From:
Sent: 22 May 2019 21:14
To: Finance Foodsuppl
Subject: Submission on behalf of the Irish ME/CFS Association:

Submission on behalf of the Irish ME/CFS Association (interested group):

Our charity covers Myalgic Encephalomyelitis/Chronic Fatigue Syndrome (ME/CFS). We are a low-cost group, run by volunteers: this is our busiest time of the year being our awareness month. So unfortunately we do not have the resources to give as detailed a submission as we would like, but we thought we would raise some issues.

A lot if not most supplements do not have patents attached to them. This means there is not the incentive for pharmaceutical companies to invest millions or more in clinical trials as another company can sell the product without having had to pay for the research, so could offer it at a lower price. This means that the evidence base for supplements is not as strong as it is for some drugs. However, that doesn't mean that supplements are necessarily inferior to drugs: it's basically not a fair competition. When there is evidence regarding supplements, trials tend to have to be quite small as they are often done with small budgets.

A number of studies have found benefit for some supplements with ME/CFS (1-10). We have appended a list below of some studies, but do not claim it is a definitive list. This does not necessarily mean we recommend them, but raises the possibility that they may be of benefit.

There are few large clinical trials into ME/CFS specifically except for behavioural interventions. This means there are very few evidence-based therapies. Patients and clinicians are then faced with a difficult choice: what do they do after reading about a supplement that has shown some benefit in one or more trials? The likelihood is that there will be no definitive research on this in the short to medium term, but patients' lives are passing by and they can be struggling with many debilitating symptoms.

ME/CFS puts a huge strain on people's financial situation (11-15). Many are forced to give up work while others have to reduce the number of hours they work. This means that any extra taxes could mean they would not be able to avail of some supplements. From a financial point of view, if a supplement is helping a patient, it could in some circumstances have a financial benefit to society. For example, the person may be able to be more economically productive. Alternatively they may not need as much formal or informal social care. They may take fewer other drugs that are paid for by health systems and generally cost health systems less. Also, even if a supplement does not have a direct economic benefit, it is usually recognised in cost-benefit analyses, that improving health related quality of life is a worthy aim in itself for society and health systems. In some circumstances, supplements could be improving quality of life. Studies have found that health-related quality of life (and similar measures) is on average quite badly affected in people with ME/CFS (16-20).

Even when a supplement has not been found to be useful to specifically address ME/CFS symptoms, it could be useful for specific individuals with the condition. For example, some people with ME/CFS may not be able to get sufficient vitamin D from sunlight due to light sensitivity, mobility impairments and/or heat intolerance. Supplementing with vitamin D could help prevent bone loss, even though a clinical trial trial did not find benefit with regard to fatigue (21,22). Some people with ME/CFS could have difficulty maintaining a fully balanced diet due to food intolerances and/or difficulties with food preparation. Supplementing with particular vitamins and minerals could be justified in some cases.

References:

Some studies which reported some benefit for some supplements in ME/CFS:

1 Fukuda S, Nojima J, Kajimoto O, Yamaguti K, Nakatomi Y, Kuratsune H, Watanabe Y. Ubiquinol-10 supplementation improves autonomic nervous function and cognitive function in chronic fatigue syndrome. Biofactors. 2016 Jul 8;42(4):431-40. doi: 10.1002/biof.1293. Epub 2016 Apr 29.

2 Ostojic SM, Stojanovic M, Drid P, Hoffman JR, Sekulic D, Zenic N. Supplementation with Guanidinoacetic Acid in Women with Chronic Fatigue Syndrome. Nutrients. 2016 Jan 29;8(2):72. doi: 10.3390/nu8020072.

3 Castro-Marrero J, Cordero MD, Segundo MJ, Sáez-Francàs N, Calvo N, Román-Malo L, Aliste L, Fernández de Sevilla T, Alegre J. Does oral coenzyme Q10 plus NADH supplementation improve fatigue and biochemical parameters in chronic fatigue syndrome? Antioxid Redox Signal. 2015 Mar 10;22(8):679-85. doi: 10.1089/ars.2014.6181. Epub 2014 Dec 18.

4 Maric D, Brkic S, Tomic S, Novakov Mikic A, Cebovic T, Turkulov V. Multivitamin mineral supplementation in patients with chronic fatigue syndrome. Med Sci Monit. 2014 Jan 14;20:47-53. doi: 10.12659/MSM.889333.

