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HANSARD – Illustrations of Debates and Parliamentary Questions on Myalgic Encephalomyelitis

Compiled by Margaret Williams   14th December 2014

23rd February 1988: HC (House of Commons) 167: The Myalgic Encephalomyelitis Bill brought in by Mr Jimmy Hood and others: *"Research shows that ME appears to be caused by viral infection, combined with a dysfunction of the immune system. There is no doubt that ME is an organic disease. The nature of the disease is such that it primarily strikes the central nervous system, the brain and body muscles….Sufferers are denied proper recognition, misdiagnosed, vilified, ridiculed and driven to great depths of despair"*. The Bill passed through its first reading unopposed; it was ordered to be read a second time on 15th April 1988 and to be printed.

5th November 1998: HL (House of Lords): 368-369: Medical Treatment: Right of Refusal: The Countess of Mar: *"Is (the noble Baroness) aware that there is a growing list of children diagnosed as suffering from ME who are being placed by Social Services on the at risk register? Is she aware of … the fact that some of the children are being forced into psychiatric hospitals for treatment which many practitioners agree is not the right treatment for ME?"*

9th December 1998: HL: 1013: The Countess of Mar: the first official reference to Professor Simon Wessely et al as "the Wessely School": *"colloquially known as the Wessely School".*

21st December 1999: HC 147WH – 166WH (Westminster Hall): there was a lengthy debate chaired by Sir Alan Haselhurst recording MPs' deep concern about the malpractice of the medical insurance industry towards people with ME/CFS; MPs were adamant that doctors working for medical insurers (who include psychiatrists Professors Peter White and Michael Sharpe and other members of the Wessely School) are not allowed to come into conflict with a claimant's own medical advisers and that insurance doctors should not be allowed to insist on a particular form of intervention (such as CBT and GET). Concerns voiced about various insurance companies included the following:

- ***"All (ME) claimants are sent to a psychiatrist, whose diagnosis is subject to questionable decisions"***

- ***"If they have been treated by an ME specialist who favours another method of diagnosis and treatment, they may find that their disability insurance payments cease"***
- ***"Several patients were forced to attend named psychiatric clinics and to receive cognitive therapy, graded exercise and psychoactive drugs. They were told that if they did not they would lose their pension rights".***

Seven years later, the increasingly hostile battle with the insurance industry faced by people with ME was recorded in November 2006 in the Gibson Report's "Inquiry into the status of CFS/ME and research into causes and treatment" which recommended that these psychiatrists be investigated for a possible conflict of interest because they did so much work for large insurance companies. Senior Parliamentarians found Professor White's close financial involvement with the insurance industry ***"to be an area for serious concern and recommends a full investigation by the appropriate standards body"*** (http://erythos.com/gibsonenquiry/Docs/ME_Inquiry_Report.pdf). This has never been done. Those Parliamentarians who expressed this concern included the former Chairman of a House of Commons Science and Technology Select Committee and former Dean of Biology; a member of the Home Affairs Select Committee; a Minister of State for the Environment; a former President of the Royal College of Physicians; the Deputy Speaker of the House of Lords, and a former Health Minister and Honorary Fellow of the Royal College of Physicians.

There is another disturbing aspect concerning conflicts of interest of the PACE Trial Principle Investigators (Professors Peter White, Michael Sharpe and Trudie Chalder). The Minutes of the Joint meeting of the Trial Steering Committee and the Data Monitoring and Ethics Committee held on 27th September 2004 record that Professor White confirmed that letters had been received from all TSC members confirming that no-one had any conflicts of interest.

This was a serious issue, because there is written evidence that Professors Peter White, Michael Sharpe and Trudie Chalder may have been less transparent than was required of them.

Notably, the same people (Professors White, Sharpe and Chalder) were involved with the production of the NHS Plus Guideline on returning people with "CFS/ME" to employment (Occupational Aspects of the Management of Chronic Fatigue Syndrome: a National Guideline; October 2006), where they also declared no conflict of interests.

