

## **Brief background for Robert Francis QC on the need for an independent investigation into the ME/CFS scandal**

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### Reason for needing Leading Counsel's Opinion

There is another medical scandal of equal magnitude to that of the Mid Staffordshire NHS Foundation Trust and it is on-going. It concerns the prolonged abuse of UK patients suffering from myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS) by a group of doctors – mostly psychiatrists -- known as the Wessely School (Hansard: Lords: 9<sup>th</sup> December 1998:1013) who work with and for the permanent health insurance industry.

The Wessely School exert far-reaching authority not only over Government itself and Departments of State but also over such bodies as the Medical Research Council (where they hold influential positions), the medical Royal Colleges, NICE, numerous advisory bodies, and over the Science Media Centre (which controls the media's presentation of medical and scientific matters to the public and in particular how ME/CFS is perceived).

Since 1969 ME has been classified by the WHO as a neurological disorder but the admitted intention of the Wessely School (led by Professor Sir Simon Wessely from King's College Hospital and the Institute of Psychiatry) is to "eradicate" ME by dropping "ME" from "CFS/ME" when expedient (having inverted ME/CFS to "CFS/ME") and then to reclassify "CFS" as a behavioural disorder under syndromes of chronic "fatigue" which fall under "functional" or mental and behavioural disorders in the WHO's classification. "Functional" or behavioural disorders are excluded from PHI payments by insurers and merit lower rates of State benefits.

There is a significant international evidence-base which disproves the Wessely School's assertion that ME/CFS is a behavioural disorder for which medical investigation, research and intervention is not appropriate: UK Coroners' reports show that people die from ME/CFS.

Leading Counsel's opinion is needed as to how to move this distressing matter forwards, in particular about the setting up of an independent public investigation as a matter of some urgency.

### Classification of ME/CFS as a neurological disorder

Not only is ME/CFS classified as a neurological disorder by the WHO, but on 16<sup>th</sup> August 1992, the Rt Hon Stephen Dorrell MP, UK Minister of Health, went on public record confirming that: *“ME is established as a medical condition”*. The Department of Health has officially confirmed in writing that it accepts ME/CFS as a chronic neurological disorder and since 2003 ME/CFS has been classified in the UK Read Codes used by all GPs as a neurological disease (at F 286). Furthermore, since its inception in March 2005 the UK National Service Framework on chronic neurological conditions includes ME/CFS, and the Department for Work and Pensions has confirmed in writing that it does not consider ME/CFS to be a mental disorder (letter of 21<sup>st</sup> November 2011 to the Countess of Mar signed by Lord Freud, Minister for Welfare Reform).

However, the Wessely School continue to disregard this evidence, together with the substantial international evidence-base of organic pathophysiology; they insist that it is a behavioural disorder and that it should be managed as such throughout the NHS.

### The Permanent Health Insurance Industry

According to the insurance industry itself, it was about 1987 when the first permanent health insurance (PHI) claims for ME/CFS began to arise and the industry is greatly exercised about the increasing number of ME/CFS claims. At that same time, the Wessely School began their campaign of denying the existence of ME as an organic disorder.

### NICE’s Clinical Guideline on “CFS”

In 2007, advised by the Wessely School, NICE produced its Clinical Guideline (CG53) on “CFS” which was widely interpreted by the insurance industry as confirming that ME/CFS is a behavioural disorder, since only Wessely School psychological interventions were to be permitted throughout the NHS (refusal to concur resulting in loss of benefits).

In summary, NICE constituted a Guideline Development Group that (1) excluded all NHS biomedical ME/CFS specialists, even the Medical Advisor to the ME Association; (2) failed to define the target patient population as the GDG targeted anyone with chronic tiredness (which is not a specific disease); (3) failed to consider the international biomedical ME/CFS evidence-base; (4) failed to uphold its statutory obligation to abide by WHO taxonomy; (5) effectively proscribed necessary investigations that reveal the organic nature of the disorder, such as immune assays and viral serology; (6) failed to adhere to the European Union AGREE Instrument for guideline construction to which NICE is a signatory; (7) included only Wessely School adherents such as Dr William Hamilton (the Chief Medical Officer for three permanent health insurance companies); (8) against the mandate of its own

Guideline Development Manual, included GDG members who, on their own admission, do not see or treat ME/CFS patients and have no experience with such patients; (9) failed to report GDG members' conflicts of interest; (10) recommended only psychotherapy (cognitive behavioural therapy and graded exercise therapy) despite the already-known harm caused by such interventions as documented by the ME charities, which found that CBT was ineffective and that GET made at least 50% of participants worse to the extent that some became bed or house-bound.

