

From: Mr Kevin Short, Norwich (full address previously supplied). skevin@onetel.com

31st December 2005

Dr Ian Gibson MP
House of Commons
Westminster
London SW1A 0AA

Dear Dr Gibson,

Group on Scientific Research into ME - Your Letter Dated 9th December 2005

Thank you for your letter to me of 9th December 2005, replying to my open letter/email to you of 5th December. I am again responding openly to you and shall post this letter/email to various M.E. activist web sites and to the individuals specified below. As well as by email, this text will be sent to you on paper, by Royal Mail recorded delivery, with all enclosures mentioned below.

I am grateful for your time and welcome some of the comments you make. However, certain aspects of your reply concern me and the statement you make regarding the terms of reference of your group leaves me somewhat astonished. I shall respond to your letter point by point - though in a different order of sequence to yours.

Terms of Reference - 1: Politics & Broken Promises.

In your group press release of 1st December 2005, under terms of reference, you state:
"The Group on Scientific Research into ME has been established to assess the progress of scientific research on M.E., since the publication of the Chief Medical Officer's Working Group Report into CFS/ME in 2002." [Ian Gibson MP, Press Release, 1st December 2005].

With regard to my 5th December comments concerning said press release and the terms of reference contained therein; in your letter to me of 9th December 2005, you state:
"I [you] do feel that your [my] reaction to this and the terms of reference that I have set out for the group's inquiry to be unfair. When you approached me to ask if I would be able to instigate such an inquiry you wanted me to form a fair and balanced inquiry into the Scientific Research of ME. This is exactly what I am in the process of doing." [Ian Gibson MP, Letter to K Short, 9th December 2005].

I am saddened by this statement; I feel it to be revisionist and misleading for the following reasons:

(A) Any Inquiry which merely focuses on the "scientific research on M.E." alone - even without restricting itself to post 2002 - will emphatically not be "fair and balanced". I have sought to hammer home to you many times the crucial point that, whilst more research would be welcome, a huge existing body of biological research evidence (and clinical expertise) has been systematically ignored through a process of extremely dirty and dishonest political chicanery and, that patients have been, and are being, mistreated and persecuted. Frankly, for you and other colleagues who have given up a career in science for one in politics, to imply by

omission that political matters pertaining to ME do not matter, smacks of hypocrisy. It is simply and utterly impossible to have a "definitive" and "fair and balanced" inquiry that "gets to the bottom of things" without a full and thorough airing of such matters. You have been repeatedly told this and supplied with supporting evidence by myself (and many others) on numerous occasions.

Thus for example, at our meeting on 8th August 2005, Professor Hooper presented you with an eight-point discussion document (see APPENDIX-1 below/enclosed) which does not remotely limit itself to science matters alone, was the subject of wide discussion in which Wessely School and establishment shenanigans were clearly covered, and to which you responded by announcing the need for a "definitive inquiry" to "get to the bottom" of matters. Some examples of my own primary emphasis on political aspects conveyed to you are given in statements set out in APPENDIX-2 below/enclosed. It is simply untenable, as anyone can see from the information supplied in appendices 1 & 2 (below/enclosed), to hold the view that you were asked by me to look into scientific matters alone and not the political aspects of ME. This however, seems to be what your 9th December statement (responding to my criticisms that you have broken promises made regarding terms of reference) that "you wanted me to form a fair and balanced inquiry into the Scientific Research of ME" is disingenuously implying. Please clarify.

To add to my own repeated statements on the need for the inquiry terms of reference to be broad-ranging, I personally handed you, at our meeting on November 4th, a copy of Professor Hooper's paper, dated 2 November 2005, entitled: *'Parliamentary Inquiry into ME/CFS; Outline Proposals'* (see APPENDIX-3 below/enclosed) - this paper clearly spelled-out that your inquiry should not be limited to looking at scientific research. The fact is, not once during 2005 did you indicate to me, in writing or verbally, that your "inquiry" would be limited to looking at science alone - Your 1st December terms of reference therefore came as a great shock to myself, Professor Hooper, Jeff Brown and others. Had you made any such indication that you intended to render your inquiry grossly inadequate in this way, I would have immediately complained strongly and publicly - as indeed I did it on December 5th.

(B) Your statement seems to imply that you did not lead members of the ME community to believe your inquiry would be an inclusive and wide-ranging one and, that you did not in fact give a commitment that your inquiry panel would examine political matters and not just a limited review of research. Such an implication, if this is your intention, is grossly misleading, smacks of political spin, and renders my faith in the parliamentary process to an all-time low. To remind you of what you did actually say, I will quote extracts of the verbal exchange from around 20 minutes into our meeting on 4th November 2005. The meeting was also attended by Jeff Brown and Barbara Robinson (NB: this meeting was recorded, with your agreement, as a private aide-memoire - the sound quality is not perfect but the following is clear. I will send you a personal CD copy of this recording along with the paper version of this letter):

[B Robinson]: *"Is the remit, perhaps you can clarify this, is the remit essentially the direction of research?"*

[Ian Gibson]: *"I, that's my, that is my bias..."*

[B Robinson]: [continues and asks about looking into DWP/benefit/children issues]...

