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Chronic Fatigue Syndrome Changing the Name

by Roger Burns

Roger Burns publishes the 'CFS-News Electronic Newsletter', which is distributed via the Internet to over 2700 individuals and organisations in 30 countries. He also serves as moderator for several Internet-based CFS discussion groups. Roger is promoting international discussion amongst people with CFS on suitable alternatives to the name 'Chronic Fatigue Syndrome'.

Why does the name need to be changed?

We are shackled by the disease. But the name 'Chronic Fatigue Syndrome' also holds us down. The word 'fatigue' - the 'F' word - connotes to most people a merely mild tiredness. That weak-willed image tragically re-inforces the negative perceptions of 'no proven illness', 'all in the head', and 'malingering' that are still in the minds of the public and of most medical doctors, not to mention employers and those who make decisions about disability benefits. The name CFS is therefore a major obstacle in our efforts to obtain appropriate medical treatments, and fair decisions on disability benefits. In addition, it is too often used pejoratively as a term of derision against patients in their daily lives by those who don't, or don't wish to, understand this illness.

What should the new name be?

This is a difficult question. There are two major obstacles in choosing a new name.

- Almost all scientists oppose changing the scientific name before the cause of the illness can be found and verified. They are concerned that if we change now and then later the cause is found and the proven cause turns out to be in conflict with the second name that was chosen, then we will all be obligated to choose a third name at that point. And that will lead to much confusion, perhaps even a loss of what little credibility we've been able to earn so far. (Scientists also have other reasons for opposing a change. See below).
- While virtually all CFS patients want the name changed, it seems that almost every patient has a different idea of what the new name ought to be, and many strongly oppose the alternatives proposed by others. This itself is quite an obstacle, since if the scientists oppose a change, then a lack of consensus by the patients in addition would seem to guarantee failure. Included below is a discussion of possible alternatives from which to choose a new name.

There may be ways to overcome these obstacles. Consider the following:

- Many diseases have both a scientific name *and* an eponym, ie. a name taken from a person associated with the disease. If we choose an eponym, then it could be used in parallel with the scientific name. The scientists could go on using the name they prefer, unhindered by the eponym promoted for use by the public outside of the scientific community.
- If there is a broad and thorough discussion within the world-wide CFS community about what name to choose, *then* perhaps we can come to a consensus, and then move to promote that new name for public use. Again, see below for a discussion of alternative names/eponyms.
- If we can't form a consensus on a single eponym, then we might instead consider

promoting one of the less-widely used scientific names that is already in use that may be less offensive than the current name. (Some alternatives are: one of the variants of 'M.E.'; Post-Viral Fatigue Syndrome; CFIDS.) See the discussion below.

Arguments that oppose changing the name

- To repeat what has been mentioned above: almost all scientists oppose changing the scientific name before the cause of the illness can be found and verified. They are concerned that if we change now and then later the cause is found and the proven cause turns out to be in conflict with the second name that was chosen, then we will all be obligated to choose a third name at that point. And that will lead to much confusion, perhaps even a loss of what little credibility we've been able to earn so far; some progress has been made in legitimising the illness in the eyes of researchers, clinicians, grantsmakers, legislators and the media; that which has been gained may be lost if confusion is added by creating yet another name; scientists would also object to any new name or eponym because of the need to add a new keyword to indexes for medical articles, making literature searches by scientists more difficult; there are many keywords for CFS as it is.
- 'Fatigue' is a broad medical adjective, covering a wide variety of conditions including exhaustion. As a medical term it is widely understood, therefore (it is argued) there should be no misunderstanding about it, and thus there is no need to change the current name.

A counter-argument to scientists

- There are compelling reasons to change the name that is used commonly in public discussion; adopting an eponym to be used in parallel to the scientific name that is used solely among researchers should not interfere with scientists' needs at all; to hold off on any name change until the cause may be found might be tantamount to waiting for an event that will never happen. Noted researcher Mark Demitrack MD has suggested that CFS may have no single cause but rather may be a generalised condition, just like high blood pressure has no one cause yet is a known medical entity with accepted treatments. If Demitrack is right, then we may as well add an eponym now since there may be no 'single etiology breakthrough' to wait for.

