

Dr Ian Gibson MP/All Group Members
The Group on Scientific Research into ME
House of Commons
London SW1A 0AA

1st May 2006

Dear Dr Gibson/Group Member,

Clinician/Researcher Testimony, Your Group's Remit & UK Democratic Standards

I am very concerned that, as far I can ascertain, your group has not yet issued formal witness invitations to key researchers/clinicians disposed to a balanced scientific approach concerning Myalgic Encephalomyelitis. Given your stated intent to conclude your group's work by the summer parliamentary recess, this will place unfair time demands upon very busy professionals who are otherwise willing to attend your hearings. I wrote/copied a letter/email to you and your group administrative assistants, on this matter on 15th April 2006 (copy enclosed herewith) but have not received a reply as yet.

I do appreciate that you and your group are very busy and have limited administrative resources at your disposal. However, if you do not contact such extremely important witnesses soon this may preclude some of them from giving oral testimony and thereby render your final report substantially the poorer for it. Things are difficult enough for the UK specialists (Dr Abhijit Chaudhuri, Professor Malcolm Hooper, Professor Basant Puri, Dr Nigel Speight, Dr Vance Spence/MERGE, Dr Irving Spurr, Dr Willie Weir, Dr John Gow, Dr Jonathon Kerr *et al*) but this is clearly more so for North American specialists such as Dr Byron Hyde, Dr Bruce Carruthers, Professor Anthony Komaroff, Professor Leonard Jason *et al*. It does seem a particular shame if your group cannot interview Doctors Hyde and Carruthers when they happen to be in the UK anyway from May 10th and 8th respectively. Just to reiterate, scientific and clinical knowledge on ME is not confined to UK specialists, neither therefore should oral witness testimony to your group be similarly limited.

Given the controversy and confusion surrounding the terms of reference of your 'science' group, I would just like to emphasise that it is important you interview specialist clinicians as well as scientists/researchers. Often the role of clinician and researcher is combined anyway; thus for example, clinical specialist Dr Abhijit Chaudhuri can present recent autopsy evidence of demyelination and spinal cord inflammation - unequivocally demonstrating the superiority of the WHO-backed Encephalomyelitis label over the unofficial and research-ignoring Encephalopathy and 'Chronic Fatigue' labels. Indeed, this adds to the substantial amount of biomedical evidence from Dr John Richardson and others on such matters prior to 2002 (your group's previously stated arbitrary chronological cut-off point?).

Evidence that such scientific research has been systematically ignored by the establishment/CMO/MRC/DWP, and that ME patients have been subject to a 15 year long industry-backed campaign of persecution¹ by the Wessely-School group of psychiatrists, has been supplied to you/your group. Dr Ian Gibson initially gave an unequivocal commitment to me, Professor Hooper and others that his "inquiry" would examine such matters. On November 4th 2005, in direct reference to such matters he stated to me, Jeff Brown and Barbara Robinson: **"...it's open season for evidence as far as I'm concerned; nothing ruled in, nothing ruled out. We've just got to get to everybody all the evidence we can. I'm sorry for the committee 'cos they are gonna have to read a lot... [Ian Gibson MP - recorded on tape]."** It is just not right that you have backtracked on this commitment². I say again, the problem with UK policy towards ME is not just that insufficient scientific biomedical research has taken place; it is that existing research has been systematically disregarded, obscured and abused by powerful vested interests. This is well documented and such documentation has been supplied or made available to your group - including an open invitation to visit the extensive documentary library of the excellent medical-legal researcher Margaret Williams. How can your group possibly, as you promised, "get to the bottom of matters" by

ignoring such unscientific establishment behaviour? **What is the point of having scientists in this country if the facts they uncover are simply buried by the expedient financial requirements of a new anti-enlightenment priesthood of the powerful? Indeed, what is the point of electing/appointing politicians such as yourself if you hold an examination of crucially relevant political shenanigans to be dispensable? Parliamentarians are meant to be interested in matters political; and they are meant to serve the public and hold power to account.**

This is all (along with: 'cash-for-questions', 'loans for peerages', 'corporate-skewed university science', 'the CMO Working Group bias', 'the MRC/PACE Trial inclusion criteria fraud', 'science ministry/peerage given to a vested-interest biotech industry New Labour supporter') a national tragedy. This is not an unwarranted rant on my part: these are measured words describing facts backed up by evidence. As an ex Labour Party member, I am appalled that the party, elected on a ticket to reform the House of Lords, chose to appoint an unelected, non-scientist, biotech venture-capitalist as science minister (Lord David Sainsbury). It is not right that national science/research policy is entrusted to an unelected man with clear vested financial interests in controversial GM biotechnology etc. Along with many other observers, I simply do not believe that his £7,000,000.00 donation (plus loans) made to New Labour had no influence on his award of the science ministry/peerage. Some politicians may feel they can 'tough out' such highly questionable behaviour but there is a long term cost to both national democracy and science by such actions - in the increasingly evident national cynicism it creates. As an ME sufferer, I simply despair that, after his private 'Linbury Trust' funded deceitful, science-ignoring, Wessely-School psychiatric studies (rubber stamped by his disgraceful CMO's working group which excluded biomedical researcher testimony and evidence), Lord Sainsbury's MRC ignores biomedical evidence and funds the scientifically fraudulent³ 'PACE Trial into ME/CFS.' Public money has also been wasted on a national network of abusive CBT/GET 'ME treatment centres' based upon scientific falsehoods - even before the sham justification of the PACE 'results' are in. My God; is it any wonder that neurological ME patients are angry, that the public are skeptical about national scientific probity, and voters increasingly refuse to lend ballot-box legitimacy to politicians?!

Finally, I would just like to add: because I continue to point out uncomfortable facts and fight my corner does not mean I am ungrateful for any genuine attempts to seek truth and justice by you and your group. I would appreciate it if you would contact the above-mentioned clinicians/researchers as soon as possible. I would also like you to tell me if you have already contacted Professors Simon Wessely, Peter White or Michael Sharpe. I look forward to your early reply. I have sent this letter to you by Royal Mail Recorded Delivery and e-mail - along with copies sent to your group administrative assistants. In the interests of openness, I am also copying the text to various M.E. groups on the Internet with personal details removed. For your information I am enclosing copies of: *MERGE – Energising Biomedical Research in ME/CFS, a DVD lecture by Dr Vance Spence; Some of the Abnormalities that have been Demonstrated in ME/CFS by Eileen Marshall & Margaret Williams; What the Experts Say about ME/CFS by Margaret Williams*. Thank you for your attention to these matters.

Yours sincerely,



Kevin Short.

Encs (7).

Cc: Mr Ian Woodcroft; Professor Malcolm Hooper; Dr Bruce Carruthers; Dr Byron Hyde; Dr Vance Spence/MERGE; Professor Basant Puri; Dr Abhijit Chaudhuri; Dr Nigel Speight; Dr Irving Spurr; Dr Willie Weir; Dr John Gow; Dr Jonathan Kerr; Margaret Williams; Doris Jones; RiME; Jeff Brown.

¹ The word 'persecution' is not used as a device of rhetoric; you and your group have been sent large volumes of evidence to support this charge by me and many others.

² See my letter to Dr Gibson of December 5th 2005 in response to your press release/terms of reference; his reply of December 9th and my detailed response on December 31st 2005 (previously sent/enclosed).

³ The charge of fraud is not an empty one: you/your group have been sent hard evidence of how the MRC/DWP backed Wessely-School 'PACE Trial' has deliberately cheated on its patient inclusion/exclusion criteria.