[Ian Gibson]: *"if you've got points to make about that, let me have that; in your evidence, in your evidence."*

[B Robinson]: [talks more on children's/family issues]...

[Ian Gibson]: *"tell us that, when we ask for evidence for this Inquiry, you give me the areas that you think are important in the evidence. We will, we will want, I want every bit of evidence on ME that's around even if it fills the room."*

[K Short]: *"it's not just got to be on the research and the..."*

[Ian Gibson]: *"No, I know."*

[K Short]: *"... it's really got to be looking at..."*

[Ian Gibson]: *"I know."*

[K Short]: *"... the vested-interest and the way the whole people at MRC etc is skewed, because what they have done is they have twisted, you know, established illness, they've used really dodgy research criteria..."*

[Ian Gibson]: *"Well, you're making accusations of the MRC. Write to them, get Colin Blakemore in and cross-question Blakemore."*

[K Short]: *"... I mean why? You know as a scientist you've got to have proper boundaries between control groups and patients, and they, that's how they fudge the results."*

[B Robinson]: [interjection by Ms Robinson]...

[Ian Gibson]: *"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; and it may be you think they've not given themselves enough time and I might think that too as chair..."*

[Ian Gibson]: *"I think Carruthers' would be worth quite a turn; somebody told me Carruthers would come over at his own expense to give evidence."*

[K Short]: *"Carruthers' and Byron-Hyde are absolutely indispensable."*

[Ian Gibson]: *"Yes, Byron told me that, he said that: we come over at our own expense."*

[Ian Gibson]: *"Put in all this stuff about your experience; give us tapes, present the evidence how you want to present it, OK? It's up to the committee to read it, watch it, you know? Or ask questions, you know, to ask for a return from you. You know we require from you and say, you know, we don't understand this; would you amplify it a bit more?"*

[K Short]: *"... but can I just clarify something; you are open to try to find a QC or a Judge?"*

[Ian Gibson]: *"Oh absolutely, absolutely."*

[Ian Gibson]: *"Is that all right then? And you get the nature of all and you know exactly where we're at now? I'm still trying to get the committee."*

[Extracts of verbal exchange at a meeting on 4-November-2005 between Ian Gibson MP, K Short, J Brown and B Robinson].

In addition to the above statements made by you on 4th November, there are others. Thus for example, comments made on our BBC Radio Norfolk interview on August 8th and your written comment to an ME sufferer in Kent stating: *"Since I have raised this issue in the media I have been contacted by many people with different viewpoints from all over the country. It is clear that it is high time there was a definitive inquiry."* I am far from alone in taking the view that what you offered in your 1st December press release could not be remotely described as a "definitive inquiry" and that it is considerably less than what you led ME sufferers to hope for. I therefore respectfully request that your group honours the words of its chairman and broadly looks at the issues affecting ME sufferers as was previously agreed. Specifically, it is imperative that your inquiry thoroughly examines the material contained in, and documents referred to, the paper produced for you on 7th November by Professor Malcolm Hooper, Eileen Marshall and Margaret Williams entitled: *For UK Parliamentary Inquiry into ME/CFS - chronological list of documents relevant to the inquiry authored by Professor Malcolm Hooper, Eileen Marshall and Margaret Williams* (enclosed).

You also state that: *"I do not want you to be under the impression that through its terms of reference the group has in any way biased the outcome of the evidence it will receive."* I'm afraid I have to disagree, if your committee is to rule out a thorough examination of political matters and instead have a blinkered focus on research alone, then a skewed outcome will be precisely what transpires and will facilitate further deceit by the psychiatric lobby.

Terms of Reference - 2: Shifting Goalposts & Implications.

(1). In your 9th December letter you state that: *"should you [I] oppose the CMO's report and findings, then I would ask you to submit this as part of your written evidence, so that this can be taken into account by the group.* This is a welcome statement. However, given the restricted nature of the terms of reference made public on 1st December, this is rather fiddling with the stable door after the horse has bolted: many people will have already not submitted evidence on this matter because they believed you had ruled it out. I submit that more time now needs to be allowed to rectify this.

