



Coalition 4 ME/CFS

One Voice, One Community, One Cause!™

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October 18, 2011

To: Clinicians, researchers and other medical professionals with interest in ME/CFS

Re: Coalition 4 ME/CFS proposal to revise the United States ICD-10-CM concerning CFS (chronic fatigue syndrome)

Dear Professionals,

Following the September 2004¹, August 2005² and May 2011³ recommendations of the federally-appointed Chronic Fatigue Syndrome Advisory Committee (CFSAC), the Coalition 4 ME/CFS submitted a [proposal](#)⁴ to the ICD-9-CM Coordination and Maintenance Committee (C&M) to restore CFS to Chapter 6, "Diseases of the Nervous System", code G93.3 in the ICD-10 Clinical Modification (ICD-10-CM) in the U.S. This proposal is referred to as "Option 1" and was submitted for expedited review. Benign myalgic encephalomyelitis (ME) and post viral fatigue syndrome (PVFS) are already in the G93.3 code. The coalition's recommendation is to remove "benign" or put it in parenthesis after "myalgic encephalomyelitis," as there is nothing benign about this disease.

Coalition 4 ME/CFS Rejects NCHS Option 2

At the September 14, 2011 ICD-9-CM C&M meeting, the National Center for Health Statistics (NCHS) countered with another option that puts CFS in the nervous system diseases chapter but with a different subcode from ME and PVFS. This option is based on the erroneous premise that CFS does not have a viral trigger. Additionally, the NCHS option, referred to as "Option 2," recommends a new label for G93.3 of "Post viral and other chronic fatigue syndromes." Thus, if Option 2 is adopted, the coding for G93.3 section of the ICD-10-CM will look like this:

Chapter 6 – Diseases of the Nervous System

Tabular

G93 Other disorders of brain

G93.3 Post viral and other chronic fatigue syndromes

G93.31 Post viral fatigue syndrome

Benign myalgic encephalomyelitis

G93.32 Chronic fatigue syndrome

Chronic fatigue syndrome (NOS)

Excludes2: chronic fatigue unspecified (R53.82)

The Coalition 4 ME/CFS **rejects Option 2** on the following grounds:

- A. It contradicts the World Health Organizations ICD-10 G93.3 coding⁵ and contradicts the clinical modification manuals used in most other countries, including Canada, England, Germany and Australia.
- B. It contradicts the expert consensus from years of research studies that CFS often does have a viral trigger⁸. (Please see the background information at the end of this letter, the coalition [proposal](#) and addendum on our website for additional studies.)
- C. It contradicts the [CDC's description](#) that virus infections can lead to an illness meeting the CFS criteria⁶.
- D. It contradicts the [National Institutes of Health description](#) of the one disease as "ME/CFS"⁷.
- E. It creates physician confusion in diagnosing and applying pertinent research to patient care.
- F. It contradicts much of today's research that uses the two terms together: "myalgic encephalomyelitis / chronic fatigue syndrome" or vice versa.
- G. It creates unnecessary diagnostic challenges because the CFS criteria require symptoms for six months, a time when a virus trigger cannot be proven.
- H. It puts an unnecessary burden on physicians to investigate the trigger before diagnosing and treating.
- I. It makes viral-induced CFS have two diagnostic codes.
- J. It will confuse data collection as prior CFS data included those with viral triggers.

Coalition 4 ME/CFS Recommends Coalition Option 1

The coalition's proposal is referred to as "Option 1." If coalition Option 1 is adopted, the coding for the ICD-10-CM G93.3 section will look like this:

Chapter 6 – Diseases of the Nervous System

Tabular

G93 Other disorders of brain

G93.3 Post viral fatigue syndrome

Myalgic encephalomyelitis (benign)

Chronic fatigue syndrome

Excludes chronic fatigue unspecified (R53.82)

The coalition is **urging adoption of Option 1** on the following grounds:

- A. Option 1 matches the [recommendations](#) of the CFS Advisory Committee (CFSAC)^{1,2,3}.
- B. Option 1 matches the World Health Organization mortality and morbidity coding (ICD-10)⁵.
- C. Option 1 matches the clinical modification manuals in most countries, including Canada, England, Germany and Australia.
- D. Option 1 is in harmony with scientific research that shows CFS often has a viral trigger^{6,8}.
- E. Option 1 provides for CFS research and treatments to be applied to CFS patients, regardless of the trigger, as long as they meet the diagnostic criteria.
- F. Option 1 is a stepwise approach to doing away with the term "CFS"⁴.
- G. Option 1 is in harmony with the [NIH](#), which refers to the disease as "ME/CFS" regardless of the trigger⁷.

