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From Malcolm Hooper Ph.D.,B.Pharm.,C.Chem.,MRIC

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Chief Scientific Adviser to the Gulf Veterans' Association

President: the National Gulf War Veterans and Families Association, NGVFA, (2002)

19 February 2010

Dear Sir Michael,

I am a 'blast from your past'. I was at Sunderland School of Pharmacy and you were at Newcastle in Clinical Pharmacology when the M.Pharm course in Pharmacokinetics was developed. Congratulations on your eminent status and knighthood.

Since 1997, when I retired as Professor of Medicinal Chemistry, I have been involved with the emerging and widespread complex chronic multi-system illnesses (Gulf War Syndrome/Illness, Myalgic Encephalomyelitis/Chronic Fatigue Syndrome, ME/CFS, multiple chemical sensitivity, MCS, Aerotoxic Syndrome, organophosphate and other pesticide poisonings) that are of growing concern and are medically challenging -- writing and lecturing, locally, nationally and internationally.

This letter is linked to my concerns about ME which involves some 240,000 people in the UK with varying degrees of disability. Some 25% are housebound or bed bound and have formed their own group, www.25megroup.org/ .

The 442 page report “Magical Medicine, how to make a disease disappear”, copy attached with the press release, together with a copy of my letter to the Minister, Lord Drayson, currently the Minister responsible for the MRC, brings together an extensive and fully referenced review of the literature on ME.

It provides the evidence supporting my complaint about the MRC PACE Trial to Lord Drayson.

The entire report, the press release and the letter of complaint have now been circulated worldwide on the internet and have received much acclaim and support from the major ME organisations in various countries and numerous individuals, as well as academic institutions. The report is to be discussed by the International Association of CFS/ME at its next board meeting in early March, as confirmed by the President, Professor Fred Friedberg from the US.

Despite the vast amount of biomedical literature (some 5000 papers) going back to 1934 and the classification of ME as a neurological illness by the WHO (ICD-10 G93.3) since 1969, the official UK attitudes as demonstrated by the MRC, DWP, Department of Health, and to some extent your own organisation NICE:

- a.** ignore all this evidence
- b.** show an ideological commitment to a psychosomatic/behavioural model of the illness which is no longer tenable
- c.** recommend only cognitive restructuring techniques (CBT and GET) that are “not remotely curative” and have been shown to be of no lasting value and in the case of GET to be positively

harmful (Peter White's assertion that this is because the interventions have been incorrectly administered has been shown to lack credibility)

- d. proscribe any investigative tests to identify the disorder, leading to missed diagnoses and misdiagnosis
- e. support cruel, even vicious, actions that lead to patients being wrongly sectioned and parents, particularly mothers, accused of Munchausens'-Syndrome-by-Proxy, MSBP.
- f. the result is that essential benefits and insurance payments to support patients and their families have not been paid or have been granted only after protracted and expensive legal action. All this adds to the burden of the illness for patients and for those who care for them.

The psychiatrists' argument that what they refer to as "CFS/ME" is substantially different from past epidemics of ME does not withstand scrutiny in the light of current knowledge. It is beyond question that ME is associated with a severely disrupted immune system which renders patients more susceptible to both further viral and chemical challenge and reactivation of latent viruses and persistent viral-specific symptoms.

For the psychiatrists to amalgamate 25 different disorders (Holgate, RSM July 2009) and to focus on "medically unexplained fatigue" whilst ignoring cardinal symptoms of ME is a travesty of medical science.

Of special concern and relevance are the legal and ethical requirements facing doctors today, in particular, the legal requirement for doctors to keep up to date with developments in medicine and medical science (as clearly set out in *"Good Medical Practice: Duties of a doctor. The duties of a doctor registered with the General Medical Council: 'Keep your professional knowledge and skills up to date' and 'Never abuse your patients' trust in you or the public's trust in the profession'* (http://www.gmc-uk.org/guidance/good_medical_practice/duties_of_a_doctor.asp).

