Cystic Fibrosis Foundation

...adding tomorrows every day.

Foundation Facts

Established in 1955, the mission of the Cystic Fibrosis Foundation is to assure the development of the means to cure and control cystic fibrosis (CF) and to improve the quality of life for those with the disease.

The Cystic Fibrosis Foundation:

- Promotes high-quality, state-of-the-art, specialized care for individuals with CF by supporting and accrediting more than 115 care centers nationwide. These centers -- located at major teaching and community hospitals -- offer diagnosis services and comprehensive treatment for people with CF and their families.
- Facilitates the advancement of CF research and care by providing grants to scientists to conduct CF research throughout the world. Grants include new investigator and clinical research, research and clinical fellowships, and student traineeships, among others.
- Supports the advancement of CF laboratory science by funding its own Research Development Program network of 10 CF research centers at leading universities and medical schools throughout the United States. By applying state-of-the-art scientific techniques to targeted research opportunities, these centers are discovering new ways to find a cure. The CF Foundation was the first voluntary health agency to create and fund such a network.
- Works in conjunction with Cystic Fibrosis Foundation Therapeutics (CFFT), the non-profit drug discovery and development affiliate of the Cystic Fibrosis Foundation. CFFT supports and governs the many stages of drug development and clinical evaluation of CF therapies. Total support of CFFT is provided by the CF Foundation.
- Carries out an innovative Therapeutics Development Program, through CFFT, that supports the full spectrum of CF drug development -- from the discovery of a promising drug to clinical evaluation in patients. The dynamic program incorporates the latest in drug discovery technology and brings these potential drugs to the laboratory for further study. If successful, they are then evaluated in people with CF through clinical trials at the CF Foundation's centralized network of 14 centers known as the Therapeutics Development Network. The scope of this project is unrivaled by any other voluntary health organization.
- Funds multiple clinical trials, including those to correct the basic defect in CF cells, fight respiratory infection, thin the CF mucus, reduce inflammation, and enhance digestion/absorption of food and nutrients, among others.
- Offers matching grants to biotechnology companies to encourage them to become partners in the development of new CF drug treatments.
- Supports a centralized laboratory to provide accurate and rapid identification of the lethal *Burkholderia cepacia* complex bacterium. Proper identification of *B. cepacia* complex in an individual's lungs decreases the time it takes for a physician to prescribe the best drug therapy.
- Initiates and conducts two annual medical conferences to promote innovation and discourse on the latest knowledge of the disease: 1) The Williamsburg Conference convenes researchers to focus on basic CF science and drug discovery efforts; 2) The North American CF Conference focuses on the latest advancements in CF research and care and includes thousands of scientists and medical care professionals. Both meetings generate new ideas for future research strategies.

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The Cystic Fibrosis Foundation:

- Conducts an annual fund-raising walk-a-thon, GREAT STRIDES, at more than 600 walk sites around the country. GREAT STRIDES, held primarily during the third weekend in May, raises millions of dollars for CF research and care programs each year.
- Supports its research and medical programs with the help of more than 300,000 volunteers. These volunteers are part of fund-raising efforts at 80 chapters and branch offices across the country.
- Maintains a Web site on the Internet at www.cff.org, which provides information about the diagnosis of CF; living with CF; updates on CF research and clinical trials; legislative action issues; fund-raising events and volunteer opportunities; and the CF Services Pharmacy, Inc., a specialized national pharmacy subsidiary of the CF Foundation. The CF Foundation also provides educational brochures, fact sheets and videos, free of charge.
- Remains one of the top voluntary health organizations in the country at efficiently using its funds raised to invest in medical and research programs. *SmartMoney* magazine has cited the CF Foundation as a charity that "won't waste your money."
- Advocates for increased funding for the National Institutes of Health, and testifies before the U.S. Congress to encourage more federal investment in basic science research. The CF Foundation works closely with the U.S. Congress, the Food and Drug Administration and pharmaceutical companies to speed the development of drugs to treat CF, while encouraging state governments to improve medical coverage programs.
- Works in partnership with CF Services to persuade insurance providers to cover CF therapies and to direct individuals in need to financial assistance programs. CF Services provides patients with access to the best prices for their medications and equipment.

Adding Tomorrows Every Day

Since the defective CF gene and its protein product were discovered in 1989, the pace of CF research has greatly accelerated. Scientists are now addressing the root cause of CF through a variety of technologies including gene therapy (see **Gene Therapy and CF** fact sheet).

To bring these lifesaving research programs to fruition, the CF Foundation depends on the support of individuals, families and corporate sponsors alike. The generosity of these donors has already enabled scientists to identify the gene that causes CF, to develop new treatments for CF, to correct defective CF cells in laboratory dishes and much more (see *Progress in CF Research* fact sheet). The CF Foundation has nearly two dozen clinical trials in progress for CF.

In short, the potential of promising new drug therapies and the range of new drug discovery technologies being applied to CF, with support from the CF Foundation and its volunteers and contributors, are painting a very bright future for the likelihood of significant, and even lifesaving new treatments for people with CF.

For more information about the CF Foundation and the programs and services available to people with the disease, or to learn how you can volunteer and help make a difference, please visit **www.cff.org or call (800) FIGHT CF**.

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