- H. Option 1 will give clinicians a basis for conducting tests and administering treatments based on the neuroendocrine-immune nature of the disease.
- I. Option 1 protects the integrity of CFS data by keeping all CFS patients in the U.S. still under one code.
- J. Option 1 provides for clinicians to diagnose and treat based on a patient's current disease process and its manifestations without regard to the initial trigger.
- K. Option 1 will end the CFS ambiguity physicians avoid, leading to more patients being accurately diagnosed with ME/CFS, an important issue as over 80% of U.S. ME/CFS patients have not received an accurate diagnosis.

The [ICD-9-CM Coordination Committee](#) "open comment" time is now until November 18, 2011, during which they are receiving public comments. The NCHS director will make a decision sometime in December. At this time, only two options are "on the table." Discussions with administrators at the NCHS reveal that great weight is given to comments from those who use the code or track data; this would include clinicians. They are expecting to receive comments from professionals in the medical field. We are asking you to join other professionals in signing the accompanying letter rejecting NCHS Option 2 and supporting Coalition Option 1. This letter will be public.

Additionally, we are inviting you to send in your individual comments rejecting NCHS Option 2 and supporting Coalition Option 1 to the NCHS administrator. We also ask you send us a copy of your comments and let us know if you want those comments to be kept private or released to the public. Please include a comment that this change should be made prior to implementation of ICD-10-CM (expedited review) in 2013, as the timing of the change is a separate issue to be decided. Also, during the September 14 meeting, some in attendance expressed concern that CFS data be protected. We ask that your comments show how Coalition Option 1 protects the integrity of CFS data.

For further information, please see the coalition's [FAQ](#)⁹, [written proposal](#)⁴ and background and references below. If you have further questions or concerns, please contact any of the members of the Coalition 4 ME/CFS Steering Committee below.

We appreciate your time and your much-needed expertise in this scientific initiative that will improve patient care in the United States of America.

Sincerely yours,

Steering Committee – Coalition 4ME/CFS

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[PANDORA – Patient Alliance for Neuroendocrine-immune Disorders Organization for Research & Advocacy, Inc.](#)
[Phoenix Rising](#)
[Rocky Mountain CFS/ME & FM Association \(RMCFA\)](#)
[Vermont CFIDS Association Inc.](#)
[Wisconsin ME/CFS Association, Inc.](#)

References:

1. CFSAC website September 27, 2004 recommendations concerning the Department of Health and Human Services: “We would encourage the classification of CFS as a ‘Nervous System Disease’ as worded in the ICD-b G93.3.”
2. CFSAC website August 2005 recommendations concerning the Department of Health and Human Services: “We would encourage the classification of CFS as a ‘Nervous System Disease,’ as worded in the ICD-10 G93.3.”
3. CFSAC website May 10-11, 2011 recommendations concerning the Department of Health and Human Services: “CFSAC rejects current proposals to code CFS in Chapter 18 of ICD-10-CM under R53.82: Chronic fatigue, unspecified > Chronic fatigue syndrome NOS. CFSAC continues to recommend that CFS should be classified in ICD-10-CM in Chapter 6 under “diseases of the nervous system” at G93.3, in line with ICD-10 and ICD-10-CA (the Canadian Clinical Modification), and in accordance with the Committee’s recommendations of August 2005. CFSAC considers CFS to be a multi-system disease and rejects any proposals to classify CFS as a psychiatric condition in US disease classification systems. (Note: no disease classification system under HHS’ control proposes to move or to include CFS in or among psychiatric conditions.)
4. Coalition 4 ME/CFS written proposal: http://coalition4mecfs.org/ICD_final_w-cover_and_addendum_7-15-2011.pdf
5. World Health Organization ICD-10 tabular coding:
G93 Other disorders of brain
 G93.3 Post viral fatigue syndrome
 Benign myalgic encephalomyelitis

Chronic fatigue syndrome is listed in the index and appointed the G93.3 code.
6. Centers for Diseases Control and Prevention Website, under “Chronic fatigue syndrome, Causes, Infectious Agents: “Recently published research suggests that infection with Epstein-Barr virus, Ross River virus and Coxiella burnetti will lead to a post-infective condition that meets the criteria for CFS in approximately 12% of cases,”
7. Trans NIH ME/CFS Working Group website: “Chronic fatigue syndrome, sometimes referred to as myalgic encephalomyelitis (ME) or chronic fatigue immune dysfunction syndrome (CFS), is a debilitating disease that lacks a universally accepted case definition, etiological agent, diagnosis, or treatment.”
8. Komaroff A. et al (September 30, 2011), Role of Infection and Neurological Dysfunction in Chronic Fatigue Syndrome, Seminars in Neurology
9. Coalition 4 ME/CFS ICD-10-CM proposal FAQ: <http://coalition4mecfs.org/ICDFAQ.html>

