**European ME Alliance**

*Alliance of European ME Support Organisations*
*Raising Awareness of Myalgic Encephalomyelitis (ME/CFS)*

# The disappearance, continued absence and its consequences of the enforcement of the ICD-10 G93.3 within the linearization of the ICD-11 Public Beta Draft Version

**18 November 2016**

Dear **Dr. B. Üstün**,

WHO/ICD Revision Coordinator, Project Management Team

## Introduction

The European ME Alliance (EMEA) is a collaboration of European organisations[1] supporting patients suffering from Myalgic Encephalomyelitis (sometimes referred to as Chronic Fatigue Syndrome or ME/CFS) all over Europe.

There are estimated to be between 500,000 and 5 million [1] ME-patients in Europe, depending on which diagnostic criteria are used. The number of patients differs so much due to the prevalence rate varying from 0,1 percent to 1,0 percent, or more.

Within the Myalgic Encephalomyelitis community a great deal of concern has been expressed with regard to the development of the WHO ICD-11 classification. Therefore, on behalf of this sizeable group of patients, EMEA would like to address a number of very important issues.

## Challenges

During 2015 an email was sent by EMEA informing the WHO about the difficulties regarding recognition and identification/diagnosing of Myalgic Encephalomyelitis.

Even though the disease is currently classified under ICD-10 G93.3, the majority of clinicians in Europe continue to view Myalgic Encephalomyelitis as a 'Fatigue Syndrome' classified under 'Mental and Behavioural Disorders' (ICD-10 F48.0).

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[1] European organisations in 13 Member States: Belgium, Denmark, Finland, Germany, The Netherlands, Ireland, Italy, Spain, Sweden, the UK and Norway, Switzerland and Iceland. (http://www.euro-me.org/about.htm)

This can lead to major deleterious consequences for patients, such as problems with treatments or follow-up of the disorder - not to mention the high medical costs at patients own expenses.

Currently the situation looks even worse since all commonly used terms - post viral fatigue syndrome, Myalgic Encephalomyelitis or chronic fatigue syndrome - have been removed from the ICD-11 Public Beta Draft. [2, 3]

EMEA is aware of the various issues regarding Myalgic Encephalomyelitis and the fact that the ICD-11 Revision is a work in progress. To fulfil this complicated task regarding this disease EMEA request that the WHO considers and acts upon the following recommendations:

- ***provide a suitable ICD entity title for the disease – Myalgic Encephalomyelitis***
- ***Determine the right place in the ICD-11 hierarchy for Myalgic Encephalomyelitis***
  Under which chapter(s) and parent classes will the terms, post viral fatigue syndrome, Myalgic Encephalomyelitis and chronic fatigue syndrome, currently covered by ICD-10 G93.3, be classified within ICD-11 Revision;
- ***Provide a scientific definition***
  taking into consideration all scientific research and accepting the recent 2015 assessment by the IOM as a disease;
- ***Define exclusions and exclusion terms***;
- ***Gather clear, understandable and scientifically valid knowledge domains***
  such as constellation of signs and symptoms, severity and course, as well as genetic and other information. Completed with imaging, lab- and other test results, known causes, micro-organisms, medications or genomics linkages;
- ***Capture the functional impact of Myalgic Encephalomyelitis***
  using the International Classification Functioning Disability and Health (ICF). Quality of life in Myalgic Encephalomyelitis is significantly lower than quality of life in other disorders. [4, 5] This should be indicated in the ICD-11, making it possible for patients to access the necessary benefits;

The endorsement of world-wide accepted diagnostic criteria would be a huge step forward for Myalgic Encephalomyelitis patients, healthcare professionals, health care and research into Myalgic Encephalomyelitis. It would make gathering of valid data and real economic cost estimates to society and patients possible. But mostly it would offer early care and maybe the possibility for diagnosis which can reduce the burden of stigma for Myalgic Encephalomyelitis patients.

A statement has been made that there was 'no proposal' to classify the ICD-10 G93.3 legacy terms, post viral fatigue syndrome, Myalgic Encephalomyelitis and chronic fatigue syndrome, under Chapter 07 '*Mental and Behavioural disorders'*.

Looking at the ICD-11 Public Beta Draft, it is clear that the term '*Bodily Distress Disorder (BDS)'*, defined very broadly, leaves much room and real possibility for including non-psychiatric disorders in this entity – and this must not be allowed to happen with regard to Myalgic Encephalomyelitis.

In light of this aspect EMEA wishes to express its deepest concern regarding the absence of the ICD-10 G93.3 legacy terms in the exclusions of BDS.