In "Advances in Psychiatric Treatment" (2010:16:1:doi:10.1192/apt.16.1.1) the Editor, Joe Bouch, stated about ME/CFS: *"There are many vested interests: not just clinicians, but governments, NGOs, lawyers, researchers, public health practitioners, Big Pharma and patient groups. Vast sums are at stake – everything from welfare benefits and compensation claims to research budgets... chronic fatigue syndrome (is) 'bitterly contested in terms of its status as a physical, psychiatric or psychosomatic condition' and viewed by healthcare staff as a 'less deserving' category"*.

**On the advice of the Wessely School, people with ME/CFS continue to be denied appropriate NHS health and social care that is accorded to those suffering from far less serious disorders. This would seem to be a human rights issue and it is a matter of immense public interest.**

#### Previous challenges to the Wessely School's control of the ME/CFS situation

The Wessely School have worked assiduously to achieve their aim and their efforts have been very successful in that most grass roots UK doctors have been brain-washed into accepting that ME/CFS is a mental disorder, so for over two decades some ME charities, MPs and clinicians have done their best to challenge the Wessely School's demonstrably false assertions that ME is nothing but an "aberrant belief" when the evidence-base shows it to be a complex, chronic, multi-system inflammatory disorder with an increased early death rate.

**1. Leading Counsel's Opinion:** on 6<sup>th</sup> April 2000 the Countess of Mar obtained a *pro bono* Opinion from Lord Campbell of Alloway QC of 2, Kings Bench Walk, Temple, who advised:

*"On the document you have sent me there is an overwhelming case for the setting up of an immediate independent investigation as to whether the nature, cause and treatment of ME as considered by the Wessely School is acceptable or consistent with good and safe medical practice.*

*"There is substantial doubt as to whether such could be the case..."*

*A formal request should be made to the GMC to set up such an enquiry.... It is all but essential that a reputable firm of solicitors should be instructed to make such request and as suggested an approach to Lord Mischcon would be well advised.*

*"It could well be that the Department would wish to send an observer to the enquiry and (if so advised) participate...."*

It proved impossible to obtain legal aid or to find affordable solicitors sufficiently competent and willing to take on the task of a formal inquiry, so the Wessely School psychiatrists continued to exert their influence, to the significant detriment of countless ME/CFS sufferers: despite letters from Ministers of State confirming that ME/CFS is a serious organic disorder, the NHS still provides no appropriate services or care for such patients and, advised by the Wessely School, DWP staff continue to target ME/CFS as a behavioural disorder from which claims assessors and decision-makers assert sufferers can recover with psychological interventions as administered by the Wessely School.

**2. Judicial Review:** two ME sufferers, supported by international ME/CFS clinicians, sought permission for a Judicial Review of the NICE Guidelines. Legal aid was obtained and the Permission Hearing was on 17<sup>th</sup> June 2008 before Mr Justice Cranston, who in his Judgment said:

*" Mr Hyam (Jeremy Hyam of 1 Crown Office Row for the Claimants) has identified some ...points which are arguable. He has pointed, for example, to the lack of balance in the composition of the group drawing up the guidelines".*

*"Given... the great public interest... it seems to me that this case ought to go forward for a full hearing"* ([2008] EWHC 1916 (Admin) CO/10435/2007: CO/10408/2007: Approved Judgment, 17<sup>th</sup> June 2008).

The JR was heard on 11<sup>th</sup> and 12<sup>th</sup> February 2009 before Mr Justice Simon in Court 76 of the High Court Administrative Division in London (Case No: CO/10408/2007).