Two years later, after sustained representations, on 20th November 2008 the Department of Health confirmed (in writing) in relation to the NHS Plus Guideline about Professors White, Sharpe and Chalder: *"I can confirm that the guideline contributors gave written confirmation that they had no conflicts of interest".*

Since it was believed that Professors White, Sharpe and Chalder all did have obvious and serious conflicts of interest and since any such conflicts had been denied by them, further representations were made questioning why their known conflicts of interest had been denied.

Following these representations, on 23rd December 2008 a remarkable revelation was made – in writing – by Dr Ira Madan, Director of Clinical Standards, NHS Plus (who, with Wessely and Chalder, was based at King's College):

"The Department of Health have asked me to investigate your concern that one of the guideline development group members, Professor Trudie Chalder, and the two external assessors, Professor Michael Sharpe and Professor Peter White, had conflicts of interest whilst involved in the production of the guideline. ***I can confirm that I was aware of the potential for competing interests that you have stated. The roles that Professor White, Professor Sharpe and Professor Chalder have undertaken for the agencies and companies that you stipulate*** **(i.e. the DWP and the medical and permanent health insurance industry)** ***were in the public domain prior to the publication of the NHS Plus guideline.*** *I am content, as the Director of that guideline, these potential competing interests did not in any way influence the synthesis of the evidence or the guideline recommendations"*.

There is thus written confirmatory evidence from Dr Ira Madan that Professors White, Sharpe and Chalder all did have what she referred to as *"competing interests"*, but that she was "*content*" about the situation.

However, the MRC PACE Trial Minutes twice record that these same people had declared no conflicts of interest (recorded first in the Minutes dated 22nd April 2004 and again in the Minutes dated 27th September 2004).

Thus there is written evidence -- from Dr Madan at the Department of Health -- illustrating how the normal rules of independent peer review and conflicts of interest seemed to have been suspended when it came to the "evidence-base" for CBT/GET in people with ME/CFS because, in relation to the NHSPlus Guidelines, two reviewers were allowed to sit in judgment on their own publications, with the prior knowledge and permission of Dr Ira Madan.

Furthermore, they were not required to make conflict-of-interest declarations, even though their conflicts were known about by Dr Madan. This is not peer-review as the rest of the scientific world understands it.

Professor White also does paid and unpaid work for Universities, the UK Government, the United States Centres for Disease Control, and for legal claimants and defendants (BMC Health Services Research 2003:3:25) which were not declared in The Lancet article published in February 2011 that provided selective PACE trial results.

White was in fact lead advisor on "CFS/ME" to the Department for Work and Pensions and was a prominent member of the group that re-wrote the chapter on it in the DWP's Disability Handbook used by Examining Medical Practitioners, by DWP decision-makers and by members of the Appeal Services Tribunals. It is the DWP's known intention to remove as many people as possible from state benefits, and to this end ME/CFS (or CFS/ME) is a specifically targeted disorder. It is the case that the PACE Trial is the only clinical trial that the DWP has ever funded, and that the DWP had open access to participants' medical records.

Another potential financial conflict of interest is to be found in the entry criteria for the MRC PACE Trial: these were the Wessely School's own criteria (Oxford 1991), which were funded in part by Professor Peter White's own money (JRSM 1991:84:118-121), thus giving him an unusual interest in the outcome of the PACE Trial.

In relation to the FINE Trial, by letter dated 24th June 2005, Alan Carter of The Directorate of Corporate Services at the University of Manchester stated: ***"if the treatments under investigation in this Trial are successful, The University of Manchester would wish to develop training packages for use by PCTs (Primary Care Trusts)"*** and he specifically referred to his wish not to "***endanger the University's commercial interests in developing treatment packages as detailed above"***.

It is understood that similar commercial packages existed in relation to the PACE Trial, which would be an undeclared vested interest on the part of the PIs.

