, Mary posed the question, "What am I working for, Richard?" "You are working for 65 Roses," he answered so sweetly. Mary was speechless. She went over to him and tenderly pressed his body to hers. He could not see the tears running down Mary's cheeks as she stammered, "Yes Richard, I'm working for 65 Roses."

Since 1965, the term "65 Roses" has been used by children of all ages to describe their disease. But, making it easier to say does not make CF any easier to live with. The "65 Roses" story has captured the hearts and emotions of all who have heard it. The rose, appropriately the ancient symbol of love, has since become a symbol of the 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 and typically remain small.

There are 1 in every 4 people that carry 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 or she will be a carrier of CF.

The treatment of CF depends upon the stage of the disease and the organs involved. Clearing mucus from the lungs is an important part of the daily CF treatment regimen. Chest physical therapy is a form of airway clearance done by vigorous clapping on the back and chest to dislodge the thick mucus from the lungs. Other types of treatments include TOBI® (tobramycin solution for inhalation), an aerosolized antibiotic used to treat lung infections; Pulmozyme®, a mucus-thinning drug shown to reduce the

number of lung infections and improve lung function; and azithromycin, an antibiotic recently proven to be effective in people with CF whose lungs are chronically infected with the common *Pseudomonas aeruginosa* bacteria.

The 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 five. Most children did not live long enough to enter Kindergarten. Today, one half of all individuals affected by CF live into the early 30's.

The mission of the CF Foundation is to assure the development of the means to cure and control CF and to improve the quality of life for those with the disease. It funds medical research and care programs which are improving the length and quality of life for people with CF. Join us at the 2006 Moonlight Martini's, The 2006 Destin Charity Bowl, or the 2007 Great strides Walk and help make a difference in our local area.

Let roses have a different meaning for you as they do for all families with CF. Roses say I love you, and stand for respect and courage, but rose leaves are also a symbol of hope. Hope for quality of life, and ultimately hope for a cure.