



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

Email: info@euro-me.org

web: 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.

Kathleen McCall
Chairman Invest in ME
www.investinme.org

References

1. 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, Bsted 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.

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]

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