

Illnesses like CFIDS/ME (Chronic Fatigue and Immune Dysfunction Syndrome/Myalgic Encephalopathy) and FM (Fibromyalgia) are not only challenging and disabling, but they have put individuals in the unique situation of having to speak out for their own needs. Advocacy efforts started in the late 1980s when a handful of sick, but very determined individuals started to devise strategies by which to raise awareness about the illnesses and plead for research. Two decades later, there have been improvements, but the "mission" is not yet accomplished. This generation of patients must find ways to continue the efforts of those who laid the groundwork and who had brought advocacy from its infancy to the present day.

Grassroots Action Center Listserv Alerts: <http://cfids.org/advocacy/alert-digest.asp>

The CFIDS Association of America's system of Advocacy Alerts provides patients with the opportunity to join in organized advocacy efforts to lobby for research, education, and other critical CFIDS issues. This site will provide the latest alerts and news as well as the ability to sign up for breaking alerts, by clicking on the "CFIDS Activist" link.

May 12th—Awareness Day

May 12th (Florence Nightingale's birthday) is designated as International Awareness Day for CFIDS/ME and FM. It is a time when individuals and groups engage in some type of activity or campaign to help increase awareness about these illnesses. One of the most prevalent activities is writing letters to government officials.

Individuals can describe their personal experiences with these illnesses, as well as emphasize the need for national recognition and increased research funding of CFIDS/ME and FM. Educating others, communicating the needs of this patient community and/or taking action on other issues goes well beyond what can be achieved in a single day. Responding to various opportunities or situations that may arise throughout the year is a constructive way to make use of one's knowledge and experience of the illness.

Individuals can always write to their express needs or concerns for government help, but it is particularly important to make a special effort to support the international movement. Letters do make a difference as they help to remind federal health officials and government representatives that the needs and rights of this patient population have not been met. A sample letter (below) can be used as a guide.

Write to Congresspersons, representatives and other officials!

[Please click this link to view Sample Letter](#)

[Write To Congress](http://www.congress.org/congressorg/dbq/officials/) : <http://www.congress.org/congressorg/dbq/officials/>

State Senators and Representatives of Massachusetts can be found by cities and towns at: <http://www.mass.gov/?pageID=mg2homepage&L=1&L0=Home&sid=massgov2> and click on legislature.

May 12th Awareness Day was initiated by Tom Hennessy, the founder of "Repeal Existing Stereotypes about Chronic Immunological and Neurological Diseases" - R.E.S.C.I.N.D.:

<http://www.rescindinc.org/>

Tom Hennessy has been advocating for a Name Change since 1988 and clearly, the name of the organization is its mission.

The Chronic Fatigue Syndrome Advisory Committee (CFSAC) is a group comprised of federal representatives, physicians, and patient advocates whose stated mission is to develop public policy on CFIDS and to coordinate efforts of the government toward research, education, and disability assistance. The committee had operated under the federal Department of Health and Human Services (HHS) but in November 2008, administrative and management support was transferred to the Office on Women's Health (OWH). More information about CFSAC meetings, recommendations and notices can be viewed at: <http://www.hhs.gov/advcomcfs/>

This website documents the relentless struggles by the late Judy Morris, M.D. against a major private disability insurance carrier and corporate crime in healthcare: <http://graham.main.nc.us/~bhammel/INS/judydoc.html>

Employee Retirement Income Security Act of 1974—ERISA outline: <http://www.harp.org/erisa.htm>