European ME Alliance

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Dear **Members of the Funktionelle Lidelser Working Group**,

The European Myalgic Encephalomyelitis Alliance (EMEA) is an organisation of national patient organisations and charities in thirteen European countries campaigning for better research and more funding for research into Myalgic Encephalomyelitis (ME or ME/CFS), as defined by WHO-ICD-10-G93.3.

EMEA is aware that your group will be deciding how to evaluate and treat ME patients in Denmark.

We urge you to recommend that a centre be established for the treatment of ME, that is separate from the overly-broad research concept of Funktionelle Lidelser or MUS.

Such a centre should follow the model of centres in Sweden and Norway and it should be using the latest bio-medical treatments and management strategies for ME.
The centre in Norway has experts in the fields of immunology, microbiology, psychology and neuro-chemistry [1].

A Danish ME centre should draw on the expertise found in international ME research centres, such as the ME/CFS Initiative at Stanford University (USA) [2] and the National Centre for Neuroimmunology and Emerging Diseases, Griffith University (Australia) [3].

We urge you to recommend the immediate end to the current practice of treating ME patients with cognitive behavioural therapy (CBT) and graded exercise therapy (GET).
CBT and GET have been shown to be ineffective for ME patients and GET can cause a worsening of the illness [4] that can last months, years or be permanent [5, 6].

<u>CBT and GET are not evidence-based treatments.</u>

A recent review of CBT and GET by Sten Helmfrid, PhD in a Swedish journal, Socialmedicinisk Tidskrift [7], states –

> "There have been a number of studies on Cognitive Behavioral Therapy (CBT) and Graded Exercise Therapy (GET) for ME/CFS based on a treatment model where the disease is perpetuated by cognitive processes.
> Although the studies are flawed and the model lacks scientific support, the treatments are described as evidence based. The studies are non-blinded and rely on subjective outcomes.

> There are no objective measures of adherence. The diagnostic criteria vary, and the participating patients often have one or several psychiatric diagnoses apart from suffering from chronic fatigue.
>
> The underlying model has no theoretical foundation and is at odds with physiological findings.
> Surveys suggest that the efficacy of CBT is no better than placebo and that GET is harmful.
> Therefore, cognitive behavioral therapy and graded exercise therapy for ME/CFS are not evidence based."

We agree with these comments.

Two reports from large official bodies [8, 9] in the US have downgraded evidence from CBT and GET studies.

CBT, as it is currently used in Denmark, is harmful to patients as it tells them to ignore their symptoms. It teaches them that their illness is caused by a stress-response, is maintained by the patient focusing on their illness and by the belief that their illness has a physical cause.
This hypothesis is completely unproven and coercing the patient into thinking that they are responsible for their inability to get well is extremely harmful.

GET harms patients by pushing them to do more than their system can tolerate. There is a large and growing body of evidence that explains why ME patients have exercise intolerance. Exercise intolerance is, in fact, the hallmark of ME.
It is therefore completely illogical to assume that GET would be a curative or helpful treatment for ME.

ME is a complex, chronic, multi-system illness which seems to have several distinct subsets. It should be studied and treated by itself, and not included in the overly-broad research group of Funktionelle Lidelser.

In 2008, a Danish working group recognised the need for an ME centre to be established in Denmark.
Sadly, this never happened.

There are approximately 15.000 ME patients in Denmark and most of them are too ill to work.
They need your help.

We implore you to recommend that a true ME Centre be established as soon as possible.

Yours Sincerely

EMEA Board

Anna-Louise Midsem	Ellen Piro	Richard Simpson
Alice Vertommen	Nancy Van-Hoylandt	Rebecca Hansen

References:

1 http://ous-research.no/home/dgm/ME%20CFS%20Centre/12921?submenu=2

2 http://med.stanford.edu/chronicfatiguesyndrome.html

3 https://www.griffith.edu.au/health/national-centre-neuroimmunology-emerging-diseases/publications-and-conferences

4 https://www.ncbi.nlm.nih.gov/pubmed/19855350 A review on CBT and GET in ME/ CFS: CBT/GET is not only ineffective and not evidence-based, but also potentially harmful for many patients with ME/CFS, *Twisk, Maes*

5 http://tidsskriftet.no/2011/05/brev-til-redaktoren/gradert-treningsterapi-kan-ha-skadelige-effekter#reference-5

6 http://web.archive.org/web/20130115105558/http:/www.iacfsme.org/BULLETINFALL2011/Fall2011KindlonHarmsPaperABSTRACT/tabid/501/Default.aspx

7 https://www.researchgate.net/publication/309351210_Studies_on_Cognitive_Behavioral_Therapy_and_Graded_Exercise_Therapy_for MECFS_are_misleading

8 http://annals.org/aim/article/2322804/national-institutes-health-pathways-prevention-workshop-advancing-research-myalgic-encephalomyelitis

9 https://www.hhs.gov/ash/advisory-committees/cfsac/recommendations/2016-05-17/cfsac-iom-p2p-working-group-recommendations/index.html#_edn3