

Is a Name Change for Chronic Fatigue Syndrome in the Horizon?

By Marly C. Silverman

There are many disagreements within the neuroendocrine-immune community as it relates to chronic fatigue syndrome, but there is one issue that the majority in our community feels very strong about it – the name used to address an “illness” which is believed to affect *4 million individuals in America (CDC - See note below) Physicians, patients and advocates across the country are constantly debating this important issue.

In 2006, Rich Carson, a CFS survivor and “master thriver”, founder of [Pro-Health, Inc.](#), a company which caters to CFS, FM and related illnesses individuals, started a national extremely meaningful advocacy endeavor - “The Campaign for a Fair Name for CFS” - in which the primary goal is to find a suitable name for CFS, that would removed the stigma of laziness perceived by the word fatigue within the name of the illness.

Carson’s inspiration and determination for this campaign came from thousands of fellow individuals diagnosed with CFS who over the years have written to him about daily struggles, coping techniques and the quality of life challenges faced by these individuals notwithstanding his own challenges with CFS as well. One continuing sore point for these individuals as well as for Carson, is how the name CFS trivializes the illness; creates great difficult in their attempts to be taken seriously within the medical community when addressing treatment; and ultimately influences very little research funding from the government and pharmaceutical companies. (A side note: In Japan the government over the years has addressed the issue of “fatigue” in many levels as it relates to work ethics, culture, and epidemiology. They have embraced the word “fatigue” as part of a chronic illness. They realized that the loss of productivity caused by “chronic fatigue” creates a financial toll on their economy in the tune of billions of dollars. The Japanese government has provided greater funding for research on CFS/ME and the work is supported by fatigue research centers, university and pharmaceutical companies. Some American researchers believe that the Japanese “fatigue researchers” or CFS/ME researchers are and or will be ahead on the curve for future scientific breakthroughs.)

Carson organized a group of [CFS experts and prominent CFS researchers](#) who met on January 12, 2007 during the [8th IACFS Conference on CFS, FM and Other Related Illnesses](#). This conference was co-sponsored by [P.A.N.D.O.R.A.](#) and the [Centers for Disease Control and Prevention \(CDC\)](#). The overall 5-day conference gathered researchers and physicians from 21 countries as well as national and international advocates who participated in the Advocates Extraordinaire© Advocacy and Media Training sponsored by [P.A.N.D.O.R.A.](#) through the generosity of our [donors and sponsors](#).

In the group of physicians and researchers participating in the January 12, 2007 meeting included Anthony Komaroff, MD, David Bell, MD, Leonard Jason, Ph.D., Charles Lapp, MD, Lucinda Bateman, MD, and Paul Cheney, MD. (Daniel Peterson, MD was absent, but provided his input by phone). These researchers established a strong consensus that a

name change should be pursued now and have agreed that the acronym ME be included before the acronym CFS when giving the diagnosis of CFS to a patient to ease the transition into the new name.

ME would then signify “myalgic encephalopathy” – because it describes nervous system pathology with associated muscle pain. They steered away from “myalgic encephalomyelitis” (brain inflammation), one name definition favored by CFS patients in the US. The “blue ribbon panel” chose myalgic encephalopathy because through their research and clinical observations a large number of CFS patients do not have the symptoms that apply to myalgic encephalomyelitis. In choosing the acronym ME it leaves open to two well known definitions favored by advocates.

There are many voices within the advocacy community who feel that although a name change is promising and should be addressed, are worried about disability issues, insurance companies approach to medical payments to a “new” illness, case precedents and the fact that the government is spending a large sum to educate the nation about CFS and now we want a new name which will it dilute the educational campaign efforts? Will it create additional and more unproductive concerns? But nonetheless, these same voices also accept that the name CFS currently being used does carry a stigma difficult to remove.

Another area of concern express by other mainstream advocates focus on the fact that ME, which is largely used in Europe, also carries a stigma too. They are aware that in parts of Europe, there are advocates who will not use their real names when conducting advocacy efforts for fear of exposure to possible employers, clients and family members. “So, why embrace another name/acronym that can be as troublesome as the CFS one?”

In addition, the name/acronym ME used in Canada defines **myalgic encephalomyelitis**, not **myalgic encephalopathy** which is the name/definition the American scientific research blue panel endorsed. And lastly, let’s not forget that other advocates also think that the ME acronym leaves behind other important symptoms of the illness related to cardio and blood pressure and others are also concerned about the overlapping of CFS with fibromyalgia, Gulf War syndrome.

During the 3-day professional conference a vote by the executive board of the IACFS – International Association for Chronic Fatigue Syndrome proposed to change its name as well to include the acronym ME on its official name for the professional association. A general membership vote will be place on the ballot.

Many advocates also are following with great interest the [national educational campaign for CFS \(Spark\)](#), through the [CFIDS Association of America](#), funded by the [CDC](#), which has created huge media interest for CFS and converged with the state of the art scientific research findings that are coming to light. On a side note I am proud to say that [one article on CFS and P.A.N.D.O.R.A.](#) written by Nancy McVicar, medical reporter from the Sun-Sentinel, reached across the nation in at least 33 newspapers markets, becoming one of the most single successful media exposure for CFS in a long time!

P.A.N.D.O.R.A. was also featured on Telemundo (international Media Exposure and in the “EL Nuevo Herald” too.

So the question then being asked by many researchers and patients advocates is “Would this well versed educational campaign produce results which would remove the “stigma” related to the words “chronic fatigue” as it is intended? And if so, shouldn’t the name remain as it is known?” I understand that the results of the educational campaign will be shared with the neuroendocrineimmune disorders community at large and it might shed much needed light on the subject.

There has not been a reaction from the CDC or from the NIH and from the DHHS on what some are calling a “symbolic gesture” from these well known and well respected researchers and physicians, and one, as some might view without any teeth, resulting on a lackluster embracement by governmental health agencies.

Whether the name change will be accomplished soon remains to be seen, but it does send a very strong message to the national and international scientific research and advocacy communities that this is an issue well worthy pursuing and that current scientific evidence warrants a name change. The underlined result of advocates requiring a name change across the board re-vitalizes and re-charges our advocacy movement. Neuroendocrineimmune disorders are “emerging illnesses” and as such the construct of how they are to be perceived, researched, felt and defined falls on every major player that has a stake on the issue.

As a patient advocate I am excited about the fact that chronic fatigue syndrome is generating great interest in the country as well as overseas. As the founder of [P.A.N.D.O.R.A.](#) I worry about quality of life issues affecting our community, but I also keep an eye on the horizon, looking for that special one that will bring hope to our community and will ultimately unlock the medical mystery which surrounds CFS. A name change accomplishment ought to be found on that horizon too.

Jan 2007 ©

Sources:

* Although an official from the CDC has told P.A.N.D.O.R.A. that the figures of “four million individuals with CFS in the U.S”, is a “comfortable estimate” of the current demographics in the US for CFS, no official statement has been made by the CDC in the matter. Current literature by the CDC states that “over one million Americans are estimated to have CFS.”

[Pro-Health, Inc](#) – The Campaign For a Fair Name for CFS – January 2007 Newsletter

[Phoenix Rising](#), A CFS/FMS Newsletter by Cort Johnson, Special Edition, Laymen’s Guide to the 8th IACFS Conference.