

For clarity this document uses only ME in reference to the neuroimmunological disease Myalgic Encephalomyelitis. CFS in reference to idiopathic chronic fatigue. CFS/ME when referring to the attempts by psychiatrists to merge the two and redefine Myalgic Encephalomyelitis as a somatoform disorder (i.e. psychiatric).

We the undersigned petition the Panorama Team to conduct an investigation into the conduct of The Department of Health, Medical Research Council and National Institute for Clinical Excellence with regards to the diagnosis, treatment and research of the neuroimmunological disease Myalgic Encephalomyelitis (ME)¹ the disease that affected the late Lynn Gilderdale²

Why has The Department of Health allowed psychologists to dismiss a seriously debilitating, potentially fatal, neuroimmunological disease as so called “chronic fatigue syndrome”? Why have psychologists been allowed, even encouraged, to monopolise a psychosomatic approach to both treatment and research of a neuroimmunological disease?

These government bodies are responsible for sufferers of ME being given a meaningless “waste basket” diagnosis of “chronic fatigue syndrome” and then prescribed cognitive behavioural therapy “to correct their abnormal illness beliefs” in addition to being coerced into potentially dangerous and unproven graded exercise therapy programs. When this approach to treating a neuroimmunological disease fails to work, or results in further disability, it is the patient that is often blamed for failing to recover.

The UK is a member of The World Health Organisation which has defined ME as a neurological disease since 1969. The criteria for ME is best described by the Canadian Consensus Document³. Psychologists use their own vague Oxford Criteria⁴ which requires neither myalgias or encephalomyelitis, the main criteria being only “fatigue”. Those using the Oxford Criteria in relation to “CFS/ME” are in fact studying only idiopathic chronic fatigue and claiming otherwise.

The Wessely School⁵ psychiatrists claim ME does not exist⁶, that patients are in fact suffering from so called “chronic fatigue syndrome” a somatoform disorder (i.e. psychiatric). They insist that doctors should avoid legitimisation of symptoms⁷ and recommend that no investigations should be performed to confirm the diagnosis.⁸ Despite well documented evidence to the contrary⁹ in 1997 Michael Sharpe stated his view that “Suicide is the only cause of death in CFS”¹⁰. The Wessely School “medical” advisors are influential in the UK benefits system and are in opposition to disability benefits being paid to “ME/CFS” claimants.¹¹ In 1999 Michael Sharpe revealed his view towards “CFS/ME” patients by referring to them as “the undeserving sick” There have also been attempts to have ME reclassified as a psychiatric disorder¹²

NICE does not acknowledge or recommend the tests that diagnose ME. Instead NICE recommends tests known not to show disease and as a result there is no empirical diagnosis available on the NHS. The abnormalities found in ME patients¹³, when the correct tests are done, include abnormal blood flow to the brain, brain lesions, abnormal spinal fluid and immune system dysfunction.

The MRC, funded by the DoH, is intended to be an independent body that supports research across the biomedical spectrum. With regards to ME, this is not the case. The soon to be published MRC PACE¹⁴ trial, studying the effects of CBT and GET, is just one example of government funds going to solely psychologically based studies. This misuse of millions of pounds of tax payers money is an insult to ME sufferers and their care givers.

Professor Malcolm Hooper lodged a formal complaint against the MRC PACE trial highlighting the dangers of such a study on ME patients. Sir Michael Rawlins, the chairman of NICE, is ultimately responsible for providing guidance on the appropriate treatment and care of people with specific diseases and conditions. He refused to even read the Report of Evidence¹⁵ Professor Hooper sent

him supporting his complaint.

Sufferers of ME desire to know why the MRC is withholding files on ME that date back to 1988 from the general public? These files are to remain closed until at least 2071, an extraordinarily long period for files that are of great significance to public health¹⁶

A peer reviewed study, recently published in *Science*, strongly links the newly discovered human retrovirus XMRV to a well defined cohort of ME patients. Why was a UK XMRV study, involving psychiatrists, then quickly rushed through and given only four days for peer review? The resulting study was unable to find XMRV in any of the 186 samples, when the Whittemore Peterson Institute¹⁷ study found XMRV in 3.7% of controls. Even if every patient of the Imperial College London study cohort had idiopathic chronic fatigue and not ME they should still, if their testing had been done adequately, have detected XMRV in several samples.

