

The CFIDS Association of America

Working to conquer chronic fatigue and immune dysfunction syndrome

Association Overview

CHRONIC FATIGUE SYNDROME

Our mission

The CFIDS Association of America is the nation's largest and most active charitable organization dedicated to chronic fatigue syndrome (CFS), also known as chronic fatigue and immune dysfunction syndrome (CFIDS). Since 1987, the Association has invested more than \$26.8 million in initiatives to bring an end to the pain, disability and suffering caused by CFS.

Our Mission

For CFS to be widely understood, diagnosable, curable and preventable.

Our Strategy

To stimulate research aimed at the early detection, objective diagnosis and effective treatment of CFS through expanded public, private and commercial investment.

Our Core Values

To lead with integrity, innovation and purpose.

The CFIDS Association offers information and resources to patients, family members, caregivers, support groups, media professionals, the general public and health care professionals. The Association is proud to lead national efforts in research, public policy and communications that will advance understanding, diagnosis, treatment and prevention of CFS.

Fast facts

- Since the organization was founded in 1987, the Association has invested more than \$26.8 million in initiatives to bring an end to the pain, disability and suffering caused by CFS.
- We have funded more than \$5.1 million in research, making our organization the largest source of CFS research money aside from the federal government.
- Careful stewardship of our financial resources is a top priority for us. The Association has a stellar record of keeping our overhead, management and development expenses considerably below the national average for non-profit organizations. With a supporting services ratio of just 11.07% in 2007, the Association earned the highest rating - four stars - for the second consecutive year from Charity Navigator, the nation's largest charity watchdog. Only 18% of the charities rated by Charity Navigator receive at least two consecutive 4-star evaluations.

- In 2007, the Association launched The Campaign to Accelerate CFS Research with an unprecedented goal of raising \$1 million, which was met in August 2008 with donations from both long-time and first-time supporters. The CFIDS Association is now actively building the capacity of the scientific community to transform CFS into a condition that is treatable, preventable and curable.

- With more than 1,500 pages of information about CFS available on our website (www.cfids.org), almost 2 million people visited the site in 2008.

- The Association's print publication, *SolveCFS*, shares news of interest to those who are committed to our cause. We also publish a free online newsletter *CFIDSLink*, which goes out to thousands of people each month.

- In 2008 the Association secured private funding to partner with Medscape, the world's leading source of health information for consumers and health care professionals, to develop a clinical course on CFS. In collaboration with Medscape editors and expert CFS clinicians, an online course was developed to deepen clinically relevant information for health care professionals such as physicians, physician assistants, nurses, pharmacists and other clinical staff in 19 general and specialty medical professions. Through March 30, 2009, the course has attracted 15,309 professionals who have completed the program for credit, with about 52,000 reading the material for informational purposes.

- The Association led a six-year effort to document and hold the Centers for Disease Control and Prevention accountable for funding earmarked for CFS research. The effort paid off in 1999 when federal investigators reported that \$12.9 million allocated to CFS between 1995 and 1998 had been diverted to other CDC programs. That money was restored to CFS research. Now the Association is working to strengthen CDC's CFS program and has submitted two series of detailed recommendations to CDC in March and June 2009.

- Thanks to a three-year effort led by the CFIDS Association, the Social Security Administration's landmark ruling, SSR-99-2P, was issued in May 1999, making it easier for CFS sufferers to get federal disability benefits. (According to a 2004 CDC study, 25% of Americans with CFS are unemployed and disabled by the illness. Those who continue to work lose one-third of their annual income to reduced hours and other factors related to CFS.)