At the 11<sup>th</sup> hour, NICE (for whom Beachcrofts were acting) took issue about what it considered were unjustified allegations of bias causing reputational damage to certain GDG members. NICE threatened a significant wasted costs order against the Claimants' lawyers, as a result of which approximately 60% of the Claimants' evidence of bias on the part of GDG members was withdrawn by their lawyers without their knowledge or consent and an apology by their solicitor was made to the Court and to NICE. Consequently, a substantial amount of the Claimants' evidence supporting the challenge was not heard by Mr Justice Simon. In the event, the Claimants' solicitor's firm (Leigh Day & Co) was served with a wasted costs Order and fined £50,000 and their solicitor was also compelled by the Legal Complaints Service to pay them compensation for *"a failure of the solicitor's service"*. The Claimants' barrister was clearly fearful for himself and threatened the Claimants that if they resiled from his amended evidence that he put before the Court without their knowledge and if they insisted on seeking leave to appeal, he would notify the Legal Services Commission that there was no merit. Without legal aid, this would have placed the Claimants at risk of significant costs from both sides, so they had no option but to comply.

Notably, in his email dated 13<sup>th</sup> February 2009 to the Claimants and their medical advisors, solicitor Jamie Beagent was unequivocal: ***“...the ME community was really denied a full and fair hearing because of the distractions over the allegations of bias”***. Given the extent of the evidence of bias that was available but not used, this was little short of a travesty of justice.

**The evidence that was withdrawn without any discussion with the Claimants included Statements from at least 20 international ME/CFS medical experts confirming that the interventions promoted and used by the Wessely School do not work and may be dangerous for ME/CFS patients. It also included hard evidence that one of NICE’s key witnesses, Dr William Hamilton (and hence NICE’s Counsel, Charles Bear QC) seriously misled the Court.**

Mr Hyam’s failure to act without fear or favour and his failure to act on his lay clients’ clear instructions and in their best interests was the subject of a formal complaint to the Bar Standards Board (BSB). On 15<sup>th</sup> June 2010 the BSB wrote:

*“The Committee considers that your complaint could not fairly be determined within the disciplinary process because the matter is too complex, would involve the examination and analysis of a very large volume of documentation and because this dispute is such that it cannot be fully and fairly decided on paper....There is no appeal against the Committee’s decision”.*

**3. Complaint to the General Medical Council:** as the JR had failed, a formal complaint about Dr Hamilton was lodged with the General Medical Council on 26<sup>th</sup> April 2010 by Professor Malcolm Hooper, one of the Claimants’ expert witnesses; it alleged that Dr Hamilton perverted the course of justice by knowingly and willingly misleading the High Court in his witness statement.

**The reason for the complaint to the GMC was to establish that Dr Hamilton (and consequently the entire Wessely School) was wrong to regard and treat ME/CFS as a functional disorder, thereby harming patients as well as disqualifying thousands of PHI claimants from legitimate benefit and preventing NHS patients from receiving appropriate medical care and vital social support.**

After considerable delay, the GMC rejected Professor Hooper’s complaint.

**4. Further Opinion of Counsel:** the Claimants were able to show that statements made by Dr Hamilton in his Witness Statement were untrue, that he knew them to be untrue, and that his false evidence was a material and determining factor in the outcome of the Judicial Review, so they and their medical supporters sought (funded privately) the Opinion of a leading criminal barrister who is also a Deputy High Court Judge, Miss Bobbie Cheema of 2, Hare Court. Relevant documentation was provided for her and a Conference was held at her Chambers on 28<sup>th</sup> October 2010.

In her Advice dated 1<sup>st</sup> November 2010 Miss Cheema said:

- It was in the Claimants' favour that this was a documentary case in which the evidence is written: it will not disappear and is not dependent on memory
- misleading the Court is a way of perverting the course of justice and is a common law offence; if proven the person could go to prison
- the Claimants would have no difficulty in proving that Dr Hamilton's WS was material because of what Mr Justice Simon said was the reason for his judgment – paragraphs 81 and 82 of the Judgment are proof that Dr Hamilton's WS was material
- Dr Hamilton had to have a basis for his Statement of Truth that he signed
- there is no way that his WS can be conceived as "inadvertent" – it was a considered statement and was in writing
- If Mr Justice Simon were to refuse permission, the Claimants should approach the Attorney General.

It proved to be impossible to obtain legal aid to approach the Attorney General, so nothing could be done in legal terms in respect of the false information put before the High Court.