Additional Information Concerning ICD-10-CM and Coalition 4 ME/CFS Proposal

Background Information:

The ICD-10-CM will replace the ICD-9-CM in 2013 for use in clinical settings for diagnosing, filing insurance claims, and mortality and morbidity data collection. The coalition's proposal is necessary because the proposed ICD-10-CM had moved CFS to the R53.82 code under "Symptoms, signs and abnormal clinical and laboratory findings, not elsewhere classified," which is contrary to the code manuals used in the rest of the world, which have CFS with the same code shared by ME and post viral fatigue syndrome (PVFS).

The coalition's ICD-9-CM proposal was not accepted for review as ICD-9-CM is in "lock down," with no further changes allowed.

The Diagnostic and Statistical Manual of Mental Disorders (DSM-5) proposes a new psychiatric condition, complex somatic symptom disorder, with such broad criteria that CFS patients may erroneously be misdiagnosed as having a psychiatric condition if the ICD-10-CM does not list CFS as a neurological disease. Protecting ME/CFS patients from this misdiagnosis is what moved the CFSAC to make the recommendation in May 2011 to restore CFS to G93.3, where it is in the rest of the world's mortality and morbidity code manuals. The CFSAC made similar recommendations in September 2004 and August 2005.

While ME/CFS is an illness with multi-system dysfunction, ICD-10-CM does not have a multi-system disease category. This may be an option for ICD-11, but that will not be in use in the U.S. for many more years. The Diseases of the Nervous System chapter is a good fit for CFS because of the large body of peer-reviewed research showing brain and neuroendocrine-immune abnormalities. Plus, this is where ME is classified, and much of today's research includes ME or uses ME/CFS in the CFS studies.

The coalition's proposal, Option 1, listed references to many studies showing CFS patients have brain white and gray matter loss¹⁰, reduced brain blood flow¹⁰, abnormal EEG readings¹¹, abnormally-high levels of spinal fluid lactate¹², increased spinal fluid proteomes (reflecting brain inflammation)¹³, cognitive function tests showing abnormal brain activity when under a cognitive challenge¹⁰, abnormal function of the hypothalamus in concert with the pituitary and adrenal glands¹⁴, autonomic nervous system dysfunctions¹⁵ and sleep disruption of alpha waves interfering with deep sleep.

The ICD-9-CM Coordination and Maintenance Committee met on September 14, 2011 where the coalition also gave an oral presentation. Members of the audience spoke favorably in recommending that CFS be put in Chapter 6 labeled "Diseases of the Nervous System."

However, in response to the coalition's proposal, the National Center for Health Statistics countered with their own option, referred to as "Option 2." This option would put ME and PVFS with a code of G93.31 and CFS as a code of G93.32, all under the neurological (G93.3) heading of "Postviral and other chronic fatigue syndromes." The basis for this division is their premise that CFS does not have viral triggers, whereas PVFS and ME do. The coalition rejects this option as it is arbitrary, unfounded and without precedent.

The coalition is asking for expedited review so that the changes are made to the ICD-10-CM code prior to its implementation in 2013. This will allow for the CFS change to be included in the physician training given in the transition to ICD-10-CM. This is a way to educate physicians on the true nature of CFS and prevent unnecessary harm from CFS being placed in the wrong code again.

For Physicians:

Many ME/CFS patients spend years seeking knowledgeable physician care until some end up under the care of a clinician who specializes in ME/CFS treatment, the physicians of last resort. By this time, the patient may have experienced great loss and been given wrong treatments that ultimately make his / her condition worse. He may have to travel over state lines to find such a physician. Many patients do not have access to these specialists. Many physicians find ME/CFS obscure as they do not closely follow the research, as noted ME/CFS specialists do.

The coalition's proposal, Option 1, will guide and inform all physicians as to the true nature of the illness. Having CFS classified as a neurological disease is a step closer to ME/CFS being treated with the same respect as multiple sclerosis, another neuroendocrine-immune disease.