New name - the options

1) Eponyms

Gilliam-Ramsay Syndrome

For: Drs. Gilliam and Ramsay have been leaders in researching outbreaks of CFS or CFS-like illnesses.

Against: This suggested name may get confused with Guillian-Barre Syndrome, or Ramsey's Disease. The term 'syndrome' may still be weak. The new name should be short and easy, not hyphenated. It's not clear that the outbreaks researched by Gilliam and Ramsay were CFS/ME.

Florence Nightingale Syndrome

For: Florence Nightingale is a widely respected, world renowned figure who founded the International Red Cross and the first formal school for nursing. For decades she had an undiagnosed illness whose symptoms seem consistent with CFS.

Against: Women's diseases often have difficulty in getting recognised and accepted, therefore choosing a female eponym may compound the kinds of problems that we are trying to avoid. Also, a widespread oral tradition among professional nurses is that Nightingale's undiagnosed illness was actually syphilis. That image may not help our cause. Tom Hennessy, founder of the May 12 movement, explains that there are good historical arguments to show that that story is not true. But it may nonetheless be difficult to overcome such a belief that is widespread within a major health profession. Lastly, the shortest version of a name is what tends to get used most often, and 'Nightingale Syndrome' might sound to many like it is a bird's disease.

Charles Darwin Syndrome

For: Darwin is another world renowned figure who had an undiagnosed, debilitating

illness.

Against: The fact that Darwin's illness was undiagnosed can be counted as a negative by many who are concerned that CFS is itself an unproven illness. Also, many patients and their organisations have already invested much effort in promoting May 12 Day which is associated with Florence Nightingale, and so making this switch might be confusing for many.

2) Alternative scientific names

One of the strategies discussed above is that if no consensus can be reached about an eponym, then we might consider instead promoting one of the other already-established scientific names more widely. Some alternatives are described below:

Myalgic encephalomyelitis

For: Along with CFS, this is already one of the most widely used names of the disease, recognised all around the world, but not in the USA.

Against: 'Myelitis' means spinal cord inflammation. There is little or no evidence of this in CFS, so this old name is outdated. Many scientists already oppose this term.

Myalgic encephalopathy

For: 'Encephalopathy' merely means brain disease, for which there is some evidence in the medical literature. This small variation of the widely used name myalgic encephalomyelitis may find easy acceptance and might not be scientifically objectionable. Since its acronym would still be 'M.E.', the many groups that are already wedded to that acronym may be quite at ease with this proposal.

Against: This variant of M.E. is not yet in general use.

Post-Viral Fatigue Syndrome

For: A name already used in many medical articles.

Against: This name may be a weak candidate because the evidence for viral infection is not clear at all, so for all we know this theory may be overturned some day, making the name obsolete. Also, the evidence that there is for viral infection is seen only in certain cases of CFS, not all, so even if true, it might not characterise all who have the disease. Expect scientific opposition.

CFIDS - Chronic Fatigue and Immune Dysfunction Syndrome

For: This name is becoming widely used in the USA. As a longer variant of CFS, it tends to dilute the 'F' word (fatigue).

Against: This name still contains the 'F' word, which is what we are trying to avoid. Scientifically, there is a big question as to whether immune dysfunction is truly one of the two most prominent characteristics of this disease. Also, the name CFIDS is not used at all outside of the USA, and it is rarely used in medical literature.

The challenge

You can see that there are important difficulties for each alternative that has been mentioned above. Can we overcome these obstacles to form a world-wide consensus behind one of the choices? OR, are there other alternatives that would be more viable?

Have your say! You can propose and comment on new names by sending recommendations to Roger Burns. Please include a reasoned argument about why the name is a good choice. Give biographical information about any person associated with an eponym you might propose. Send to Roger by e-mail at CFS-NEWS@LIST.NIH.GOV or by postal mail to Roger Burns, 2800 Quebec St. NW, Suite 1242, Washington, DC 20008-1240, USA. The latest version of this document can be obtained on the web or by e-mail. Web: <http://www.alternatives.com/cfs-news/name.htm>
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