

M.E. LAW & POLICY CENTER

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BY EMAIL

Ms. Donna Pickett
co-chair
ICD 9CM and ICD 10CM Committees
National Center for Health Statistics
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with request to forward to:

All other Members of the ICD 9CM and ICD 10CM Committees

Re: Request that the ICD Committee adopt the Recommendations by the Coalition 4 ME/CFS of July 14, 2011 on ICD coding of M.E., PVFS and "CFS"
http://coalition4mecfs.org/ICD_final_w-cover_and_addendum_7-15-2011.pdf

Esteemed Members of the Committee:

The M.E. Law & Policy Center (hereinafter "the Center") **fully supports the July 14, 2011 Recommendations by the Coalition 4 ME/CFS on ICD coding of Myalgic Encephalomyelitis** (hereinafter "ME"), PVFS and "CFS" (hereinafter "the Report").¹

One of the listings in the proposed ICD 10CM is for "Chronic Fatigue Syndrome, NOS" as the only condition under "General Symptoms and Signs; Malaise and Fatigue; Unspecified Fatigue." This is a travesty. Need it be said once more that ME ("CFS") is not synonymous with the symptom of "unspecified fatigue"?

ME is the only condition listed under "Post-Viral Fatigue" While "Post-Viral Fatigue" should be listed under ME, it is inappropriate to do the converse.

1. http://coalition4mecfs.org/ICD_final_w-cover_and_addendum_7-15-2011.pdf

All of the recommendations of the Report must be adopted by the Committee especially that **ME should be kept where it is in neurological diseases, but "Post-Viral Fatigue" should be listed under ME, not vice-versa as is currently suggested. Additionally, "CFS" should be either eliminated or also listed under ME.**

The Center adds one more request that the Report did not make. **"Benign" must be dropped from "Benign M.E." since it gives the egregiously misleading impression that ME is benign.**

As the Committee is aware, the current ICD 10CM proposal to split ME and "CFS" and place "CFS" under "General Symptoms and Signs," is incompatible with WHO's ICD 9, ICD 10 and the current proposal for ICD 11. It is contra to the assurances made in writing by National Center for Health Statistics, Office of the Center Director, Data Policy and Standards in its March 2001 report stating that "in keeping with the placement in the ICD-10, Chronic Fatigue Syndrome (and its synonymous terms) will remain at G93.3 in ICD-10-CM."²

The proposed listing is also incompatible with all of the accepted US and international case definitions including the CDC's own current Fukuda "CFS" case definition.³ Additionally, it contravenes WHO's license agreement with CDC that ICD 10CM follow all WHO regulations and rules. The proposal is also contra to the medical opinions of the world's foremost ME clinicians and scientists as embodied, inter alia, in the explanatory text and treatment guidelines of the 2003 ME/CFS Canadian Consensus Criteria⁴ and the 2011 International ME Criteria.⁵ It is also directly contra to the HHS CFSAC's strong and specific recommendations of May, 2011.

For all these reasons, and those others embodied in the Report, **the Center respectfully and strenuously requests that this Committee immediately adopt all of the changes to ICD 9CM and ICD 10CM and, in addition, remove the misleading word "Benign" from "Benign M.E."**

Ladies and Gentlemen, you now possess the extraordinary chance to do something that will immeasurably improve the science and medical treatment of ME as well as the lives of millions afflicted with this devastating neuro-immune disease. I can not emphasize enough the incredible good you will do. My greatest thanks in advance.

Sincerely,

/S/

Justin Reilly, esq. for
M.E. Law & Policy Center

2. A Summary of Chronic Fatigue Syndrome and Its Classification in the International Classification of Diseases. March 2001 http://www.co-cure.org/ICD_code.pdf

3. CDC 1994 Fukuda "CFS" Case Definition. http://www.cdc.gov/cfs/general/case_definition/index.html

4. Myalgic Encephalomyelitis/ Chronic Fatigue Syndrome: Clinical Working Case Definition, Diagnostic and Treatment Protocols. Bruce M. Carruthers et al.; J. of CFS, 2003 <http://www.cfids-cab.org/MESA/ccpcd.pdf>

5. International M.E. Criteria, Carruthers et al.; 2011 <http://www.research1st.com/2011/07/25/me-case-definition/>

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