Many ME/CFS specialists have had to use codes for other illnesses in order for their patients to have appropriate treatments covered by health insurance policies or protect their disability insurance benefits. Restoring CFS to the nervous system disease chapter will show companies that neurological testing and treatments are appropriate for CFS.

The NCHS proposal, Option 2, with ME and PVFS in one code and CFS in another, is based on the premise that CFS does not have a viral trigger and is a different illness. This has no basis in the medical literature as multiple studies show that many CFS patients have a viral trigger. Thus, Option 2 would have the NCHS defining the illness instead of peer-reviewed scientific research defining the illness. This is unacceptable and will confuse physicians as to what is the appropriate diagnosis for their patients, as often a viral trigger is difficult to confirm.

None of the criteria for diagnosing CFS, including the most popular CDC-endorsed Fukuda, exclude patients with a viral onset. Making this arbitrary distinction will confuse and corrupt record-keeping and data collection, and it will insert a division of CFS that has not occurred before and does not reflect the diagnostic criteria.

The coalition's Option 1, with CFS in the same code as ME and PVFS as it is in the rest of the world, is in harmony with what research has now discovered about the illness. Harvard Medical School professor, physician and researcher, Dr. Anthony Komaroff, said in a recent paper⁸, "As with other diseases without a well-defined pathologic etiology, such as M.S., there may be multiple underlying triggers of an inflammatory process, which in certain susceptible individuals leads to the clinical manifestations of CFS."

As Dr. Lucinda Bateman said, physicians form their opinions about a disease "by the classification of the code." She continued: "The insurance companies make a decision about the severity of an illness or how they're going to reimburse. It's a way of teaching people what we know about the illness."

For Researchers:

Many ME/CFS researchers have spent years establishing the physiological abnormalities in ME/CFS. Moving CFS out of an ICD-10-CM category that focuses primarily on symptoms and into the nervous system disease chapter will validate that research, turning that research into scientifically-based practices at the clinical level that improve patient lives.

Most researchers recognize ME/CFS as a multi-system disease. The neurological abnormalities have been confirmed in the medical literature explaining some of the symptoms patients describe. Similar to multiple sclerosis, the “first cause” is not known, but the neuroendocrine-immune biological abnormalities are demonstrated in objective tests, according to multiple studies. That makes this the right time to put CFS back in the nervous system diseases chapter of the ICD-10-CM, in harmony with the World Health Organization ICD-10 classification.

Restoring CFS to the nervous system diseases chapter will emphasize the nervous system abnormalities and better distinguish ME/CFS patients from those who only suffer from depression, a problem that has confounded the quality of ME/CFS research.

The Coalition 4 ME/CFS Option 1, with ME, PVFS and CFS in the same code, will show research into ME, PVFS and CFS are all relevant to the patients, preventing confusion of what research applies to what disease. It also provides for one disease to have one code, no matter the cultural / national name given the disease. Thus, the one disease can be sub-grouped according to any of a number of biomedical or symptom factors the researcher chooses and not just by the trigger.

The NCHS Option 2, which separates ME from CFS, will set a precedent for separating or subgrouping ME/CFS patients according to viral trigger or no viral trigger. If this leads to criteria differences, researchers will have the burden of first identifying patients as having a viral trigger or not to label what disease cohort is being studied. If CFS becomes known as an illness without a viral trigger, this will confuse the application of the research findings and the data based on the CFS patients that have a viral trigger.

8. Komaroff A. et al (September 30, 2011), Role of Infection and Neurological Dysfunction in Chronic Fatigue Syndrome, *Seminars in Neurology*
10. Lange, G., Cognitive Function in CFS. A measure of disability? Presentation in 2010 to HHS CFSAC.
11. Duffy, F., McAnulty, G., McCreary, M., Cuchural, G., Komaroff, A., EEG spectral coherence data distinguish chronic fatigue syndrome patients from healthy controls and depressed patients --- A case control study *BMC Neurology* 2011, 11:82 doi:10.1186/1471---2377---11---82 <http://www.biomedcentral.com/content/pdf/1471---2377---11---82.pdf>
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14. Papanicolaou, D.A., Amsterdam, J.D., Levine, S., McCann, S.M., Moore, R.C., Newbrand, C.H., Allen, G., Nisenbaum R., Pfaff, D.W., Tsokos, G.C., Vgontzas, A.N., Kales, A., Neuroendocrine aspects of chronic fatigue syndrome. *Neuroimmunomodulation* 2004;11(2):65---74. <http://www.ncbi.nlm.nih.gov/pubmed/14758052>
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