(2). Regarding my comments on your 1st December TOR statement (that your group *"has been established to assess the progress of scientific research on M.E., since the publication of the Chief Medical Officer's Working Group Report into CFS/ME in 2002"*), on 9th December you state that: *"Further, your assertion that by including reference to the report ruled out taking into account the body of work produced prior to this point is wrong. ...I see no reason why, as part of the terms of reference provided, that we have to preclude any evidence that would help us further understand scientific research into ME."* This is also a welcome statement. However, again, we have a problem in that this appears to be shifting the goalposts from those stated in your 1st December press release and many people will therefore have submitted evidence to you on the assumption that pre 2002 research would not be admitted. I would also like you to clarify the following points:

- Will your group be comprehensively looking at all research to date, including epidemiological (see enclosed: *MERGE Reference Index of Papers Published on Epidemics of ME 1934 - 80*), and that specified by a Professor Hooper, Eileen Marshall and Margaret Williams in their paper to you of 12th December, 2005? This paper is subtitled: *Illustrations of Clinical Observations and International Research Findings from 1955-2005 that demonstrate the Organic aetiology of Myalgic Encephalomyelitis/Chronic fatigue Syndrome* (enclosed).
- Will you be taking into account researcher's inclusion/exclusion criteria and their professional integrity, political motivation and personal vested interests when assessing and comparing "scientific research"? For example, will you take into account that Professor Peter White, currently head of the MRC PACE trial, has long served the vested interests of the insurance industry and is utilising unscientific 'research' criteria? Will you also take into account the fact that Professor Simon Wessely was rebuked by the WHO for fraudulent and misleading abuse of their disease classification framework? Given that much of the evidence relied upon by the CMO was the private "research" of Professor Wessely and it had not even been peer-reviewed let alone published, concerns such as these are well justified within the ME community.
- This spring, I arranged for a donated copy of Dr Byron Hyde's book (entitled: *The Clinical and Scientific Basis of ME/CFS*) to be hand-delivered to you at Westminster by a kind third-party. A copy of Dr John Richardson's book (entitled: *Enteroviral and Toxin Mediated Myalgic Encephalomyelitis/Chronic Fatigue Syndrome and Other Organ Pathologies*) is on its way to you from me. Will these, and other crucial textbooks (as specified by Professor Hooper, Dr Byron Hyde, Dr Bruce Carruthers and others), be read by all committee members?

Terms of Reference - 3: Nomenclature/Disease Classification.

You also state that: *"you have also raised questions over the name of the group itself. I am keenly aware of the ongoing debate under way over what title should be ascribed to the condition. I am also keenly aware for the purpose of holding an un-biased inquiry into the condition I have to find a term that appeals to at least the bare minimum of acceptance for all sides in what is an extremely controversial field."* This however is in itself an extremely controversial statement in that it is allowing the Wessely-School - a minority psychiatric cult - to set the agenda. Surely, the nomenclature agenda should be set by the WHO International Classification of Diseases to which the UK subscribes. Myalgic Encephalomyelitis patients want a proper inquiry into Myalgic Encephalomyelitis (also listed by the WHO as: PVFS/CFS). We do not want an inquiry into 'Myalgic Ecephalopathy' or 'Chronic Fatigue' or some other unrecognised or nebulous heterogeneous patient grouping/label - terms which have, by political design (see Bruce Carruthers' statement on this), been concocted to fudge the issue and allow insurance companies etc to deny patients' rights.

You go on to state that: *"this does not stop you raising in detail why it is that you feel the issues surrounding terminology have, in your opinion, had an impact on research of the condition. Already, I have some detailed evidence submitted from you and others over this point, which will help enable the group to assess this argument, and I remain completely open in my opinion on this matter."* This is a welcome statement. However, again this seems to be backtracking from the terms of reference stated in your 1st of December press release. And again, brings with it the problem that people have already submitted limited evidence thinking that you had ruled out examination of the extensive political skulduggery surrounding disease nomenclature and classification. More time is therefore needed.

Terms of Reference - 4: The Need for Public Clarification/Transparency.

Whether intended or not, your 1st December press release gives the impression that a.) you will only look at scientific research and not related political issues and, b.) that you will only examine material post 2002/CMO's Report. If your group's terms of reference are not to be restricted in such a way - as you are clearly saying in your private letter to me of 9th December 2005 - then it is imperative that you make an urgent public statement to this effect for the sake of clarification.

Bias Towards the CMO's Working Group/2002 Report?

In your 1st December press release you stated: *"The Chief Medical Officer's report into CFS/ME represented an important step in Government's recognition of the seriousness of ME."* In response to my criticism of the statement you say, in your letter to me of 9th December, that: *"The reference to the CMO's Working Group Report in 2002, makes the group's inquiry both timely and relevant to policy makers and leaders."* My response to your statements is that, I believe you are underestimating the extent of the establishment stitch-up and setback that the CMO's Working Group/Report represented for ME sufferers. Moreover, it has been pointed out to me that for a committee of MPs to make such prejudicial statements, before the inquiry has even sat down to consider evidence may be in breach of Parliamentary protocols. I will seek advice on this matter.