16th February 2000: HL 1243-1246 (Debate on The Rowntree Report): The Countess of Mar: *"Some leading psychiatrists are of the opinion that that best way to treat patients is with antidepressants, cognitive behaviour therapy and, in the case of CFS/ME patients, graded exercise. There is very little sound evidence that this regime is effective. In fact, it has been criticised severely outside the UK".*

27th November 2001: HL 1659 / Questions for Written Answer: The Countess of Mar: *"To ask Her Majesty's Government whether the psychiatrists on the Chief Medical Officer's Working Group on Chronic Fatigue Syndrome have withdrawn; if so, for what reason".* On **17th December 2001 Lord Hunt of Kings Heath replied (PQ 2934/2001/2002):** *"We understand that the psychiatrists on the Group felt unable to support it, as it does not sufficiently meet their concerns".*

6th February 2001: HC 304- 311 WH: major debate on CFS (Mr Tom Clarke): *"As the (the CMO's) report discloses, we invest virtually nothing in research into an incredibly destructive illness that varies in intensity among people….'Inaction due to ignorance or denial of the condition is not excusable'…General practitioners are never given proper guidance".* Mr Anthony Wright: *"In essence, the Chief Medical Officer said that from 11th January (2002) people with ME are entitled to the same support as those with other long-term chronic illnesses….Those who have (ME) must cope with* *an illness that to a great extent destroys their lives and suffer…prejudice and ignorance…It is hard for any of us to imagine what it must be like to endure the effects of a serious condition and a constant barrage of scepticism, cynicism and disbelief from those who should have helped them".* The Minister of State, Department of Health (Jacqui Smith): *"I want to start by recognising how distressing and debilitating the condition can be for individuals, their carers and their families….I want to make it clear that we fully endorse the view of the independent working group that CFS/ME is a chronic illness. Health and social care professionals should recognise it as such….no one form of treatment suits every patient….we are aware that there is controversy about some approaches used for managing CFS/ME".*

16th April 2002: HL 894-910: Chronic Fatigue Syndrome/ME: The Countess of Mar: *"My Lords, in view of the publication in the British Medical Journal of 13th April 2002 of its survey of so-called 'non-diseases' and the prominence given by the press to chronic fatigue syndrome/myalgic encephalomyelitis as a non-disease, this debate has come at a very appropriate moment….Since 1969 ME has been formally classified by the World Health Organisation as a neurological disorder….However, since 1987 Dr – now Professor – Simon Wessely has been relentless in his proposition that ME does not exist….I have mentioned the article about non-diseases in the British Medical Journal of 13th April. I refer the Minister to a letter in the same journal, headed: 'What do you think is a non-disease? Pros and cons of medicalisation'. It is signed by 'Simon Wessely, Professor'…..Wessely has chosen to highlight CFS/ME in his letter and, of course, the press picked it up….It is extraordinary that this man and his group of followers, colloquially known as the Wessely School, have been allowed to dominate all debate on ME for 15 years. They have unquestionably been responsible for a relentless and sustained attack on the credibility of an increasing number of severely ill patients, dismissing and trivialising their suffering….There are many documented instances where he is in direct conflict with other competent medical opinion. His tactics include manipulation, distortion, invention, misquotation, suppression, exploiting public ignorance and deliberately constructing his presentations to fit his audience….He has disingenuously amalgamated his own definition of chronic fatigue syndrome with ME by stating that ME may be referred to as CFS and is thus, he claims, a mental disorder….Simon Wessely and, in particular, Michael Sharpe, Anthony David and Peter White – all psychiatrists – proceeded systematically to flood the UK literature with their own beliefs about the non-existence of ME. They commandeered medical journals and the media….Their influence pervades every aspect of ME sufferers' lives, including their ability to obtain social security and private medical insurance benefits…..My Lords, the influence of Wessely is clearly manifest in the report to the Chief Medical Officer* (CMO's Working Group Report 2002). *Not only is the terminology ambiguous and confusing, it specifically advises that vital investigations such as immunological and nuclear medicine scans are inappropriate and unnecessary. Those are the two areas which are delivering hard evidence of organic pathology….In fact, the report's effect will be to compound inaction, ignorance and even denial: inaction in not investigating the patient's illness or not providing any treatment – management is not the same as treatment – ignorance by promoting inappropriate and possibly harmful interventions; and denial of the true nature of ME".*

