

Ms Fiona Fox
Chief Executive
Science Media Centre
215 Euston Road
LONDON
NW1 2BE

3 April 2018

Dear Ms Fox

Re: Science Media Centre Factsheet – CFS/ME – The illness and the controversy.

On behalf of Forward-ME I write to ask you to retract and replace your factsheet on CFS/ME, published on 21 March 2018, following the publication of a paper by Dr Carolyn Wilshire of the University of Wellington, New Zealand, which found that the findings of the Principal Investigators of the PACE trial were ‘not robust’ and showed ‘no long-term benefits’.

The factsheet includes numerous inaccuracies and distortions; it denigrates patients and some doctors; it fails to reflect the numerous peer reviewed papers, published since the release of some of the raw data from the trial following legal action, which demonstrate serious defects in the PACE trial, and it fails to take into account the extensive research from the USA published since 2014. This will all have been available to you.

The factsheet states: *“CFS/ME is highly controversial with longstanding disagreements between the mainstream medical community and campaigners about its cause and treatment”*. It also states that *“amongst the mainstream medical research community, CFS/ME and NICE recommend management that is not especially controversial.”*

These claims are patently inaccurate. The mainstream medical community in the USA concluded that the “campaigners” have actually been correct about the nature of the condition, stating that “ME/CFS is a serious, chronic, complex systemic disease” (Academy of Medicine), that it is not a primary psychological disease in etiology” (National Institutes of Health). They state that guidance for managing ME/CFS should include a “declaration that the disease is not the result of fear-based avoidance of activity”, and a clear indication that the disease is not a psychiatric or somatoform disorder” (Chronic Fatigue Syndrome Advisory Committee of the Department of Health and Human Services). There certainly is controversy and disagreement at this time, but that disagreement is not between professionals and “campaigners”. It is between professionals in the UK and professionals elsewhere.

The factsheet claims that: *“After sustained pressure from activists the CDC has removed mention of CBT and GET from its website”*. This, too, is patently inaccurate and even a cursory investigation of the facts would make that clear. The CDC changed its recommendations at the urging of the Academy of Medicine, the National Institutes of Health, the Department of Health and Human Services, and the Agency for Healthcare Quality and Research, all of whom emphatically agree that the CDC’s former recommendations – that is, the current NICE recommendations – lack evidence based support.

The author of the factsheet states that existing evidence in favour of CBT and GET is “cited by the scientific community”, as if there are no reputable members of the scientific community, and no

reputable health policy authorities who disagree. They go on to state that “those who disagree cite review articles and reanalyses of trial data published in low impact factor journals such as *The Journal of Health Psychology and Fatigue: Biomedicine, Health and Behaviour*”.

It is concerning that a reputable resource like the Science Media Centre would publish such a grossly inaccurate claim, one that can be so readily overturned. Those who disagree with the evidence for CBT and GET cite the extensive investigations of the US governmental health authorities. In particular they cite the Agency for Healthcare and Research Quality Publication No. 15-E001-EF, “Diagnosis and Treatment of Myalgic Encephalomyelitis/ Chronic Fatigue Syndrome”. That document is readily available online and a quick investigation will reveal that it offers a very long and detailed list of unscientific practices and biases in the research that claims to support CBT and GET. There are a great many such reports by US governmental health organisations. It is unacceptable for the Science Media Centre to write as if these investigations did not take place; as if these documents do not exist – and it is unacceptable not to note that, by comparison, the professional reputations of these organisations far outstrip those of the PACE trial researchers.

The reality is that at this time there are no US governmental health authorities who agree that the PACE trial is “good quality”. It is absurd for any “Factsheet” on ME/CFS to overlook this fact.

Your Trustees’ Report for the year ended 31 March 2016 gives among the SMC objectives its overall goal to help to achieve the aim of the House of Lords Science and Technology Committee which sought to renew public trust in science “by working to promote more balanced, accurate and rational coverage of the important science, health and environment stories that appear in the media.” In the case of the promotion of the science relating to CFS/ME the Science Media Centre have singularly failed in its objectives over many years.

If you are not prepared to retract this factsheet I regret that we have no option but to report our concerns to the Charity Commission.

I look forward to hearing from you shortly.

Yours sincerely

Countess of Mar
Chairman – Forward-ME

Copy to: Professor Jonathan Baker, Chair of Trustees