**5. Opinion of different Counsel about the GMC's failure to co-operate:** when the GMC rejected Professor Hooper's complaint, Miss Cheema subsequently advised that the GMC was obliged to reveal – by JR if necessary – on what basis it rejected his complaint about Dr Hamilton. Despite Miss Cheema's advice, applications to the GMC under both the FOIA and the Data Protection Act were refused.

On 7<sup>th</sup> March 2011 a new barrister (Tim Buley of Landmark Chambers) provided Advice about the GMC's repeated refusals to release information about Dr Hamilton; he advised that the public interest over-rides any FOIA/DPA duty of the GMC to withhold the information requested:

*"It does seem to me that there is a basis for arguing that this is a case in which the legitimate interests of the Claimants outweigh any prejudicial effect on Dr Hamilton such that the information requested should be disclosed on Sch 2 para 6 grounds. I do think that this is worth pursuing, especially given the paucity of reasons in the GMC's decision letter.*

*"In particular, this is a case where the GMC has carried out an important public function of investigating an allegation against Dr Hamilton. In those circumstances, the principle that justice ought to be done in the open would seem to be engaged.*

*"I am troubled by the idea that Dr Hamilton needs to be protected by the GMC, in a case where it has concluded that he has done nothing wrong.*

*"If that conclusion is correct, it is difficult to see how he would be damaged by disclosure.*

*"If it is incorrect, then the public interest in having disclosure of the evidence relied upon by the GMC is all the greater.*

*“In other words, Dr Hamilton only needs the protection of the DPA to the extent that he has done something wrong, and to this extent the interest in disclosure is very high.*

*“If he has done nothing wrong, the public interest in disclosure may be reduced...but so too (is) Dr Hamilton’s interest in resisting disclosure.*

*“There appears to be, at least, a reasonable argument that it is not legitimate to withhold all of the information withheld....there is here an arguable case which would be worth taking to the next level.*

*“The complaint taken forward would be, in broad terms, that (i) the disclosure would be fair and lawful and (ii) necessary for the purposes of legitimate interests pursued by the Claimants; and (iii) not unwarranted by reasons of prejudice to the rights and freedoms or legitimate interests of Dr Hamilton.*

*“I would advise that the extent of the Claimants’ interest in the disclosure is fully particularised in a letter of appeal to the GMC’s Information Access Manager and that the arguments addressed as to why the Claimants’ interests outweigh those of Dr Hamilton in this case – I note that brief points along these lines were made in the FOIA 2000 request of 2 August 2010”.*

*“I would strongly urge the Claimants to commence the above as soon as possible”.*

Further requests to the GMC as advised by Counsel were also effectively rejected; on 10<sup>th</sup> May 2011 the GMC’s Information Access Manager, Julian Graves, wrote: *“I would wish to make clear that, in my view, all of the data previously withheld from disclosure is not Professor Hooper’s personal data. There is therefore no entitlement to these data under the terms of Section 7 of the DPA”.*

Unfortunately, despite robust efforts, legal aid was unobtainable and no lawyers could be found who would take on the case.

**Hence, the Wessely School continued to wield its influence and ME/CFS continues to be regarded as a functional disorder at grass roots level, especially by GPs, with patients consequently suffering iatrogenic harm.**

#### The Wessely School’s PACE trial

Currently, the Wessely School’s PACE trial is the latest ammunition in their armament against incredibly sick people.

As one severely affected ME sufferer wrote: *“When they publish the PACE ‘results’ there will be widespread suffering on a scale hitherto unknown”* (letter to the charity Action for ME, 8<sup>th</sup> June 2007).

The PACE trial can be seen to be a calculated attempt to cover up the significant failure of the Wessely School’s behavioural model of ME/CFS and the accompanying document sets out in detail evidence of possible scientific fraud by the PACE trial Investigators in their efforts to categorise ME/CFS as a functional disorder.

As the GMC has proved to be of no help, it seems the only way of moving matters forwards is by an independent public inquiry, which would require the services of leading Counsel.

Further information about the role of the Science Media Centre in the propagation of false information about ME/CFS and about its acknowledged campaign to discredit ME/CFS sufferers in conjunction with the Wessely School is available if required.