Ignoring vast swathes of evidence is not keeping up to date. For any registered medical practitioner – consultant or GP -- to dismiss or ignore this widely available evidence which invalidates the behavioural model of "CFS/ME", together with the prescription of inappropriate interventions, is in clear breach of the GMC regulations and consequently raises issues of medical indemnity.

As noted in the report: *"since the general body of knowledge known about by other clinicians and researchers working in the field of ME/CFS is now so great, the question repeatedly asked is: at what point will that body of scientific knowledge be so great that it will be considered serious professional misconduct to ignore it and to continue to deceive patients by pretending that it does not exist?"*.

The recommendation not to carry out appropriate investigative tests is inconsistent with the Hippocratic Oath in its ancient or modern form.

The offering of treatment that is known even by its proponents to be ineffective is a betrayal of doctors' responsibility to their patients. Merely to pronounce that the onus is on the individual doctor, when adherence to NICE Guidelines is to become compulsory, is unacceptable.

Inappropriate sectioning of patients and false diagnoses such as MSBP represents a further betrayal.

To rely on only a few studies, showing very modest efficacy, all of which having been shown to have very serious flaws (as is the case with the PACE Trial) and enshrine this inadequate information in official directions, publications and statements from authorised bodies, including NICE, is utterly unacceptable and dishonours the name of medicine as well as being destructive of lives of sick people and those who care for them.

I draw to your attention the commissioned editorial in last week's BMJ by Alistair Santhouse, who you will be aware was a member of the CG53 GDG. Please read the attached eBMJ response submitted by Horace Reid, a former long-serving NHS clinician. It was rejected for publication, a fact that is revealing in itself, given that it is impeccably accurate.

I would ask you in your role as Chairman of NICE to engage fully with our report and act accordingly to right the long standing wrongs that people with ME have suffered for the last 20 years.

With best wishes

A handwritten signature in black ink that reads "Malcolm Hooper". The signature is written in a cursive style and is underlined.

2nd March 2010

Professor Sir Michael Rawlins responds to Professor Malcolm Hooper

<http://www.meactionuk.org.uk/Rawlins-response-to-MM.jpg>

From: Professor Sir Michael Rawlins FMedSci

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To: Professor Malcolm Hooper

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02 March 2010

Dear Malcolm,

Thank you for your letter and for enclosing "Magical Medicine: How to Make Disease Disappear".

You are obviously aware that NICE has, in the recent past, been involved in defending an action for Judicial Review over the ME/CFS guideline we published a couple of years ago. Although judge found in favour of the Institute the legal costs were considerable. I am afraid, therefore, that I am not prepared to enter into any correspondence on this matter.

I am returning your document.

Yours sincerely,

Professor Sir Michael Rawlins FMedSci

Chariman

5th March 2010

This is Professor Malcolm Hooper's reply to Professor Sir Michael Rawlins' unscientific refusal to address the biomedical evidence that exists about ME/CFS:

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05 March 2010

Dear Sir Michael,

Thank you for your letter and the returned copy of Magical Medicine which I found very disappointing and disconcerting.

To be faced, yet again, with the denial and dismissal of the comprehensive amount of biomedical evidence about ME that has been presented in some 5000 published and peer-reviewed papers is disturbing and has sinister connotations devoid of any compassion.

Failure to consider this evidence means that any policy towards people with ME will be "built upon sand" in defiance of the basic principles of scientific inquiry and any consideration for very sick people, their families and carers

As a fellow medical scientist I find the continuing denial and unwillingness to face the biomedical evidence both puzzling and incomprehensible.

We know Government is committed to funding research that is perceived to support policy, an attitude that has, in this case, lead to lack of scientific rigour, integrity and humanity in order to avoid developing a policy based on the biomedical evidence available in this complex and difficult

area of medicine.

With best wishes

Malcolm Hooper