12th June 2002: HC 973: Debate on ME: Mr John Bercow: *"In the House since 1997, interest in ME or chronic fatigue syndrome has been manifested in no fewer than 116 written and oral parliamentary questions, a number of early day motions – three, if I remember correctly…and several Adjournment debates….Millions of days are lost to ME in the workplace each year. The monetary impact is estimated to be about 4 billion* (pounds sterling)….*I should have stated more bluntly that the Government should…put their foot up the backside of those who have consistently misunderstood and displayed insensitivity towards people suffering badly….Does (the Minister) accept that, historically, the bias of research projects has tended to be towards psychiatric explanations of the disease rather than its physical causes?".*

22nd January 2004: HL 1180: Myalgic Encephalomyelitis: The Countess of Mar: *"Wessely School psychiatrists are about to receive £11.1 million…in an attempt to strengthen the very weak evidence that his regime actually works for those with ME. Among his 53, largely undeclared, interests, it should be noted that he is a member of the supervisory board of a company called PRISMA that is supplying such rehabilitation programmes as CBT to the NHS for those with ME, even though such regimes have been shown, at their best, to be of limited and short-lasting benefit and, more importantly, at their worst, to be actively harmful to those with the disorder. The constant theme running through the Wessely School's published papers is that ME does not exist, that CFS is a psychiatric disorder and that the factors that play an important role in the perpetuation of the disorder include female gender, too much focus on normal bodily sensations, discrete personality traits, avoidance behaviour, learned helplessness, faulty thought processes, lack of motivation, secondary gain, inadequate coping strategies, interpersonal conditioning and contagious social hysteria….Wessely has made numerous statements about the non-existence of the disorder that can only be described as savagely cruel to the ME community. For example, he refers to ME as a 'myth'. He believes that it 'should not be dignified by its own formal case definition and body of research'. He asserts that symptoms found in ME 'have no anatomical or physiological basis' and that 'muscle weakness is simulated'. He advises that, to the majority of professionals, ME symptoms 'are indeed all in the mind'….Neither the fact that they may be wrong nor the well-documented errors of psychiatrists in the past who authoritatively misdiagnosed Parkinson's Disease, multiple sclerosis, epilepsy, diabetes and thyrotoxicosis as mental disorders before medical science revealed their true aetiology seem to have occurred to the Wessely School. It is certain that it, alone, is right. As the world-renowned psychologist, Dr Dorothy Rowe, pointed out: 'People who know absolutely that they are right are very dangerous'. The group's activities have stifled access to research funding for any UK researchers who want to consider organic causes of the disorder. Crucially, researchers have shown that ME may be either virally or chemically induced. There is substantial and significant published evidence not only of neurological deficits, including cerebral hypo-perfusion and hypo-metabolism, but also of endocrine dysfunction, immune system dysfunction, vascular disturbances and convincing laboratory evidence of serious abnormalities in muscle, including abnormal recovery after exercise – not the result of de-conditioning through voluntary lack of use, as Wessely claims….As long ago as 1994,Professor*

Paul Levine from the US National Cancer Centre stated that: 'the spectrum of illnesses associated with a dysregulated immune system must now include ME/CFS'….Wessely's response is that those who disagree with him are 'radicals' who are fighting for a 'lost cause' with 'lies and gross distortion'. Such is that man's influence that, when faced with ME patients, clinicians now collude with each other to ensure that patients receive no investigations, support, treatment, benefits or care – in fact, nothing at all. Patients are effectively abandoned".

