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*Dear Dr O'Sullivan*

I write to you as an Independent crossbench member of the House of Lords where I have been since 1975. I am a Deputy Speaker in the House. For more than 20 years I have represented the interests of people with ME/CFS and other MUPS. I am patron of several ME charities and Chairman of Forward-ME.

I have read David Aaronovitch's review of your book: "It's all in Your Head – True Stories of Imaginary Illness" and I have listened to what you had to say on Radio 4's Start the Week programme yesterday, though I have not read your book. Aaronovitch quotes you in the introduction to the chapter on ME as admitting that "to include ME/CFS in a book primarily concerned with the description of those suffering from psychosomatic illness is foolhardy to say the least." He goes on to say that "This is because the reaction of many ME sufferers, their relatives and friends and the organisations that represent them, to the idea that the condition is psychosomatic – caused by the mind and not by a disease – is intensely hostile. I have experienced this hostility." I assume the last sentence refers to him personally.

Sadly, both you and he are right about the hostility to the views you both promote, but you give the wrong reasons for that hostility. In recent years there have been a host of papers that demonstrate that ME/CFS is a disease as well as an illness. Firstly the Canadian Consensus document on ME/CFS, published in 2003, gave good guidelines for diagnosis and treatment of people with ME. This was followed by the more comprehensive Myalgic Encephalomyelitis - International Consensus Document published in 2011. More recently, the highly respected US Institute of Medicine in its report "Beyond Myalgic Encephalomyelitis/Chronic fatigue Syndrome: Redefining the Illness" released on 10 February 2015, made clear that the primary message of the Committee's report is that **"ME/CFS is a serious, chronic, complex systemic disease that often can profoundly affect the lives of patients."** Patients with the disease have always known this and are, understandably, deeply hurt and offended by the denigration they receive from some medical practitioners.

I admire the fact that you believe that people who suffer psychosomatic illnesses should be treated with compassion and understanding but I am equally disappointed that you appear to have failed dismally to keep abreast of current research into ME/CFS. Had people like you in senior positions really tried to discover what is at the root of the symptoms suffered by the patients that you see more progress might have been made in the diagnosis and treatment of this dreadfully neglected disease.

For example, on 30 May this year in *Metabolomics* *Armstrong et al* wrote: "Metabolic profiling reveals anomalous energy metabolism and oxidative stress pathways in chronic fatigue patients." Have you ever thought of metabolic profiling for your profoundly fatigued patients, I wonder? I do realise that there are vast numbers of papers of variable quality published each year, but I really do think that if one is professing an expertise in a particular disease or illness one should try to keep abreast of current research, don't you?

You appear to be unaware that research shows that ME is an organic multi-system neuro-immune disorder with protean symptomology; some consider it likely to be an autoimmune disease with the target organ being the vascular endothelium.

For the avoidance of doubt, here are some facts that may have escaped you:

- Since 2005 ME has been included in the UK National Framework for long-term neurological conditions.
- On 30 January 2006 the then health Minister, Lord Warner, said on record: "There is only one World Health Organisation International Classification of Disease code for chronic fatigue syndrome/Myalgic encephalomyelitis, which is G93.3." (HL3612)
- On 2 June 2008 the Parliamentary Under-Secretary of State, Department of Health (Lord Darzi of Denham) stated: "*My Lords, the Government accept the World Health Organisation's classification of CFS/ME as a neurological condition .... My Lords, I have acknowledged that CFS/ME is a neurological condition.*" (HLPQ: Health: Chronic Fatigue Syndrome/Myalgic Encephalomyelitis)
- On 21 November 2011 Lord Freud, Minister for Welfare Reform, confirmed in a letter to me that the Department for Work and Pensions does not consider ME/CFS to be a mental disorder. The letter was unequivocal: "*the Department of Health has indicated that they have 'always relied on the definition set out by the World Health Organisation in its International Classification of Diseases (ICD) under the ICD code G93.3, subheading other disorders of the brain'. The DWP is in agreement with this view. Therefore, for the avoidance of doubt, I can be clear that the Department does not classify CFS/ME as a mental health disorder.*"
- The US National Institutes of Health, one of the world's foremost medical research centres, convened a Pathways of Prevention working group which, in December 2014, published its draft Statement entitled "Advancing the Research on Myalgic

Encephalomyelitis/Chronic Fatigue Syndrome”. It is an important document as it signifies a major change in attitude towards ME/CFS. For example:

*“Strong evidence indicates immunologic and inflammatory pathologies, neurotransmitter signalling disruption, microbiome perturbation, and metabolic or mitochondrial abnormalities in ME/CFS.*

*“This is not a psychological disease in aetiology.*

*“fMRI and imaging technologies should be further studied as diagnostic tools and as methods to better understand the neurologic dysfunction of ME/CFS.”*

As a neurologist, I am sure you will find these views of interest.

Further research from the US posits that true ME (as distinct from the ubiquitous chronic “fatigue”) is indeed an autoimmune disorder: *“Our results indicate a markedly disturbed immune signature in the cerebrospinal fluid of cases consistent with immune activation in the central nervous system, and a shift towards an allergic or T-helper type-2 pattern associated with autoimmunity ....Profiles of ME/CFS subjects also differed from those of MS subjects, with ME/CFS cases showing a markedly greater degree of central nervous system immune activation as compared with those with MS”* (M Hornig *et al*: Molecular Psychiatry 31 March 2015: doi:10.1038/mp.2015.29)

The evidence is now so strong that ME/CFS is a serious multisystem neuro-immune disease that it becomes intellectually embarrassing for anyone to continue to consider it to be a psychosomatic disorder.

I do hope that you will take my submission seriously and reconsider your belief that ME/CFS is a psychosomatic disorder.

I look forward to receiving your considered response.

Yours sincerely



Countess of Mar

Copy: David Aaronovitch.

Chatto and Windus – Lisa Gooding, Publicity.