If it were simply a case that your 1st December statement favouring the CMO's Group/Report was made in haste and without realising how contentious it would be, then I would gladly accept your withdrawal of the statement - if indeed the statement did not reflect any actual bias on your part.

Flexible Deadlines for Submission of Evidence.

You state that: "... should I [you] be approached by any group or individual, regarding the problems they have with the length of time given for submitting written evidence to this group, I would of course be sympathetic and flexible as possible to their needs." I welcome this clarification. However, as indicated above, apparent changes to your terms of reference are likely to mean that more individuals than anticipated will require additional time to submit evidence that they thought you had ruled out.

Witness Selection/Transparency.

You state that: "*With regard to who should appear before the group's hearings, I am reserving judgment on the names of those who we will invite to appear until we have received written evidence and the group membership has been announced. However, due to time constraints, we will not be able to wait for any late written evidence before making a determination on who we should invite to give oral evidence.*" This is problematic and unjust: Your above clarification/modification of the terms of reference given in your 1st December press release will mean that many witnesses may wish to change their written submission to include aspects which they had believed to have been ruled out by you. If this means that the inevitable lateness of their amended written submission rules them out from being considered for appearing before the committee, then this is clearly not fair.

I look forward to you publishing a full list of the names of witnesses chosen to appear before your committee. Will this list be published prior to the committee's first hearing? Will there be time for fair comment to be made on the balance/inclusiveness of this witness list prior to the first hearing?

Committee Propriety and Transparency.

I say again, I believe it to be improper that, as a condition of participation, the ME community has found itself having to submit evidence to an unknown committee whose membership has not been finalised and a without knowledge of any members' conflicts of interest. When will we know the names of the members of your committee? Will potential conflicts of interest of these members, including your own, be published? When such details are published, will we have opportunity to register any possible objections to the inclusion of any of the members?

Need For Information/Transparency.

At our meeting on 4th November, you agreed with Jeff Brown that information about your committee, witness submissions etc, etc would be made available to be published on ME patients' websites. Jeff's own website at EAMEPP is available for this purpose, as is Stephen Ralph's at ME Action UK - and I am sure that others would be interested also. This information

is urgently needed. Please therefore, would you tell me when such information will be available for distribution on the Internet and from where/whom we obtain it?

Clarification, Appreciation & Disappointment.

You state that: *"When you approached me to ask if I would be able to instigate such an inquiry you wanted me to form a fair and balanced inquiry into the Scientific Research of ME..."* This statement needs correcting: I did not approach you to instigate an inquiry by an ad hoc committee of members of Parliament, and I most certainly did not ask for one limited to examining scientific research in isolation from political reality. I merely asked you last spring, along with many others - including Bishops, Doctors and Peers, to investigate all issues surrounding ME and to call for a full and proper 'Public Inquiry' (i.e. one headed by a Judge and in receipt of proper official funding). That you chose to respond by working to establish your own inquiry, with yourself as chairman, was your own idea - with which you took us all by complete surprise at our meeting with Professor Hooper on 8th August. Unlike a few in the ME community, I chose to show appreciation of your efforts to "get to the bottom of matters" and assist you in constituting an adequate inquiry. I am still grateful for your time but, sadly, it seems as though I am to be disappointed regarding the "adequate" bit.

Who is Being Unfair?

You state that: *"I believe that you have now received a copy of the press release directly from me. However, I do feel that your reaction to this and the terms of reference that I have set out for the group's inquiry to be unfair."* Firstly, I emphatically do not agree that my reaction/comments in my 5th December letter to you were unfair in any way. I put this point to two of the M.E. community's most senior and respected figures and was confirmed in my view on this matter. Secondly, I have in fact not received a copy of your press release direct from you; perhaps this is due to the Christmas post.

In Conclusion.

You state that: *"I was very disappointed that you have decided not to support the work of the group on Scientific Research into M.E. which I have established and I am writing to the urge you to change your mind."* In fact, on 15th December upon reflection and friendly advice from respected campaigners, I publicly withdrew my earlier call for an outright boycott of your inquiry/group. However, I did so for "strategic damage-limitation purposes" and only with the caveat/recommendation that participants continue to campaign for changes to your group/terms of reference - which as currently constituted has the potential to do far more harm than good. I therefore wish your group to take on board the written evidence previously sent to you by me which will shortly be added to by the said copy of Dr John Richardson's book along with eight copies of Martin Walker's book: 'Skewed' and other documents. I also wish you to note the following:

That corporate-backed lobbies have increasingly influenced and often subverted science and social policy since the Thatcher era is a given: regularly covered on any social policy course and in the media (e.g. New Scientist, 26th February 2005, page 3). That such forces are conspiring to deny justice to ME patients is also a given, and you have already been supplied much hard evidence to this effect. Some in the ME community feel you have been got at by

such a lobby and that your group's narrow terms of reference and lack of transparency and propriety reflect this. I do not know (though such concerns are understandable).

