



European ME Alliance, Sønder Alle 5, st 3, 9500 Hobro, Denmark

Email: [info@euro-me.org](mailto:info@euro-me.org)

web: [www.euro-me.org](http://www.euro-me.org)

## **THE LEGAL AND MEDICAL SITUATION OF ME (MYALGIC ENCEPHALOMYELITIS) AND CFS (CHRONIC FATIGUE SYNDROME) PATIENTS**

Myalgic Encephalomyelitis (ME) was accepted by the WHO as a neurological disease in 1969.

In some countries ME is referred to as Chronic Fatigue Syndrome (CFS). In 1993 CFS was added as an addendum to ICD-10 but the "fatigue"-based definition of CFS still causes confusion and problems for patients, as was stated by Mrs. Androulla VASSILIOU, former European Health Commissioner.

ME can occur in outbreaks: one was described for the first time in 1934. Experts have placed ME in the same category as cancer and late stage AIDS regarding quality of life and suffering.

### **We therefore request the following:**

- to respect the WHO ICD-10-Code G93.3 for ME as a neurological disease and ensure that the Member States implement this in their Health Care System;
- to respect the rights of ME patients – including children - in all Member States;
- to endorse as diagnostic criteria for ME the Canadian Consensus Criteria and the developing International Consensus Criteria;
- to encourage the development of biomedical research.

**An estimated 1.200.000 very sick ME patients in Europe are waiting for parliament to recognise the WHO ICD-10-Code G93.3.**

Declan Carroll  
Secretary Irish ME Trust  
[www.imet.ie](http://www.imet.ie)

## References

1. [www.who.int/classifications/icf](http://www.who.int/classifications/icf)

G93.3 Postviral fatigue syndrome  
Benign myalgic encephalomyelitis (ME)

2. Carruthers B, Jain AK, De Meirleir KL, Peterson DL, Klimas NG, Lerner AM, Basted AC, Flor-Henry P, Joshi P, Powles AP, et al.: Myalgic encephalomyelitis/chronic fatigue syndrome: clinical working case definition, diagnostic and treatment protocols. *Journal of chronic fatigue syndrome* 2003, 11(1):7-115.
3. Carruthers BM, van de Sande MI, De Meirleir KL, Klimas NG, Broderick G, Mitchell T et al. Myalgic encephalomyelitis: International Consensus Criteria. *J Intern Med* 2011;270:327-38.
4. Nacul LC, Lacerda EM, Campion P, Pheby D, Drachler MD, Leite JC, Poland F, Howe A, Fayyaz S, Molokhia M: The functional status and well being of people with myalgic encephalomyelitis/chronic fatigue syndrome and their carers. *BMC Public Health* 2011, 11(1):402.
5. J. Mark Van Ness, Staci R. Stevens, Kylie T. Kumasaka, Harnoor Singh, Betsy Keller, Daniel L. Peterson, Jose Montoya and Christopher R. Snell: A diagnostic test for the identification of metabolic dysfunction. *Conference abstract 9th IACFS/ME clinical and research conference, Reno, March 7, 2009.*
6. Brown, M. M., Bell, D. S., Jason, L. A., Christos, C. and Bell, D. E. (2012), Understanding Long-Term Outcomes of Chronic Fatigue Syndrome. *J. Clin. Psychol.*, 68: 1028-1035. doi: 10.1002/jclp.21880
7. Twisk, F.N., Maes, M., 2009. A review on cognitive behavioral therapy (CBT) and graded exercise therapy (GET) in myalgic encephalomyelitis (ME)/ chronic fatigue syndrome (CFS): CBT/GET is not only ineffective and not evidence-based, but also potentially harmful for many patients with ME/CFS. *Neuro Endocrinology Letters* 30 (3), 284-299.
8. KCE report: Evaluation of CBT/GET therapy. <https://kce.fgov.be/nl?SGREF=5268&CREF=11648>
9. Fluge Ø, Bruland O, Risa K, Storstein A, Kristoffersen EK, et al. (2011) Benefit from B-Lymphocyte Depletion Using the Anti-CD20 Antibody Rituximab in Chronic Fatigue Syndrome. A Double-Blind and Placebo-Controlled Study. *PLoS ONE* 6(10): e26358. doi:10.1371/journal.pone.0026358
10. Maes M, Twisk FN: Chronic fatigue syndrome: Harvey and Wessely's (bio)psychosocial model versus a bio(psychosocial) model based on inflammatory and oxidative and nitrosative stress pathways. *BMC Med* 8:35.
11. Broderick G, Fuite J, Kreitz A, Vernon SD, Klimas N, Fletcher MA. A formal analysis of cytokine networks in chronic fatigue syndrome. *Brain Behav Immun.* 2010 Oct;24(7):1209-17.
12. Komaroff AL, Cho TA: Role of infection and neurologic dysfunction in chronic fatigue syndrome. *Seminars in Neurology* 2011, in press.



