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My name is Pat LaRosa. I am President of the New Jersey Chronic Fatigue Syndrome Association and am collaborating with the Let's Get it Right Group. Patients' lives rest on the outcomes of your project. We thank you for the opportunity to speak.

My first remarks are about the name.

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What is in a name? Webster states fatigue is a word or phrase that constitutes a distinctive designation.

What is in a name?

NAME *Name*

Name **Name** *Name*

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What is this? It is edible and red. We can call it the "Edible Red Thing."

What Is It?



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What should be included in a study to learn more about it? There are many edible and red things. If you include them all, will you learn what you need to know about the specific red edible?

If you include these:



What have you learned about this?



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This is the problem with using one feature or symptom shared by many other things. It reveals nothing specific of the thing you want to know about. Yet, many ME/CFS studies use criteria that could include people who do not have ME/CFS.

This is the problem of research that uses only one feature or symptom that is shared by many other things.

It reveals nothing of the thing you want to know about.

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Is it good science to use a single common symptom as the name of a complex disease... or should the scope of the disease be considered?

Fatigue, as mentioned earlier, is a common symptom reported to doctors. The word "fatigue" does not come close to the symptom experienced by people with ME/CFS. Malaise is no better. Malaise is defined as a generalized feeling of discomfort, illness, or lack of well-being.ⁱ I am not sure there is a fitting word. "Prostration" - at its maximum - is the only word I find that comes even close.

Is it good science to use a single symptom as the name of a disease? Fatigue is just one aspect of what is happening in ME/CFS.

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Is it about edible red things?



or specifically?



Fatigue or Myalgic Encephalomyelitis

Without adding all the components of an illness there is no defining line between the causes of fatigue. The tomato, the radish and apple are the same thing - "red edibles"- and all fatiguing diseases are merely fatigue.

Outside the US, the name Myalgic Encephalomyelitis (ME) is accepted internationally, including the World Health Organization (WHO.) In recent years, ME has been accepted by US government agencies, using ME/CFS as the name. Some references might be needed for a time to redirect people to ME, but it is now time to make the change to the single factual name.

In 2011, the name "Chronic Fatigue Syndrome" was rejected by the international panel that wrote *Myalgic Encephalomyelitis: International Consensus Criteria*. In this document, ME is declared the appropriate name based on "research and clinical experience that strongly points to widespread inflammation and multisystemic neuropathology." It further states, "Using 'fatigue' as a name of a disease gives it exclusive emphasis and has been the most confusing and misused criterion." No other disease adds fatigue to its name.ⁱⁱ We urge you to adopt the name Myalgic Encephalomyelitis (ME) - a name that is appropriate to the severity of the disease.

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I would now like to turn the issue of Coding and I thank Massachusetts CFIDS/ME and FM Association, PANDORA Org and advocate Mike Munoz for the use of some of their materials.

Coding

The International Classification of
Diseases-10-Clinical Modification
(ICD-10-CM)

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1988 - ICD-9 contained Myalgic Encephalomyelitis (ME) under "Diseases of the Brain."

1991 – CFS added under "Symptoms and Signs/Malaise and Fatigue"- code 780.7.

The CDC defined and named CFS in 1988. At that time, the ICD-9 contained ME under "Diseases of the Brain." There was no listing for CFS until 1991, when it was added under "Symptoms and Signs/Malaise and Fatigue."

Diagnostic codes affect medical care and insurance benefits. The release of the ICD-10-CM raises many concerns. The issue of psychiatric diagnosis for ME/CFS may be even more likely with the publication of the Psychiatric Diagnostic Manual 5 (DSM-5) which introduces a new psychiatric diagnosis, Somatic Symptom Disorder (SSD).ⁱⁱⁱ

In the ICD-10-CM, there two places that ME/CFS might be classified.

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ICD-10-CM

G93.3 ME, CFS, PVFS

"Other Disorders of the Brain"

"Diseases of the Nervous System Disorders

- **G93.3 ME, CFS, PVFS** – "Other Disorders of the Brain", "Diseases of the Nervous System Disorders

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ICD-10-CM

R53.82 CFS

"Symptoms, signs, and abnormal clinical and laboratory findings, not elsewhere classified"

"Malaise and Fatigue"

"Chronic Fatigue Syndrome, unspecified."

- **R53.82 CFS** - "Symptoms, signs, and abnormal clinical and laboratory findings, not elsewhere classified": "Malaise and Fatigue" "Chronic Fatigue Syndrome, unspecified"

The ICD-10-CM will perpetuate the failure to properly classify this very real, organic illness. ME/CFS will remain, at least partially, classified under "Malaise and Fatigue" in the R code area. This vague and uncertain classification is detrimental to patients, since it may encourage physicians and insurance companies to misdiagnose and classify the illness as psychiatric.

G93.3 - acknowledges neurological pathologies, viral triggers and the relationship of ME, CFS and PVFS. Studies have shown differences between brains of people with CFS, healthy controls and those with psychological disorders. These brain changes justify ME/CFS as a disease of the neurological system.^{iv}

This G code enables patients to receive proper diagnosis, treatment, and disability benefits. Unfortunately, it is not very well known to physicians and a patient may be coded as having CFS in the R code, instead of ME/CFS in the G code.(iv)

The ICD-10-CM will be used to gather statistics and data for health care utilization, quality review and resource allocation. If patients are classified as having CFS under the R code, the breakdown in recognition and treatment will continue.

The ICD-10-CM is coordinated with the Centers for Medicare and Medicaid Services (CMS) and electronic record keeping. Improper diagnosis can negatively affect the response of doctors reviewing patients' records. (iv)

Social Security disability programs use the name "CFS." Many private long-term disability (LTD) providers follow the SS guidelines and also use "CFS." Some LTD plans have two-year limits for "mental impairment." A physician using the R code for vague illness of malaise and fatigue, may

possibly create, an obstacle to obtaining LTD benefits. A diagnosis of ME under the G code would be a definite improvement. The coding issue circles around to the name issue.

These aspects, “name” and “coding,” are of **major** importance. Please consider these comments as you proceed. Thank you.

ⁱ Medline Plus, <http://www.nlm.nih.gov/medlineplus/ency/article/003089.htm>

ⁱⁱ Carruthers BM, van de Sande MI, De Meirleir KL, Klimas NG, Broderick G, Mitchell T, Staines D, Powles AC, Speight N, Vallings R, Bateman L, Baumgarten-Austrheim B, Bell DS, Carlo-Stella N, Chia J, Darragh A, Jo D, Lewis D, Light AR, Marshall-Gradisbik S, Mena I, Mikovits JA, Miwa K, Murovska M, Pall ML, Stevens S. (October 2011). "Myalgic encephalomyelitis: International Consensus Criteria." *J Intern Med* **270** (4): 327–38. doi:10.1111/j.1365-2796.2011.02428.x. PMID 21777306

ⁱⁱⁱ Updated U.S. Illness Codes Perpetuate Medical Ignorance of ME/CFS. Massachusetts CFIDS/ME & FM Association, February 24, 2013.

^{iv} Proposal to reclassify CFS in the ICD-10-CM and ICD-9-CM, Prepared by Mary Dimmock. Submitted to Medical Classification Administrator, National Center for Health Statistics CDC by the Coalition 4 ME/CFS ©2011 July 14, 2011.

Thank you to PANDORA Org for some content and graphics.