Given the well documented outbreaks dating back to 1955 and the risk to public health, how can the Department of Health justify never having commissioned or evaluated any research on the relationship between ME and blood-related disorders? A Freedom of Information request revealed that, the UK Advisory Committee on the Virological Safety of Blood discussed the need to screen blood for the infection that causes ME in 1991, why was this never acted on? It is a fact that XMRV¹⁸ is in the UK, more than a dozen ME sufferers have so far tested positive through VIPdx¹⁹

To prevent further mistreatment and neglect of ME sufferers there is an urgent need for the government to recognise, manage and research ME as a serious neuroimmunological illness. Until the government corrects it's approach towards the diagnosis, treatment and research of ME, patients will remain vulnerable to coercion by doctors into GET and CBT. Those severely affected remain at risk of being sectioned under the Mental Health Act, an inexcusable action which in Sophia Mirza's case hastened her death²⁰

Yours Sincerely,

1. Myalgic Encephalomyelitis: My = muscle, Algic = pain, Encephalo = brain, Mye = spinal cord, Itis = inflammation
2. Lynn Gilderdale 1977-2008 <http://www.lynngilderdale.net/tribute.html>
3. Overview: http://www.mecfswa.org.au/UserDir/Documents/canadian_consensus_overview_me_cfs.pdf
Full document:
<http://www.mecfswa.org.au/UserDir/Documents/JCFS%20Canadian%20Clinical%20Case%20Definition%202003.pdf>
4. Oxford Criteria http://www.theoneclickgroup.co.uk/documents/ME-CFS_res/CFS%20Oxford%20Criteria%201991.pdf
5. Professor Simon Wessely, Institute of Psychiatry, King's College London and his peers including Michael Sharpe. For Simon Wessely's views see Illustrations of Wessely's Words pages 23-30 of "*Magical Medicine: How to make a disease disappear*" <http://www.meactionuk.org.uk/magical-medicine.pdf>
6. "*The label of CFS avoids the connotations of pseudo-disease diagnoses such as ME*" Chronic fatigue syndrome and occupational health. A Mountstephen and M Sharpe *Occup Med* 1997;47:4:217-227
7. "*The conventional wisdom is that illnesses are made real when they are legitimised by a doctor's diagnosis..... reinforcement of unhelpful illness beliefs can have an unhelpful effect on patients*" "ME: What do we know (real physical illness or all in the mind?)" Lecture given in October 1999 by Michael Sharpe, hosted by the University of Strathclyde. Referenced from http://www.meactionuk.org.uk/Quotes_from_Mike_Sharpe.htm
8. "*The use of tests to diagnose the chronic fatigue syndrome should be done only in the setting of protocol-based research.....We consider a mental status examination to be the minimal acceptable level of assessment.*" *The Chronic Fatigue Syndrome: A Comprehensive Approach to its Definition and Study*. K. Fukuda, S. Straus, M Sharpe et al *Ann Int Med* 1994;121:12:953-959
9. See ME/CFS causes death pages 15-17 of "*Magical Medicine: How to make a disease disappear*" <http://www.meactionuk.org.uk/magical-medicine.pdf>
10. *Chronic Fatigue Syndrome: A Practical Guide to Assessment and Management*. M Sharpe et al *Gen Hosp Psychiat* 1997;19:3:185-199
11. UNUMProvident Policy that underlies the MRC PACE Trial and The Woodstock Connection pages 60-62 "*Magical Medicine: How to make a disease disappear.*" <http://www.meactionuk.org.uk/magical-medicine.pdf>
12. In 2001 the WHO Collaborating Centre for Research and Training for Mental Health, Institute of Psychiatry, Kings College, London tried and failed to unofficially change the classification of CFS and ME to F48.0. See also "*Attempts to reclassify ME/CFS as a mental disorder*" on page 53 of "*Magical Medicine: How to make a disease disappear.*" <http://www.meactionuk.org.uk/magical-medicine.pdf>
13. For list of abnormalities seen in ME patients see pages 11-14 of "*Magical Medicine: How to make a disease disappear*" <http://www.meactionuk.org.uk/magical-medicine.pdf>
14. Pacing, graded Activity, Cognitive behavioural therapy: a randomised Evaluation.
15. The report entitled "*Magical Medicine: How to make a disease disappear*" is a 442 page document prepared by Professor Malcolm Hooper in support of his formal complaint with regards to the MRC PACE Trial. <http://www.meactionuk.org.uk/magical-medicine.pdf>
16. Files on Myalgic encephalomyelitis (ME)/postviral fatigue syndrome (PFS) : papers and journal articles; correspondence and enquiries with MRC replies, item code FD 23/4553/1, are being held in the National Archives at Kew.
<http://www.nationalarchives.gov.uk/catalogue/displaycataloguedetails.asp?CATLN=7&CATID=-5475665&j=1> For further reading see *The MRC's Secret Files on ME/CFS* pages 44-48 of "*Magical Medicine: How to make a disease disappear*" <http://www.meactionuk.org.uk/magical-medicine.pdf>
17. The Whittmore-Peterson Institute for neuro-immune disease in Reno Nevada.
18. Xenotropic murine-leukaemia-virus-related virus, a human retrovirus.
19. VIPdx is licensed to use the WPI's protocols, <http://www.vipdx.com>
20. Sophia Mirza, died from ME in 2005. See *The Case of Sophia Mirza* pages 81-83 of "*Magical Medicine: How to make a disease disappear*" <http://www.meactionuk.org.uk/magical-medicine.pdf> and <http://www.sophiaandme.org.uk>