European ME Alliance, Sønder Alle 5, st 3, 9500 Hobro, Denmark

Email: [info@euro-me.org](mailto:info@euro-me.org)

web: [www.euro-me.org](http://www.euro-me.org)

### For further information

1. Klimas NG, Salvato FR, Morgan R, Fletcher MA. Immunologic abnormalities in chronic fatigue syndrome. *J Clin Microbiol* 1990; 28: 1403-10. [PMID: 2166084]
2. Myhill S, Booth NE, McLaren-Howard J. Chronic fatigue syndrome and mitochondrial dysfunction. *Int J Clin Exp Med* 2009; 2: 1-16. [PMID: 19436827]
3. Peckerman, A., LaManca, J.J., Dahl, K.A., Chemitiganti, R., Qureishi, B., Natelson, B.H., 2003. Abnormal impedance cardiography predicts symptom severity in chronic fatigue syndrome. *American Journal of Medical Sciences* 326 (2), 55-60.
4. Streeten DH, Thomas D, Bell DS. The roles of orthostatic hypotension, orthostatic tachycardia and subnormal erythrocyte volume in the pathogenesis of the chronic fatigue syndrome. *Am J Med* 2000; 320: 1-8. [PMID: 10910366]
5. Kerr JR, Burke B, Petty R, et al. Seven genomic subtypes of chronic fatigue syndrome/myalgic encephalomyelitis; a detailed analysis of gene network and clinical phenotypes. *J Clin Pathol* 2008; 61: 730-739. [PMID: 18057078]
6. Tirelli U, Chierichetti F, Tavio M, Simonelli C, Bianchin G, Zanco P, Ferlin G. Brain positron emission tomography (PET) in chronic fatigue syndrome: preliminary data. *Amer J Med* 1998; 105: 54S-8S. [PMID: 9790483]
7. Goldstein JA. *Chronic Fatigue Syndrome: The Limbic Hypothesis*. Binghampton, New York: Haworth Medical Press; 1993:19, 116.
8. Chia J, Chia A, Voeller M, Lee T, Chang R. Acute enterovirus infection followed by myalgic encephalomyelitis/chronic fatigue syndrome and viral persistence. *J Clin Pathol* 2010; 63: 163-8. [PMID: 19828908]
9. Pall ML. *Explaining "Unexplained Illnesses": Disease Paradigm for Chronic Fatigue Syndrome, Multiple Chemical Sensitivity, Fibromyalgia, Post-Traumatic Stress Disorder, Gulf War Syndrome and Others*. Binghamton, NY: Harrington Park (Haworth) Press, 2007.
10. Meeus M, Nijs J, McGregor N, Meeusen R, De Schutter G, Truijzen S, Frémont M, Van Hoof E, De Meirleir K.: Unravelling intracellular immune dysfunctions in chronic fatigue syndrome: interactions between protein kinase R activity, RNase L cleavage and elastase activity, and their clinical relevance. *In Vivo*. 2008 Jan-Feb;22(1):115-21. PMID:18396793 [PubMed - indexed for MEDLINE] Free Article

For an objective view of the establishment intrigue surrounding ME we recommend:

**Magical Medicine: How to Make a Disease Disappear** by Professor Malcolm Hooper [ [www.investinme.org/Article400%20Magical%20Medicine.htm](http://www.investinme.org/Article400%20Magical%20Medicine.htm)]

Professor Hooper has made a formal complaint to the Minister of State responsible for the Medical Research Council.