

The CFIDS Association of America

CHRONIC FATIGUE SYNDROME

Our mission

The CFIDS Association of America is the largest and most active charitable organization dedicated to conquering chronic fatigue syndrome (CFS), which is also known as chronic fatigue and immune dysfunction syndrome (CFIDS). The Association leads national efforts in CFS education, awareness, public policy and research. We provide resources and educational materials for patients, family members, caregivers, support groups, the general public and health care professionals.

We work toward our mission by:

- Building recognition of CFS as a serious, widespread medical disorder.
- Securing a meaningful response to CFS from the federal government.
- Stimulating high-quality CFS research.
- Improving the ability of health care professionals to detect, diagnose and manage CFS.
- Providing information to people with CFS and enabling the CFS community to speak with a collective voice.

Fast facts

- The CFIDS Association led a six-year effort to document and hold the Centers for Disease Control and Prevention (CDC) 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.
- 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.)
- Since the organization was founded in 1987, the Association has invested more than \$25 million in initiatives to bring an end to the pain, disability and suffering caused by CFS.

- We have funded more than \$4.8 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 in recent years of keeping our overhead, management and development expenses considerably below the national average for non-profit organizations. In 2006 our supporting services ratio was below 10%, well under the 25% threshold that the best-run nonprofits stay below. In 2007 this record of financial stewardship earned the Association the highest rating—four stars—from Charity Navigator, the nation's largest charity watchdog.
- More than 1,500 pages of information about CFS are available on our main website (www.cfids.org) and campaign microsite (www.cfids.org/cfs). More than 1.5 million people visited our websites in 2007.
- Every year the Association responds to thousands of requests for information by mailing out packets on topics such as choosing a doctor, finding a support group, applying for Social Security disability and dealing with pediatric CFS.
- Educating medical professionals about CFS and providing them with the material they need for patient care is a key objective. Each year we send out thousands of CFS packets to health care professionals.
- The Association publishes a free online newsletter, *CFIDSLink*, which goes out to thousands of people each month. We also publish the *CFIDS Chronicle*, the leading magazine for the CFS community.
- The CFIDS Association has held 15 Lobby Days, which bring patients, family members and other advocates to the nation's capital to lobby for CFS appropriations and public policy initiatives.
- The Association also sponsors annual Virtual Lobby Days, enabling people who can't visit Capitol Hill to become effective advocates from their own living rooms.
- In 2007 the CFIDS Association embarked on a new research initiative to increase the pace of progress in CFS research. Our expanded research program will accelerate the discovery of biomarkers, better diagnostics and more effective treatments for CFS.