I have however, over the years, witnessed your willingness to stand up for justice in Norwich and to vote with conscience over party many times in Parliament. Indeed, I have publicly defended you over this (see enclosed EEN photocopy). I may be wrong, but my gut feeling is that you were genuinely trying to help ME patients but have backtracked from your original commitment without being upfront about the reasons for this. Perhaps it is that you have taken on more than you bargained for, or have succumbed to pressure from colleagues and elsewhere. I do not know. Whatever the case, if you really do want to do us justice, I call upon you now to action the following:

- (i). Abandon your still over-restrictive terms of reference and replace them with those discussed previously with myself, Professor Hooper and others (see APPENDIX – 3 below).
- (ii). Publish all names of your group members along with potential conflicts of interest.
- (iii). Publish a full list of witnesses as soon as possible along with written submissions (omission of private medical details/communication from this is, of course, understood).
- (iv). Withdraw your December 1st press release and replace it with one that properly and accurately spells out wider and actual terms of reference and all details of the constitution of your group.

Physically ill organic/neurological WHO ICD-10-G93.3 ME patients are facing outrageous persecution by elements of the establishment within this country. Science-ignoring psychiatrists tell the NHS not to prescribe walking sticks and wheelchairs - claiming this reinforces "sick role behaviour"; and, this summer, the DWP was plotting to not recognise patient's use of such mobility aids unless they were prescribed by a doctor. This appalling catch-22 pincer movement is thus conspiring to deny chronically ill patients both medical/mobility support and welfare/insurance payments. Added to that, there are thousands of parents in this country with M.E. children unable to go to school living in dreadful fear of being accused of Munchausen's (or the latest trendy label for it) by social workers and doctors who are in complete ignorance of the biomedical research facts. It is bad enough to have one's life ruined by this illness without being persecuted to boot. This all amounts to an utterly disgraceful national scandal. Please help us as you led us to believe you would. I am exceedingly grateful for any genuine help given to ME sufferers. Please do not think otherwise.

Yours sincerely,

Kevin Short.

Encs.

Cc: Professor Malcolm Hooper; Jeff Brown; Barbara Robinson; Margaret Williams; Bishop Graham of Norwich; Dr Bruce Carruthers; Dr Byron Hyde; Dr Abhijit Chaudhuri; Paul Davis (RiME); Simon Laurence (25% ME Group); Dr Vance Spence (MERGE); Stephen Ralph (ME Action UK); Martin Walker; Mr Ian Woodcroft.

[Permission to repost – complete and unedited with below appendices - is granted.]

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APPENDIX-1:

Professor Malcolm Hooper's Discussion Document Presented, In Person, to Dr Ian Gibson MP at the meeting of 28th July 2005. With K Short, J Brown *et al* in Attendance (Permission to repost granted by Prof Hooper):

1. ME is defined as a neurological disorder, ICD-10 G 93.3 recognised by the present Government. It is not a behavioural and mental disorder, ICD- 10 F 48.0.
2. The provision of ONLY psychiatric services offering treatment based on psychiatric/psychological techniques is a calculated act of betrayal and deception that is unacceptable.
3. The cruel and inhumane treatment of some children and parents on the advice of some psychiatrists must be abandoned and admitted immediately.
4. Munchausen by proxy or any comparable synonym is not acceptable.
5. There is ample evidence in the current and established peer-reviewed literature to show that ME is a multi-system multi-organ disorder that is an organic and not a behavioural and mental disorder.
6. Many clinical signs that identify ME and allow an accurate diagnosis have been listed.
7. Frequently a viral or microbial infection has led to ME but increasingly some chemical exposures trigger a similar response.
8. Benefits and support for ME sufferers and carers must [be] provided to enable them to live their lives to the full without fear, stigmata or compulsion.

[Professor Malcolm Hooper, July 2005.]



