



OPEN LETTER

Dr Ra'ad Shakir
Chair, WHO Neurology Topic Advisory Group
Chief of Neurology
Imperial College NHS Trust
Charing Cross Hospital
London

17th March 2014

Dear Dr Shakir

Re: WHO ICD-11 Beta draft classification

We are writing, collectively, on behalf of the estimated 250,000 people with M.E./CFS. in the UK.

As you may be aware, there has been considerable discussion and concern expressed within the M.E./CFS community regarding the WHO ICD-11 classification.

As both individuals and organisations, we have received a number of questions and concerns from people affected by M.E./CFS and are therefore writing to seek clarification to enable us to respond accordingly.

We are keen to work collaboratively with others to help empower and support people affected by M.E. and as such, would be very happy to discuss this further with you directly or welcome you to a meeting of either the All Party Parliamentary Group on M.E. or Forward M.E. (a House of Lords-led collaboration).

A summary of our current understanding

The three ICD-10 G93.3 terms, PVFS (Postviral fatigue syndrome), BME (Benign myalgic encephalomyelitis) and CFS (Chronic fatigue syndrome) have been missing from the public version of ICD-11 Beta draft since early 2013.

Prior to early 2013, in the public version of the ICD-11 Beta drafting platform, *Chronic Fatigue Syndrome* had been listed in the Foundation Component as an ICD Title entity under Diseases of the nervous system, with *Benign Myalgic encephalomyelitis* specified as an Inclusion term and *Postviral fatigue syndrome* listed under Synonyms to the *Chronic Fatigue Syndrome* Title entity. Therefore, all three terms were accounted for within the Beta draft; the terms were then removed from the public version of the Beta draft.

Currently, no entry for any of the terms, CFS, BME or PVFS, under any hierarchy, can be found within any chapter of ICD-11 Beta in the Foundation or the Morbidity and Mortality linearization, the top level category list, the PDF print version or the PDF Alphabetical Index.

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The replies that WHO Twitter admin gave to members of the public who enquired about this, stated that there was no proposal to include ME, CFS or Fybromyalgia as Mental and behavioural disorders in ICD-11. They did not say (as Parliamentary Under-Secretary of State for Health, Jane Ellison MP stated in response to a question from Annette Brooke MP) "no proposal to reclassify ME/CFS in ICD-11" (¹ [Hansard, House of Commons, Oral Answers to Questions, Tuesday, February 25, 2014](#)). A member of the public also asked on Twitter if there is a proposal to reclassify ME, CFS and Fybromyalgia as "Bodily Distress Disorders" in ICD-11, but no reply was forthcoming from WHO Twitter Admin. Also, they did not confirm a proposal to 'retain' in Chapter 07, only not to include in Chapter 05.

Points of clarification requested

1. Under which chapters and parent categories are the following three ICD-10 G93.3 entities currently proposed to be classified within ICD-11:
 - *Chronic Fatigue Syndrome;*
 - *Benign Myalgic encephalomyelitis;*
 - *Postviral fatigue syndrome?*
2. What is the current proposed hierarchy or relationship within ICD-11 between these three entities, in terms of Title term, Inclusion term, Synonym, and which of these three terms are proposed to be assigned a Definition and other "Content Model" parameters?
3. What is the reason for these three terms not currently displaying in the public version of the Beta drafting platform?
4. When does ICD-11 Revision intend to restore these three terms to the public version of the Beta drafting platform?

We very much appreciate you taking the time to respond to our request and look forward to hearing from you.

Yours sincerely

A handwritten signature in black ink, appearing to read "S. Chowdhury", enclosed within a thin black rectangular border.

Sonya Chowdhury, CEO, Action for M.E.; Secretariat, All Party Parliamentary Group on M.E.

A handwritten signature in blue ink, appearing to read "Annette Brooke".

Annette Brook MP; Chair, All Party Parliamentary Group on M.E.

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A handwritten signature in black ink, appearing to read "L. Arber", is positioned above the text.

Countess of Mar; Forward M.E., House of Lords

Dr Charles Shepherd, Medical Adviser, ME Association; Secretariat, All Party Parliamentary Group on M.E.

c.c. Tarun Dua, Managing Editor, Neurology Topic Advisory Group, WHO

Christopher Chute, Chair, ICD Revision Steering Group, WHO

Dr Geoffrey Rees, Project Manager, Mental & Behavioural Chapter, ICD-11, WHO

Dr Margaret Chan, Director General, WHO

Dr Robert Jakob, MD, Medical Adviser, WHO

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