On 6th November 2012 it was announced that Professor Simon Wessely had been awarded the inaugural John Maddox Prize for his courage in facing opposition to his views about ME/CFS and for *"standing up for science".*

In a press release about the John Maddox Prize issued by Sense about Science, Tracey Brown (one of the judges), said: *"The John Maddox Prize recognises the work of individuals who promote sound science and evidence on a matter of public interest, facing difficulty or hostility in doing so….* and she referred to *"the courage and responsibility that people are taking for communicating sound science and evidence".*

The journal Nature said it congratulated Simon Wessely: *"Simon Wessely is a psychiatrist at the Institute of Psychiatry, King's College, London, who has specialised in two areas above all – the mental health of military personnel and veterans, and chronic fatigue syndrome….He subsequently developed a treatment approach using cognitive behavioural therapy techniques…This treatment…can now be found in the guidelines of the United Kingdom's National Institute for Health and Clinical Excellence. 'All along the way', says the individual who nominated him* (Wessely's fellow psychiatrist, Professor Anthony David) *'Wessely has had to suffer continued abuse and obstruction from a powerful minority of people who, under the guise of self-help organisations, have sought to promote an extreme and narrow version of the disorder….Hostile letters, emails and even death threats have been directed at Professor Wessely over two decades. Mischievous complaints have been made against him and his clinical team, and bogus questions raised in the Houses of Parliament'".*

Writing in support of the award to Wessely, the Editor of Nature and one of the judges, Philip Campbell, said: *"We looked beyond communicating for a more unusual degree of courage. The winners of the prize demonstrated the kind of sustained resilience and determination to communicate good science that John Maddox personified"* and at the presentation he spoke of the *"acute hostility"* that Wessely had endured and said he was *"a very worthy winner".*

Professor Colin Blakemore, one of the judges, said: *"…the two winners stood out….Simon Wessely and Fang Shi-min have worked with courage and dignity to uphold the standards of science and evidence against the forces of prejudice and greed".*

Professor Sir John Beddington, Government Chief Scientific Advisor, said: *"Given the importance of science…it is more important than ever for scientists to speak up and make their views heard. This always requires conviction but often requires real courage too, and I welcome the John Maddox Prize as recognition of that".*

Sir Paul Nurse, President of The Royal Society, said: *"The John Maddox Prize is an exciting new initiative to recognise bold scientists who battle to ensure that sense, reason and evidence base play a role in the most contentious debates. The winners will be an inspiration to us all".*

26th April 2004: HC 831W: Mrs Iris Robinson: Dr Stephen Ladyman (Secretary of State for Health): *"CFS/ME remains medically unexplained…with variable symptoms from various systems in the body, including some neurological, immunological, cardiovascular, digestive and psychological symptoms".*

11th May 2004: Adjournment Debate: Myalgic Encephalomyelitis: Mr Anthony Wright: *"…access to benefits continues to present problems for sufferers. Lack of knowledge and understanding of the condition among professionals, widespread disbelief and institutional prejudice, lack of effective evaluation and plain stigmatisation mean that there is little or no consideration of the desperate problems experienced by sufferers".*

30th January 2006: HL3612: The Minister of State, Department of Health (Lord Warner): *"There is only one World Health Organisation International Classification of Diseases code for chronic fatigue syndrome/myalgic encephalomyelitis, which is G93.3".*

28th February 2007: HL GC (Grand Committee)198: Welfare Reform Bill: The Countess of Mar: *"If a group of people refuses graded exercise and cognitive behaviour therapy, on the basis either that they are afraid or that they know it will not help them, will they be penalised?"* Lord McKenzie of Luton (Parliamentary Under-Secretary of State, Department for Work and Pensions): *"There is no requirement for individuals to carry out any specific type of activity or treatment. That cannot be sanctioned".*

2nd June 2008: HLPQ: Health: Chronic Fatigue Syndrome/Myalgic Encephalomyelitis: the Countess of Mar: *"The Countess of Mar asked Her Majesty's Government: Whether the current NHS review will include consideration of chronic fatigue syndrome/myalgic encephalomyelitis (CFS/ME) as a long-term neurological condition".* The Parliamentary Under-Secretary of State, Department of Health (Lord Darzi of Denham): *"The review, which is being carried out by local multidisciplinary working groups, will increase awareness and ensure better care for people with CFS/ME and will help to support local delivery of the NSF* (National Service Framework) *for long-term neurological conditions….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".* Baroness Howe of Idlicote: *"Can the Minister explain to the House why the Royal College of General Practitioners continues to insist on categorising CFS as a mental illness?* Lord Darzi of Denham: *My Lords, the Government has made it clear that they consider that CFS/ME should be classified as a neurological condition…I will encourage the Royal College of General practitioners to look at the WHO classification, which, as I said earlier, is that it is a neurological rather than a mental condition".*