APPENDIX-2**A Representative Selection of Statements made by K Short to Dr Ian Gibson MP, in 2005, Requesting Full Examination of Political Factors Surrounding ME:**

"I say again, the UK government has allowed itself to be misled. What appeared to be budget-saving psychiatric treatments will result in thousands becoming more disabled and taking legal action against the NHS. The likes of Professor Simon Wessely of King's College and Peter White (head of the scientifically fraudulent MRC/DWP PACE Trial) have been deliberately misleading government to further vested interests. This is not just my view... See for example the enclosed paper by Professor Malcolm Hooper, entitled: The Mental Health Movement - Persecution of Patients: a Consideration of the Role of Professor Simon Wessely and other members of the Wessely-School in the Perception of Myalgic Encephalomyelitis (ME) in the UK." [K Short, letter to Ian Gibson MP, 17th January 2005.]

"There's been a well-funded and well-orchestrated transatlantic corporate campaign against true, brain-damaged enteroviral M.E. for over 15 years now (see the enclosed book by Martin Walker: 'Skewed...' - and please take note of the questionable activities of Lord David Sainsbury and his 'Linbury Trust'). ... In the UK, government has instructed the NHS to not properly bio-medically discriminate between patients because it is expensive and because it was misled by the corporate psychiatric lobby etc. This is why Sally Montague and Professor Hooper wrote their (enclosed) paper entitled: 'Concerns About The Forthcoming UK Chief Medical Officer's Report on Myalgic Encephalomyelitis..., Notably The Intention To Advise Clinicians That Only Limited Investigations Are Necessary'. It is also largely why an international panel of bio-medical M.E. experts led by Dr Bruce Carruthers published its erudite 154-page clinical diagnostic protocols (see enclosure) - known colloquially as the 'Canadian criteria'..." [K Short, letter to Ian Gibson MP, 29th January 2005.]

"The UK Government allowed itself to be over-influenced by corporate lobbies and allowed the UK CMO's working parties on M.E. to be dominated by psychiatrists with vested interests - who effectively ignored the established body of biomedical research evidence." [K Short, letter to Ian Gibson MP, 6th February 2005.]

"failure to properly differentiate between heterogeneous patient sub-groups will clearly lead to inadequate or harmful treatment. Indeed, a recent paper by Professor Leonard Jason et al ('Chronic Fatigue Syndrome: The Need for Subtypes', Neuropsychology Review: 2005: 15: 1: 29-58. (enclosed)) makes precisely this point and offers a damning critique of medical professionals ignoring such good practice. ... In spite of the above, for over 15 years, corporations, Professor Simon Wessely and other 'Wessely-School' psychiatrists' - many with clearly arguable vested interests - have systematically toiled to label ME/CFS as largely a product of the mind and to treat a whole range of illnesses as 'functional somatic syndromes'. To this end, this well-orchestrated psychiatric lobby have flooded Medical/trade journals with a highly dubious 'research' articles [see comments by Dr Abhijit Chaudhuri on the BMJ] that influence GPs who are too busy to search out opposing voices. Please understand, this is not just a case of honest professional disagreement. Good science is being ignored, and an extremely dirty war has been waged by certain protagonists against ME patients and the medical professionals defending them. ... Thus we are rapidly witnessing the setting-up of a network of psychosocial NHS 'treatment' clinics and a situation where the modern equivalent of polio victims will be mistreated as mental cases and denied proper state and insurance support. Additionally, ministers are presiding over a situation where their Medical Research Council fund scientifically flawed and prejudiced trials into dubious CBT/GET for all, yet denies funding for top quality biomedical research into ME. This is not just the assessment of

myself... And I beg you to examine the enclosed paper ('Vilified But Vindicated?') and film by Professor Malcolm Hooper et al. ... This does not, I am afraid, give me much faith in the efficacy of our 'democracy'. Who then will properly listen to patients and biomedical researchers/clinicians? On this matter Hooper et al state: 'The total inadequacy of the psychiatric approach has been repeatedly pointed out to the Chief Medical Officer and to the MRC by us and others... but the evidence was comprehensively and systematically ignored'. Indeed, significant biomedical research documentation sent to official bodies went missing - as did that in the House of Commons library - and was not distributed as it should have been.' [K Short, letter to Ian Gibson MP, 14th May 2005.]

"... The most important person to contact re documentary evidence. ... writes under the professional name of Margaret Williams... And she is one of the most knowledgeable persons in the ME community and can give you more documentary evidence on both the research and political skulduggery involved than anyone." [K Short, email to Ian Gibson MP, 28th July 2005.]

"The testimony and evidence of biomedical researchers and ME sufferers was deliberately ignored at the Chief Medical Officer's Working Groups on ME - of this there is hard evidence which can be supplied - now, thanks to you, all sides will be able to be heard and able to go on the record. Not too much to ask in a democracy! Clearly, the inquiry needs to be as independent as possible." [K Short, e-mail to Dr Ian Gibson MP, 31st July 2005.]

