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LAUSUNTO

SOSIAALI- JA TERVEYSMINISTERIÖ

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**Valtakunnallinen hoidon saatavuuden ja yhtenäisten hoidon perusteiden työryhmä  
TOIMINNALLISTEN HÄIRIÖIDEN HOIDON JÄRJESTÄMINEN –työryhmän luonnos**

Dear STM Working group,

The European ME Alliance (EMEA) [1] is an umbrella organisation of national patient organisations and charities in fourteen European countries concerned with Myalgic Encephalomyelitis/Chronic Fatigue Syndrome (ME/CFS).

EMEA uses the term ME/CFS as some countries in Europe use CFS only and others ME or ME/CFS in their documentation and EMEA endorses the Canadian Concensus Criteria that use the term ME/CFS. [2]

EMEA is a member of, and has a representative on the board of European Federation of Neurological Associations (EFNA). [3]

Due to the UK being mentioned in the document of the working group and due to time constraints the EMEA board has asked EMEA UK member – UK charity Invest in ME Research – to formulate a response to this document.

We are replying on behalf of the board of the European ME Alliance.

EMEA were alerted to this guideline by the Finnish CFS Association – Suomen CFS Yhdistys – a member of EMEA.

We have read the working group document and are concerned that the working group's proposal to divert from their original remit of producing a care pathway for ME/CFS to producing a document that includes ME/CFS under Medically Unexplained Symptoms (MUS) or Functional Disorders (FD).

This is unacceptable.

ME/CFS is not a Functional Disorder nor can it be included in MUS.

The latest international guideline and literature review, by the US Institutes of Medicine (IOM) report that you reference, states –

” ME/CFS is a serious, chronic, complex, systemic disease that often can profoundly affect the lives of patients.” [4]



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It seems that the working group's document is not written with the most important objective in mind, namely the health of the patient.

Instead, it attempts to solve a healthcare situation by deciding to gather a disparate group of patients into one care pathway – something completely illogical if the intent is to treat a patient properly.

It is also striking that the working group did not include any experts in ME/CFS despite the original remit specifically being ME/CFS. Neither did it include patients.

The working group may believe they can comment on ME/CFS but patients live it – every day!

Finland has access to good quality patient registries and could contribute to the increasing fundamental international research into ME/CFS that has been started by a growing international biomedical research community that has been facilitated by Invest in ME Research.

#### WHAT ARE FUNCTIONAL DISORDERS

The authors claim that ME, CFS and PVFS are notably missing a diagnostic code or diagnostic criteria.

This is incorrect as all these terms have been designated the code G93.3 in the WHO classification since 1969 and there are several diagnostic criteria, the latest being the US IOM report that the authors reference. [4]

Most of the current biomedical researchers use the Canadian consensus criteria in their research. [2]

It is unfortunate that some healthcare professionals and researchers have chosen to blur the issue by mixing neurasthenia and fatigue syndrome (without the word Chronic) patients (ICD-10 F48) with ME, CFS and PVFS even though the ICD10- F48 code specifically excludes G93.3 (ME and PVFS with CFS indexed to this code).

Any confusion is not due to lack of coding or criteria but lack of correct medical education – or perhaps intentional bias.

The document also refers to the forthcoming ICD-11 classification's new construct of Bodily Distress Disorder (BDD).

The BDD is in the "Mental, behavioural or neurodevelopmental disorders" chapter and the WHO has confirmed that there is no plan to relocate ME, CFS or PVFS under the mental health disorders.

Currently ICD-10 lists ME and PVFS in the nervous system chapter of G93.3 with CFS indexed to it and in 8E49 of the ICD-11 beta draft. [5, 6]

#### **Description**

*Bodily distress disorder is characterized by the presence of bodily symptoms that are distressing to the individual and excessive attention directed toward the symptoms, which may be manifest by repeated contact with health care providers. If another health condition is causing or contributing to the symptoms, the degree of attention is*



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*clearly excessive in relation to its nature and progression. Excessive attention is not alleviated by appropriate clinical examination and investigations and appropriate reassurance. Bodily symptoms are persistent, being present on most days for at least several months. Typically, bodily distress disorder involves multiple bodily symptoms that may vary over time. Occasionally there is a single symptom—usually pain or fatigue—that is associated with the other features of the disorder.*

BDD is an add-on diagnosis to any physical illness if the patient pays too much attention to their symptoms or visits the doctor too often - but who decides what is excessive?

ME/CFS patients deserve attention to their core illness and that is what is happening now in the US where the National Institutes of Health (NIH) regard ME/CFS as a biological illness and not a functional disorder. [7]

Finland is a modern, forward-thinking country with a modern healthcare system. It would be prudent for Finland to follow suit and adopt the American direction for treating ME/CFS properly.