18th March 2009: HL 316: Health: Cognitive Therapy: The Countess of Mar: *"CBT is not the cure for all ills that it is sometimes held up to be….There is a group of chronic illnesses…CFS/ME, fibromyalgia and irritable bowel syndrome, for example, that do not respond positively to CBT….Current advice to doctors is that, after routine tests have failed to point to causation, there is no need for further investigations. Some doctors take the easy route by concluding that the illness must be psychological and that CBT will provide the answer. However, many clinical tests listed in the Canadian criteria do show disease/dysfunction in many bodily systems….In August 2007 the* (NICE) *guideline was published amid a barrage of criticism from the ME community. Why was it criticised? It was because the only 'treatments' recommended by NICE on the basis of very limited and strongly criticised scientific evidence were CBT and..graded exercise therapy….The evidence-base is not as clear as NICE would have us believe. A statement from ME Research UK asserts that: 'The evidence base consists of only five trials which have a validity score of less than 10. We note that the most recently published RCT* (randomised controlled trial) *on CBT (O'Dowd 2006) states: 'there was, however, no evidence that the treatment restored normal levels of function for the majority of patients'….I have been dealing with ME sufferers for 17 years and I have never encountered a group of patients who are so maligned. The last straw for them is the requirement that they undertake a course of CBT and/or GET in order to qualify for benefits and private insurance payments….The Department of Health and the World Health Organisation acknowledge that this is not a psychiatric condition. What action is the Minister's department taking to ensure that people with ME are as respected as people with other medical conditions and that they are not forced to accept, as a condition for receipt of benefits and social care, 'treatments' such as CBT and GET that, at best, provide no beneficial effects and, at worst, are positively harmful?".* The Minister (Baroness Thornton): *"I will be pleased to investigate the issues that she has raised about CFS/ME treatment recommended by NICE….I undertake to follow up the disturbing point she made".*

On 2nd April 2009, the Minister (Baroness Thornton) replied to the Countess of Mar: *"I write in response to the issues you raised on 18 March 2009 in our debate about cognitive behaviour therapy….I think it is important to emphasise that NICE clinical guidelines are just that – guidelines for healthcare professionals. The guideline recognises there is no one form of treatment to suit every patient and it does not force patients into treatments they do not want….It goes so far as to say that healthcare professionals should recognise that the person with CFS/ME is in charge of the aims of the treatment programme".*

29th April 2009: HL 301-302: Welfare Reform Bill: Second Reading: The Countess of Mar: *"While I entirely agree with the Government that no-one should be allowed to exploit... 'the system', I cannot see the benefit of expending vast amounts of money and time on pretending to make a small group of vulnerable people supposedly fit for work…Despite the growing evidence that these illnesses are biomedical, there is still a school of thought that they are psychosocial behavioural conditions and that they can be overcome with firm handling, a course of cognitive behaviour therapy and graded exercises. It is apparent that this view still prevails at the DWP. This is so despite Ministers' repeated assurances that they and the Department for Work and Pensions' employees and agents fully agree with the Department of Health statement that they 'accept the World Health (Organisation) of CFS/ME as a neurological condition'….This Bill compounds the problems….The language is harsh, the sanctions punitive and the rule inflexible….If a person looks all right, as many people with CFS/ME do, it is likely that they will be considered well enough to work".*