Also looking at the definition of Chronic Fatigue Syndrome used in the ICD-11 Public Beta Draft before 2013:

> "*Chronic fatigue syndrome is characterized by extreme chronic fatigue of an indeterminate cause, which is disabling and does not improve with rest and that is exacerbated by physical or mental activity"*

crucial information is missing which could, in this case, lead to inclusion of psychiatric disorders in the entity.
Taking both of these facts into account the chances of classifying and diagnosing Myalgic Encephalomyelitis as a 'Mental and Behavioural Disorder' are enormous, highly realistic and very harmful towards Myalgic Encephalomyelitis patients.
EMEA calls on the WHO to protect Myalgic Encephalomyelitis patients by classifying the ICD-10 G93.3 legacy terms with the utmost care and at its rightful place in Chapter 09: Diseases of the nervous system, where it has always been.

**Questions**

EMEA acknowledges that the use of the ICD-11 will be an enlargement and improvement of the International Classifications of Diseases also for patients. But before getting there, a number of issues have to be addressed:

- ***Including PVFS/Benign* Myalgic Encephalomyelitis *in the ICD-11:***

  - ❖ Since February 2013 the ICD title term 'Chronic Fatigue Syndrome' (CFS), the inclusion term 'Benign Myalgic Encephalomyelitis' (BME) and the term in the synonym list 'Postviral Fatigue Syndrome' (PVFS), can no longer be found in the ICD-11 Public Beta Draft.
    Is it possible to clarify -
    - → On which basis the decision was made to remove these terms from the draft?
    - → Is there any intent from the WHO ICD-11 Revision Team to restore these (PVFS, BME, CFS) in the ICD-11 Revision to enable comments, remarks and additions?
      - If yes, when?
      - If not, what is the reason for that decision?

- EMEA has noticed that the parent page “Certain specified disorders of the nervous system (9H8Y - Other …, 9H8Z - Unspecified)”, the ICD-11 entity equivalent for the ICD-10 G90-G99, has been removed.
    - → Will this parent page be replaced by another page or will different diseases be added to the other pages?
    - → Will the terms Postviral Fatigue Syndrome (PVFS), Benign Myalgic Encephalomyelitis (BME) and Chronic Fatigue Syndrome (CFS) be classified under chapter 08/ Diseases of the nervous system or anywhere else?
    - → Which term will be the title term, and which will be the inclusion term and the synonym?
    - → To which term is the definition and other content parameters going to be assigned?
    - → Are diagnostic criteria going to be included?
    - → On what will the definition be based?
    - → Will the current definition be used again?

- EMEA also read a study about Functional Disorders,
    - → will this be the category where Myalgic Encephalomyelitis will be classified under “Functional Disorders” within the Neurology section?

## Conclusion

EMEA would like to collaborate with the WHO towards increasing awareness and understanding of Myalgic Encephalomyelitis, set up inter- and multidisciplinary collaboration among different partners (researchers, clinicians, care facilities, patients, family, policymakers, etc.) and provide appropriate care at all levels, as well as research and training for everyone involved with Myalgic Encephalomyelitis. This could improve the lives of Myalgic Encephalomyelitis patients and reduce the burden whilst there is no evidence-based treatment available yet.

Sometimes patients get treated as psychiatric patients and kept in psychiatric wards against their will with no attention to their physical needs. In some cases even comorbidities are being ignored leading to further deterioration of the patient’s general health. Recent European studies also show that Myalgic Encephalomyelitis patients have the poorest quality of life compared to other chronic diseases.
Recent biomedical research has produced hope for treatments to be developed. For example, B cell depletion therapy has shown promising evidence with response rates of two thirds. [6, 7] Also a 2016 study shows that mitochondrial DNA variants correlate with symptoms in Myalgic Encephalomyelitis.[8]

For decades this serious and debilitating disease has been stigmatized [9] due to a lack of application of correct scientific and ethical competence resulting in severe harm being inflicted on ME patients. This stigmatization has allowed misinformation to be perpetuated causing a lack of recognition of this serious and debilitating disease. Patients have had to deal with disbelief and trivialisation of their illness.
This leads to mis- or missed diagnoses and either mistreatment or no treatment. It also leads to insufficient data being collated regarding the illness - not only with regard to the medical needs but also in determining just how many patients there really are and how big the impact is on society, health care, patients and their families.

Due to the effects of this disorder it is almost impossible for patients to campaign for their rights. Within EMEA’s member organisations there are volunteers who have Myalgic Encephalomyelitis themselves or have family members with Myalgic Encephalomyelitis so they know first-hand what it is like to have the disease and live with its limitations. The WHO and the WHO ICD-11 can improve this situation by providing a scientific framework with valuable, reliable and validated information.

EMEA wish to thank you for your time and response to the posed questions and is looking forward to hearing from you.

We reiterate our offer to work with the WHO to effect progress in treating Myalgic Encephalomyelitis. However, we are determined not to compromise on these most serious questions. Myalgic Encephalomyelitis has for far too long been left to the machinations of vested interests who have manipulated the disease and changed the correct perception of the disease, thus diverting research funding to flawed research. This cannot be allowed to continue,

Yours sincerely,

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related stigma in PVFS-BME is 28%, social stigma 44% and feeling of bad wellbeing 30% of the participating patient population.

**NOTE:**

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