The working group document uses the inflated prevalence figure of 1-3% for ME/CFS in the UK but the officially accepted/used figure is 0.2-0.4%. [8]

You must be more precise with these figures and not make them up.

The UK 2007 CFS/ME NICE guidelines states -

*There is a lack of epidemiological data for the UK, so population estimates are based on extrapolations from other countries. Overall, evidence suggests a population prevalence of at least 0.2–0.4%. This means that a general practice with 10,000 patients is likely to include up to 40 people with CFS/ME; half of these people will need input from specialist services.*

It is illustrative of the ridiculous situation that ME/CFS patients find themselves in when no healthcare system in the world seems to be able to quote accurate numbers of ME/CFS patients and yet they rely on extrapolating figures from elsewhere.

Finland deserves better.

Why is no one extracting accurate data from patient records or keeping registries of ME/CFS patients?

Whenever the question of numbers is being asked in the UK parliament the answer is that they do not collect numbers of ME/CFS patients. Invest in ME Research receive this negligent answer from the Chief Medical Officer and from the Department of Health whenever it asks this question.

Finland has a reputation of having good quality patient registries and expertise in long-term health follow up of its citizens so perhaps this is something the Finnish healthcare system should be doing.

Finland can do it better.



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## FUNCTIONAL DISORDERS IN THE CURRENT HEALTHCARE SYSTEM

The working group rightly mentions the difficulty in diagnosing patients correctly but the problem remains if doctors do not use agreed guidelines for diagnosis.

There are, indeed, many guidelines for ME/CFS and if this is a problem for the Finnish healthcare system then it should first be agreed which guideline(s) to use. If none of them are suitable for the Finnish healthcare system then they should formulate their own – based on up-to-date information and research.

We advise you not to look at the UK health system to assist as it has been so corrupted by misinformation that it is valueless.

It is not in anyone's interest (neither that of patients nor of healthcare professionals) to try to fit a large heterogeneous group of patients into a care pathway that has no good treatment/management evidence and may lead to missing diagnosing a serious or rare condition that may take years to develop and which does not show up in early routine tests.

This may lead to substantial litigation against the service provider or the agency enforcing guidelines.

Who takes the responsibility when patients are encouraged to downplay their symptoms and rely on psychotherapists and CBT therapists to manage them with various stress reduction and life style management techniques?

It has been proven in a clinical trial of clonidine that ME/CFS is not a stress related disorder. [10, 11]

ME/CFS is a serious and complex illness that deserves its own speciality.

Without specialist knowledge in ME/CFS it is difficult to train doctors to diagnose patients correctly. It is difficult to convince funding bodies to increase fundamental research into ME/CFS that will eventually find effective treatments, prevention and a cure.

In the UK parliament The Countess of Mar recently (1 May 2018) asked a question regarding the recently established increased access to psychological therapies (IAPT) programme and its success regarding curing ME patients. [12]

*To ask Her Majesty's Government what are the recovery rates of patients with myalgic encephalomyelitis who have received treatment under the Improving Access to Psychological Therapies programme.*

Lord O'Shaughnessy answered on 15 May 2018

*This information is not available.*

The proposal written by the STM working group sounds very similar to the UK IAPT scheme and it is a shame to see Finland taking its guidance from the IAPT programme in the UK regarding ME/CFS when they could create an exemplary ME/CFS patient care pathway that others could follow instead.



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Finland should be leading the world in treating ME/CFS patients – not playing a subservient lapdog role for a failing healthcare system which already sees patients pitted against the National Institute of Clinical Care Excellence (NICE) and successive governments.

Finland must not use UK and NHS as an example.

The situation in UK for people with ME is atrocious with largescale prejudice based on poor research (e.g. PACE trial) and misinformation about the disease being propagated by corrupted media sources influenced by a cabal of psychiatrists who have long been in control of research funding and government health departments.

We are also concerned by the insinuation that patients' disabilities may be maintained by aids given to them by the disability services.

This argument is fallacious and was proposed by those defending the biopsychosocial model of care when the existing UK NICE guidelines were being formulated in 2006. [9]

The UK NICE guidelines are now in the process of being rewritten.

Draft for 2006 consultation text:

*1.3.1.8 For adults and children with moderate or severe symptoms, provision of equipment and adaptations (for example, a wheelchair, blue badge or stairlift) to allow individuals to improve their independence and quality of life should be considered, if appropriate and as part of an overall management plan.*

Response by St Bartholomew's Hospital Chronic Fatigue Services:

*Equipment and aids may hinder recovery as much as help it, and their prescription needs to consider both outcomes. We believe disability aids can help a patient towards recovery if their use encourages a widening and increase in their own activities, on a temporary basis, as a means of supporting a rehabilitation programme. They should rarely if ever be used for patients with only moderate disabilities. [13]*

St Bartholomew's Hospital Chronic Fatigue Services were heavily involved in the so called PACE trial which attempted to prove the efficacy of CBT (cognitive behaviour therapy) and GET (graded exercise therapy) in the treatment of ME/CFS.