23rd February 2010: HC Debates: Myalgic Encephalopathy: Annette Brooke: "*Professor Malcolm Hooper…has explained the implications of changing the name of the illness, stating: 'despite the claims of some psychiatrists, it is not true that there is no evidence of inflammation of the brain and spinal cord in ME; there is, but these psychiatrists ignore or deny that evidence'….It is estimated that five times as many people in the UK are categorised as having CFS/ME as have HIV. More than 70,000 are so ill that they are bedbound and require round-the-clock care….The Gibson report way back in 2006…made many more points about the need for research and a serious examination of the international evidence…so why is that not happening?....If medical tests are done on people with true ME, they would show many abnormalities and physical reasons for impairment in functioning. However, patients diagnosed with CFS/ME rarely get access to any kind of medical testing….The Government have stated that the reason why the Medical Research Council has not funded any biomedical research is because there have not been any good or innovative applications. This is just not true: one scientist, who has applied for and been denied funding, says: 'We have applied several times to the MRC'….It is clear to me that the way forward is to fund biomedical research to find causes and treatments….The current NICE guidelines, by recommending CBT and GET, do not follow World Health Organisation guidelines, which categorise ME as a neurological condition. In failing to recognise the biomedical problems of ME sufferers, the NICE guidelines also fail to recognise the needs of ME sufferers (and) I ask the Minister to take these issues forward.* The Minister of State (Public Health), Department of Health, Gillian Merron: *"I congratulate Annette Brooke on securing this important debate….I want first to put on the record that we accept the World Health Organisation's classification of ME as a neurological condition….It is clear to me that people with ME need and deserve better services….It is also important to emphasise that clinical guidelines are not mandatory….Although all patients want to get better, none should be coerced into accepting any particular form of treatment….We recognise there is scope for an expanded research programme for ME".*

10th March 2010: HC Deb c350W: Ann Keen (Parliamentary Under-Secretary, Department of Health): in answer to the question tabled by David Drew asking for what reasons people with ME may not donate blood, the Minister stated: *"People with myalgic encephalomyelitis (ME), also known as chronic fatigue syndrome (CFS), are not able to donate blood until they have fully recovered….people with the condition are deferred from donating blood as a precautionary measure to protect the safety of the blood supply for patients".*

11th October 2010: HL Debate on neurological health conditions: The Countess of Mar: *"ME has been categorised as a neurological condition at least since 1968 (sic). It is recognised as such by the World Health Organisation and the United Kingdom Government. However, for all these years, sufferers from this awful debilitating illness have been ignored, derided and mistreated….ME is a physical disease which has endocrine, immune and cardiovascular effects, as well as neurological symptoms….Despite this, there is a school of thought, dominant through the last three decades, that this is a psychosocial behavioural problem, easily dealt with by cognitive behavioural therapy and graded exercise….In the UK…there is a school of psychiatry determined to claim the condition for its own, both in the UK and internationally. After many years of working in this sphere, I have observed the means by which any valid arguments for a biological cause are mocked and eventually overwhelmed by the noisier medical opposition. They ignore internationally recognised science….By writing numerous papers which, of necessity because there is no-one else to do it, are peer reviewed by their colleagues, they appear to have proved that there is no need for further research….It seems that, no matter how often Ministers and senior officials confirm their acceptance of the seriousness of this condition, nothing will change until the culture both within and outside the NHS changes….May I ask the noble Earl whether the coalition continues to accept that myalgic encephalomyelitis is a neurological illness as categorised by ICD-10 G93.3?"* The Parliamentary Under-Secretary of State for Health, Earl Howe: "*The noble Countess, Lady Mar, asked whether the coalition accepts that CFS/ME is a neurological condition. The Government accept that it is a neurological condition".*

