European ME Alliance

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SITUAZIONE SANITARIA E LEGALE DEI MALATI DI ME (ENCEFALOMIELITE MIALGICA) E CFS (SINDROME DA AFFATICAMENTO CRONICO)

L'Encefalita Mialgica (ME) venne riconosciuta dall'OMS quale patologia neurologica nel 1969.
In alcuni Stati l'ME viene chiamata "Sindrome da Affaticamento Cronico" (CFS). Nel 1993 la CFS venne aggiunta quale appendice all'ICD-10 ma la definizione di CFS basata sulla definizione della fatica causa ancora problemi e confusione per i pazienti, come è stato dichiarato da Mrs. Androulla VASSILIOU, ex Commissario Europeo per la Sanità.

l'ME si può presentare sotto forma di epidemia: ne fu descritta una per la prima volta nel 1934. Rispetto alla qualità di vita ed alle sofferenze gli esperti hanno classificato l'ME alla pari del cancro e dello stadio terminale dell'AIDS.

Siamo pertanto a richiedere quanto segue:

-che venga rispettato il Codice ICD-10 G93.3 dell'OMS per la ME quale malattia neurologica e che venga garantito che gli Stati Membri lo introducano nel proprio Sistema Sanitario;

-di rispettare i diritti dei pazienti affetti da ME, inclusi i soggetti in età pediatrica, in tutti gli Stati Membri;

-di approvare quali criteri diagnostici per l'ME i Criteri di Consenso Canadesi e i Criteri di Consenso Internazionali che sono ancora in corso di sviluppo;

-di incoraggiare lo sviluppo della ricerca biomedica, delle terapie e del sostegno sociale.

In Europa si stima ci siano circa 1.200.000 malati gravi di ME in attesa che il parlamento riconosca la codifica ICD-10 G93.3, approvata dall'OMS.

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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, Bested 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.

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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. Binghamptom, 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. Bighamton, NY: Harrington Park (Haworth) Press, 2007.
10. Meeus M, Nijs J, McGregor N, Meeusen R, De Schutter G, Truijen 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.