5 Alegre J, Rosés JM, Javierre C, Ruiz-Baqués A, Segundo MJ, de Sevilla TF. [Nicotinamide adenine dinucleotide (NADH) in patients with chronic fatigue syndrome]. Rev Clin Esp. 2010 Jun;210(6):284-8. doi: 10.1016/j.rce.2009.09.015. Epub 2010 May 5.

6 Rao AV, Bested AC, Beaulne TM, Katzman MA, Iorio C, Berardi JM, Logan AC. A randomized, double-blind, placebo-controlled pilot study of a probiotic in emotional symptoms of chronic fatigue syndrome. Gut Pathog. 2009 Mar 19;1(1):6. doi: 10.1186/1757-4749-1-6.

7 Vermeulen RC, Scholte HR. Exploratory open label, randomized study of acetyl- and propionylcarnitine in chronic fatigue syndrome. Psychosom Med. 2004 Mar-Apr;66(2):276-82.

8 Plioplys AV, Plioplys S. Amantadine and L-carnitine treatment of Chronic Fatigue Syndrome. Neuropsychobiology. 1997;35(1):16-23.

9 Behan PO, Behan WM, Horrobin D. Effect of high doses of essential fatty acids on the postviral fatigue syndrome.
Acta Neurol Scand. 1990 Sep;82(3):209-16.

10 Teitelbaum JE1, Johnson C, St Cyr J. The use of D-ribose in chronic fatigue syndrome and fibromyalgia: a pilot study. J Altern Complement Med. 2006 Nov;12(9):857-62.

Some studies on the economic effects of ME/CFS

11 Jason LA, Benton MC, Valentine L, Johnson A, Torres-Harding S. The economic impact of ME/CFS: individual and societal costs. Dyn Med. 2008;7:6.

12 Reynolds KJ, Vernon SD, Bouchery E, Reeves WC. The economic impact of chronic fatigue syndrome. Cost Eff Resour Alloc. 2004;2:4.

13 Bibby J, Kershaw A. How much is ME costing the country? Report prepared by the Survey and Statistical Research Centre, Sheffield Hallam University. 2006

14 Collin SM, Crawley E, May MT, Sterne JAC, Hollingworth W, National Outcomes Database U. The

impact of CFS/ME on employment and productivity in the UK: a crosssectional study based on the CFS/ME National Outcomes Database. BMC Health Services Research 2011, 11:217

15 Hunter R, James M, Paxman J. Counting the Cost: chronic fatigue syndrome/myalgic encephalomyelitis. Full report 2017.
https://www.theoptimumhealthclinic.com/wp-content/uploads/2017/09/Counting-the-Cost.pdf
Accessed 21 May 2019

Some studies showing how ME/CFS can have a significant effect on health related quality of life and similar measures.

16 Falk Hvidberg M, Brinth LS, Olesen AV, Petersen KD, Ehlers L. The Health-Related Quality of Life for Patients with Myalgic Encephalomyelitis / Chronic Fatigue Syndrome (ME/CFS). PLoS One. 2015 Jul 6;10(7):e0132421.

17 Winger A, Kvarstein G, Wyller VB, Ekstedt M, Sulheim D, Fagermoen E, Småstuen MC, Helseth S. Health related quality of life in adolescents with chronic fatigue syndrome: a cross-sectional study. Health Qual Life Outcomes. 2015;13:96.

18 Goudsmit EM., Stouten B, Howes S. Illness intrusiveness in myalgic encephalomyelitis. An exploratory study. Journal of Health Psychology. 2009, 14, 2, 215-221.

19 Hardt J, Buchwald D, Wilks D, Sharpe M, Nix WA, Egle UT. Health-related quality of life in patients with chronic fatigue syndrome: an international study. J Psychosom Res. 2001 Aug;51(2):431-4.

20 Kingdon CC, Bowman EW, Curran H, Nacul L, Lacerda EM. Functional Status and Well-Being in People with Myalgic Encephalomyelitis/Chronic Fatigue Syndrome Compared with People with Multiple Sclerosis and Healthy Controls. Pharmacoecon Open. 2018 Dec;2(4):381-392.

Some references regarding vitamin D

21 Hoskin L, Clifton-Bligh P, Hansen R, Fulcher G, Gates F. Bone density and body composition in young women with chronic fatigue syndrome. Ann N Y Acad Sci. 2000 May;904:625-7. No abstract available.

22 Witham MD, Adams F, McSwiggan S, Kennedy G, Kabir G, Belch JJ, Khan F. Effect of intermittent vitamin D3 on vascular function and symptoms in chronic fatigue syndrome--a randomised controlled trial. Nutr Metab Cardiovasc Dis. 2015 Mar;25(3):287-94.