2nd February 2011: HC 323-331WH: Myalgic Encephalomyelitis: Ian Swales: *"I welcome the fact that the Department of Health now accepts ME as a genuine medical condition….and I will argue that funding and research must be focused on the biomedical factors involved….My goal is to see the Government-funded Medical Research Council work with ME sufferers and biomedical researchers to achieve a proper understanding of the condition's challenges and to change the unjust perception of it….An indiscriminate, blanket approach to treatment was advised by the National Institute for Health and Clinical Excellence in 2007, no matter what the disease process….More than 80% of the MRC's expenditure on ME research so far has been allocated to psycho-social therapies, instead of biomedical studies….Misinformation, widespread confusion and ignorance about ME and CFS have resulted in people with entirely different illnesses receiving the same diagnosis….As things stand, 250,000 men, women and children, their families and carers, face terrible injustice and neglect. I call on the Government to put that right".* The Minister of State, Department of Health (Paul Burstow): "*This is not the first time* *the House has debated these issues….There is…strong international consensus that CFS/ME is a chronic and disabling neurological illness. I want to stress that it is a neurological illness; it is not a mental health problem….The NHS does not always get it right for people with long-term conditions in general, let alone those with CFS/ME….I urge groups with an interest in CFS/ME to engage with the Neurological Alliance, use it, work through it and form connections with it, as a way of shaping and changing services in the future".*

11th October 2011: HL Debate on the Second Reading of the Health and Social Care Bill: The Countess of Mar: *"I am sure that the noble Earl cannot have failed to notice my frustration when I have been trying to get what I consider to be very reasonable recognition and treatment for people with CFS/ME – only to find that no-one is ultimately responsible for ensuring that they receive adequate medical treatment….I find it hard to believe that in 20 years of campaigning so little progress has been made. That is particularly so with members of the CFS/ME community….I can think of no other group that is systematically discriminated against by the medical profession and social services. No other illness than ME has such a big impact on the lives of so many people and yet is given such limited funding for specialist care services and scientific research…Earlier research by Sheffield Hallam University concluded that the total cost to the nation of CFS/ME exceed £3 billion….It is time that the discrimination against these patients ended".*

20th November 2012: HL 1791: The Countess of Mar: *"I have been assured that Her Majesty's Government accept the WHO's categorisation of ME as a neurological condition. The CMO report of 2002 described it as a 'genuine illness' which 'imposes a substantial burden on the health of the UK population'. The NICE guideline of 2007 stated that: 'The physical symptoms can be as disabling as multiple sclerosis, systemic lupus erythematosus, rheumatoid arthritis, congestive heart failure and other chronic conditions'. Yet there is no provision to examine the neurological aspects of this illness….The much trumpeted PACE trial, which cost taxpayers some £5 million and (was) intended to demonstrate the effectiveness of these so-called treatments* (CBT and GET) *did no such thing. There is no indication in the trial results that one single person fully recovered after a year of CBT and GET. There is no indication that any who were not working went back to work or, in fact, that there was more than a very modest improvement in those whose health was deemed to have improved….The spin on the results has had a very deleterious effect on the public perception of the illness and on the provision of health and social care for people with ME….Patients and, particularly, children are pushed by medical practitioners…to keep going to work or school on the basis that it is good for them, until they collapse….They are then encouraged to undertake programmes of cognitive behaviour therapy and guided exercise training which, at best, may help them to cope with their illness or, at worst, may exacerbate their symptoms, and they are blamed for not wanting to get better".*

6th February 2013: HL GC Debate on the PACE Trial: The Countess of Mar: see "Comments on the PACE Debate held in the House of Lords (Grand Committee) on 6th February 2013" http://www.meactionuk.org.uk/Comments-on-the-PACE-debate-held-in-Grand-Committee-on-6th-February-2013.htm

On **22nd August 2013** The Information Commissioner's Decision Notice No: FS50463661 contained statements from Professor Peter White, Chief Principal Investigator of the PACE trial, in which, referring to the above debate, he complained about what he called "*the considerable commitment*" he had to make on a continual basis to defend and justify his work:

"For example, I am often sent e-mails asking my opinion or to defend positions. (Exhibit A). I have been the subject of a recent petition to government asking that I not be allowed to participate in advising government in this subject (exhibit B). I have had to provide responses to Parliamentary Questions from members of both Houses of Parliament to allow them to understand the nature and findings of the PACE trial. In particular, I had to recently brief several members of the House of Lords so that they might speak in a critical debate about the Pace trial held on 6th February this year (exhibit C)"
(see judgment from the ICO).

This provides evidence that the so-called "debate" was nothing of the sort, but was merely a constructed paean of praise for the PACE trial.