"Dr Byron Hyde has requested that I pass on to you a copy of his latest chapter - 'The Complexities of Diagnosis' - for you to look at which I herewith enclose. Just a quick look at this will show: how crassly unsophisticated NHS diagnostics and testing are compared to overseas and, that ME is not the same thing as Chronic Fatigue states - as Wessely, White & co would have us believe." [K Short, letter to Ian Gibson, 7th August 2005.]

"However, a proper inquiry panel needs to be independent of all witnesses - and crucially, the relationships between witnesses and the All Party Parliamentary Group on M.E. (APPGME), the DWP, the MRC, the Chief Medical Officer's Working Group, other official bodies and Industry lobby groups must be fully exposed if the truth is to be got at. The latter point is stated for good reason - there are serious allegations of bias and collusion requiring examination. One needs to fully understand the historical context of M.E. sufferer concerns: which are that the psychiatric lobby are past-masters at getting their men on to official bodies (e.g. the notorious CMO's working group 1998-2002) whilst at the same time minimising the involvement of those with biomedical clinical and research expertise. This is well documented...

There has been a massive campaign to obscure the scientifically backed truth about WHO-recognised Myalgic Encephalomyelitis in the UK and I would draw your attention to the final paragraph of my above posting. In particular, my statement concerning what Charles Shepherd refers to as the two 'main UK ME/CFS charities': 'Both AfME and MEA have capitulated, appeased and participated in this occultation of The FACTS. It is now up to us [the ME community] to make sure that this Inquiry becomes an independent reality and does not do likewise.'

Just some of the many concerns about AfME/MEA are that the former refused to be democratically accountable to its membership and the latter undermines the WHO recognition of Myalgic Encephalomyelitis and consequent protection of patients. Even a cursory view of the written material put out by other UK-based M.E. groups in comparison with that of AfME/MEA will reveal a startling deficit of information provided to their respective members by the latter two groups. This failure to properly inform their membership, along with other actions, completely negates any claim that AfME/MEA speaks for or represents the M.E.

community in the UK. Also, both AfME and MEA 'medical advisers' - Tony Pinching and Charles Shepherd - have extremely limited clinical expertise with M.E. patients and are far from being at the top of the qualified specialist professional list. There are also concerns that these two Doctors have long been members of Healthwatch - a corporate-linked pressure group of which the notorious Simon Wessely is also a member.

I am in fact far from alone in my view that: a.) 'Action for ME' and 'The Myalgic Encephalomyelitis Association' have worked against the best interests of Myalgic Encephalomyelitis patients, and b.) that these two charities - or any other interested party - need to be prevented from stacking any 'independent' inquiry membership with its friends (or provide it with 'secretarial services' as they currently do with the APPGME). The devil really is in the detail with all this and evidence to support my, and others, views on such matters is provided in the following enclosed (or previously sent) documents:

'Brief synopsis re: ME/ICD-CFS for Dr Ian Gibson MP' by Professor Malcolm Hooper and Margaret Williams...; 'Skewed: Psychiatric Hegemony and the Manufacture of Mental Illness...' by Martin J Walker...; 'Wessely's Wisdom? Some More Open Questions For Professor Wessely' By Margaret Williams; 'Profits Before Patients?' By Eileen Marshall and Margaret Williams; 'The Mental Health Movement: Persecution of Patients? The Consideration of the Role of Professor Simon Wessely... in the Perception of M.E. in the UK' by Professor Malcolm Hooper; 'Experiences of a Candidate in the MEA AGM Elections' by Ciaran Farrell; 'Concerns About The Forthcoming UK Chief Medical Officer's Report On Myalgic Encephalomyelitis (ME) And Chronic Fatigue Syndrome (CFS), Notably The Intention To Advise Clinicians That Only Limited Investigations Are Necessary' by Sally Montague & Professor Malcolm Hooper; 'Concepts Of Accountability?' by Professor Malcolm Hooper, Sally Montague et al; 'Vilified But Vindicated?' by Professor Malcolm Hooper, Eileen Marshall, Margaret Williams; 'All Party Parliamentary Group on M.E.' by Paul Davis and Marion Anderson of RiME.

An independent inquiry should be led by a judge or QC committed to, and capable of, a thorough and comprehensive cross-examination of all witnesses. Only then will truth and science triumph over the political lobbying of vested interests." [K Short, letter to Ian Gibson MP, 11th August 2005.]

"With regard to the proposed inquiry, I enclose another document for your consideration ['ME: Why No Accountability? - A Synopsis for the UK Parliamentary Inquiry' by Professor Malcolm Hooper & Margaret Williams]. If you would like further copies for your colleagues please do not hesitate to let me know." [K Short, letter to Ian Gibson MP, 31st August 2005.]