Despite the trial being published in Lancet [14] and hailed as a success in the media patients and numerous international experts have uncovered serious flaws in the study and a reanalysis [15] based on the original published protocol showed that CBT and GET were not beneficial even to participants with loosely defined fatigue criteria.

The PACE Trial is now seen as an example of how not to do research and is ridiculed by more and more professionals. Questions have even been asked in parliament about possible fraud in connection with the trial.

Finland would do well not to repeat the mistakes made by the so-called biopsychosocial school of proponents elsewhere.





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Patients respect and accept honest advice and healthcare professionals should listen to the patient and believe in them.

No treatment is better than the wrong treatment and we hope that the working group reconsiders this document and provides a care pathway fit for ME/CFS as an organic illness and not as a functional disorder.

Finland can take a new direction and lead the world in correct research into ME and adequate services for patients – or it can meekly follow existing flawed healthcare systems that mistreat patients.

In Finland, you must do things differently, and do them better,

Yours Sincerely,

Richard Simpson

Chair European ME Alliance

EMEA Board:

Anna Louise Midsem

Nancy Van Hoylandt

Alice Vertonnen

Ellen Piro

#### References

1. EMEA <http://www.euro-me.org/>
2. Carruthers et al. Journal of Chronic Fatigue Syndrome 11(1):7-115, 2003. ISBN: 0-7890-227-9 © Haworth Medical Press Inc.  
[http://www.investinme.org/Documents/PDFdocuments/Canadian\\_ME\\_Overview\\_A4.pdf](http://www.investinme.org/Documents/PDFdocuments/Canadian_ME_Overview_A4.pdf)
3. EFNA <https://www.efna.net/>
4. Beyond Myalgic encephalomyelitis/ Chronic fatigue syndrome: redefining an illness. Institute of Medicine (IOM) 2015.
5. Dimmock and Chapman:  
<https://dxrevisionwatch.files.wordpress.com/2018/05/comparison-of-classification-and-terminology-systems-may-2018.pdf>
6. WHO ICD11 beta draft <https://icd.who.int/dev11/l-m/en#/http://id.who.int/icd/entity/767044268>
7. NIH announces centers for myalgic encephalomyelitis/chronic fatigue syndrome research <https://www.nih.gov/news-events/news-releases/nih-announces-centers-myalgic-encephalomyelitis-chronic-fatigue-syndrome-research>
8. NICE guidelines UK <https://www.nice.org.uk/guidance/cg53/chapter/introduction>
9. Draft for NICE consultation 2006  
<https://www.nice.org.uk/guidance/cg53/documents/cfsme-guideline-consultation-nice-guideline2>

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10. <http://sciencenordic.com/no-improvement-chronic-fatigue-new-medicine>
11. [Dag Sulheim, MD<sup>1,2</sup>; Even Fagermoen, MD<sup>3,4</sup>; Anette Winger, RN, MA<sup>3,5</sup>; et al.](#) Disease Mechanisms and Clonidine Treatment in Adolescent Chronic Fatigue Syndrome: A Combined Cross-sectional and Randomized Clinical Trial *JAMA Pediatr.* 2014;168(4):351-360. doi:10.1001/jamapediatrics.2013.4647
12. UK parliamentary question HL7468  
<https://www.parliament.uk/business/publications/written-questions-answers-statements/written-question/Lords/2018-05-01/HL7468/>
13. St Bartholomew's Hospital Chronic Fatigue Services Draft NICE Response  
<https://www.nice.org.uk/guidance/cg53/documents/nice-version-table-of-comments2>
14. White P.D., Goldsmith K., Johnson A.L., Potts L., Walwyn R., Decesare J.C., Baber H.L., (...), Sharpe M. Comparison of adaptive pacing therapy, cognitive behaviour therapy, graded exercise therapy, and specialist medical care for chronic fatigue syndrome (PACE): A randomised trial (2011) *The Lancet*, 377 (9768) , pp. 823-836.
15. Carolyn Wilshire, Tom Kindlon, Alem Matthees & Simon McGrath (2016) Can patients with chronic fatigue syndrome really recover after graded exercise or cognitive behavioural therapy? A critical commentary and preliminary re-analysis of the PACE trial, *Fatigue: Biomedicine, Health & Behavior*, 5:1, 43-56, DOI: 10.1080/21641846.2017.1259724