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## **Open Letter to Minister of Health, Magnus Heunicke**

To: Danish Minister of Health, Mr Magnus Heunicke

On March 14th 2019, a unified Danish Parliament voted to acknowledge WHO's diagnostic classification of Myalgic Encephalomyelitis (ME - G93.3) as a biological illness and to separate ME from Functional Disorders.

The proposal passed is aligned with the current international scientific knowledge about ME.

Based on analysis of more than 9.000 peer-reviewed studies, the Institute of Medicine<sup>1</sup>, Centers for Disease Control (CDC), National Institutes of Health (NIH), as well as the advisory report from the Dutch Health Council<sup>2</sup>, conclude that ME is a serious chronic multisystem, biological disease that substantially limits the activities and quality of life of patients.

ME is a complex and physical disease for which there is currently no cure. It is not a psychological or psychosomatic disease. There is strong scientific evidence of neurological/autonomic dysfunction, immunologic and inflammatory pathologies, microbiome perturbation, metabolic/mitochondrial as well as cardiac abnormalities (and more) in patients.

Based on this scientific evidence, there is an imminent need to change the narrative of ME to avoid that patients are misdiagnosed or further stigmatised by falsely equating the disease with (chronic or unexplained) fatigue, deconditioning or psychosomatic classifications, like functional disorders, medically unexplained symptoms, somatoform disorders, somatic symptom disorder, functional somatic syndrome, neurasthenia, or bodily distress disorder/syndrome.

Patients have for decades been prescribed treatments like Cognitive Behavioral Therapy (CBT) and Graded Exercise Therapy (GET), based on the idea that they suffer from "false illness beliefs", fear of exercise or that they are deconditioned. This 'deconditioning hypothesis' as well as the 'psychosomatic hypothesis' of ME is not supported by biomedical research. The treatments based on these hypotheses (CBT/GET) have produced no robust evidence in the past two decades, as the US Agency for Healthcare Research and Quality systematic literature review, and reanalysis of the largest ever study on CBT/GET (PACE trial)<sup>3</sup> have shown.

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<sup>1</sup> IOM 2015 report

<sup>2</sup> <https://www.gezondheidsraad.nl/en/task-and-procedure/areas-of-activity/optimale-gezondheidszorg/mecfs>

<sup>3</sup> <https://bmcpyschology.biomedcentral.com/articles/10.1186/s40359-018-0218-3>

The CDC has recently removed its recommendations for CBT and GET from its website.

Furthermore, and of dire importance, patients internationally for more than 20 years have continually reported deterioration from following the advice of their doctors to gradually increase their exertion levels based on a GET protocol.

Post-exertional malaise (PEM), a worsening of symptoms after minimal physical or mental exertion, is the hallmark characteristic of the disease. GET worsens PEM and has the potential to cause lasting harm for patients with ME.

There is international consensus that funding biomedical ME research is the only way to create better insights into the physiological mechanisms of this debilitating disease, so we can provide better and more efficient care based on the needs of patients and the biomedical nature of the disease, as well as effective treatments and potentially a cure. Biomarkers are also needed for accurate diagnosis.

More funding for biomedical research into ME is therefore urgently needed.

We ask that the Danish Government will strongly consider a long-term investment in biomedical ME research. It is an absolute priority and the only way to make the necessary progress to help stop what the CDC calls a “hidden health crisis”.

We would be happy to provide you with further insights based on our expertise, if needed.

This letter has also been sent to the Minister of Higher Education and Science, as well as the Danish Health Authority.

Sincerely,

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<sup>4</sup> Indeed, there is evidence that such approaches (CBT/GET) may not only be ineffective, but may actually be harmful to patients. (Davenport TE et al. **Checking our blind spots: current status of research evidence summaries in ME/CFS.** *Br J Sports Med* 2019;53:1198. doi: 10.1136/bjsports-2018-099553)



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<sup>5</sup> Post-exertional malaise is associated with changes in glycolysis and acetylation in ME/CFS patients. These changes are consistent with a hypo-acetylation state and are likely to significantly alter histone acetylation and the actions of acetylation and deacetylation in controlling cellular enzymatic events. Well-designed studies evaluating these important factors are warranted (McGregor Neil R. et al: Post-Exertional Malaise Is Associated with Hypermetabolism, Hypoacetylation and Purine Metabolism Deregulation in ME/CFS Cases <https://www.mdpi.com/2075-4418/9/3/70>)