"Please would you read the enclosed document by Eileen Marshall and Margaret Williams entitled: Proof positive? Evidence of the Deliberate Creation Via Social Construction of 'Psychosocial' Illness by Cult Indoctrination of State Agencies and the Impact of this on Social and Welfare Policy.

The paper describes the disgraceful campaign by members of the 'Wessely-School' group of psychiatrists - in their own words - to influence UK state policy for reasons and by methods that have nothing to do with good science and best medical practice. The absence of dissenting professional voices - bar one - at this drug industry sponsored conference is a disgrace and decidedly does not reflect the state of opinion within the specialist or wider medical community. The comment of the one dissenting voice at an industry-backed conference, and response to it, is very telling indeed. Evidence that insurance companies are influencing officials at DWP, Health Department and HM Treasury and skewing policy is also a serious concern in any democracy.

Any inquiry that is to be remotely independent/competent simply must examine the role of corporate-sponsored bodies like Lord David Sainsbury's Linbury Trust, the Novartis Foundation and various insurance companies etc, etc. Vested interests need to be exposed and

the question has to be asked as to why such bodies exclusively back the psychosocial theories of the 'Wessely-School' and undermine biomedical research and the real international clinical expertise of the likes of Canada's Dr Byron Hyde and Dr Bruce Carruthers? "[K Short, Letter to Dr Ian Gibson MP, 9th September 2005.]

"I am enclosing a DVD copy of the talk given by a ME specialist, Dr Bruce Carruthers... The workings of this [Dr Carruthers'] panel were, thankfully, largely immune from the dreadful politics and vested interests surrounding M.E. and, as a result, are based upon science and infinitely superior to the disgraceful output of the British establishment. I would be grateful if you would look at Dr Carruthers' film, including the question and answer session, as I believe it to be critical to the current situation.

I have said all along, science needs to determine UK medical welfare policy towards the sick: not political vested interests of the DWP, Treasury and Insurance Companies. Unfortunately, in spite of a large, and growing, body of peer-reviewed evidence for this WHO-recognized neurological disease, such vested interests are relentlessly pursued by the disgraceful and unconscionable 'Wessely-School' group of psychiatrists. Typified by the now infamous science-ignoring statement of Professor Simon Wessely that: 'ME is simply a belief, the belief that one has an illness called ME.' The fact that Wessely's identical persecution of victims of Gulf War Syndrome has now been discredited ought to ring the very loud alarm bells concerning ME issues - there is more than just deja-vu going on here.

Government presides over the setting up of a national network of ME/CFS 'Clinics' that will mistreat patients on the basis of corporate-backed psychiatric conjecture in complete disregard of science: patients are to be given psychotherapy (Cognitive Behavioural Therapy) to persuade them that their illness is maintained by 'misguided beliefs' and then encouraged to exercise more - on pain of benefits withdrawal. All in spite of the case of undeniable peer-reviewed evidence that this will cause severe harm to true ME patients - including mitochondria damage, heart and other organ failure. This is quite simply an appalling national scandal and demands a fully independent/competent public inquiry covering not only the treatment issues, but examining how government interacts with perverse, blinkered and downright wicked corporate lobbies. The inquiry must be headed by Judge and not left in the wholly inadequate domain of the APPGME...

The sick are being made more ill, parents are accused of Munchausen's/families torn apart, and desperation-borne patient suicide is all too common.

I am very angry with all this I should not have to be laying on my bed speaking to computer dictation software as a part-time political lobbyist in my own self-defence. I am too ill for this. I can barely look after myself and I'm trying to be a good father to my son. Any assistance you can give to get at truth and justice is appreciated very very much indeed. "[K Short, letter to Dr Ian Gibson MP, 29th September 2005.]

"At our meeting on 28th July, attended by Professor Malcolm Hooper and others, you agreed to call for a Parliamentary Inquiry into Myalgic Encephalomyelitis. You have said it should be both 'definitive' and acceptably 'independent'. To quote your BBC Radio Norfolk statement on 4th August: 'we really do need to have a proper open inquiry, where independence with open minds look at the condition [sic].

To get, as you say, 'to the bottom of things' will require wide consultation that is not confined to any particular interest/sub group or locality. You also talk to Ms [name withheld here for privacy purposes] of 'powerful experts' - which seems to indicate a fundamental misunderstanding on your part; The problem in the UK is that all 'power' was taken away from the biomedical clinical & research experts and given to a single corporate-backed non-expert psychiatric lobby - that ignores research and has clear conflicts of interest. I am very grateful indeed for your time, and for any genuine efforts to seek justice and the scientific and medical

excellence that beleaguered ME sufferers should, in a democracy, have by right."[K Short, letter to Ian Gibson MP, 6th October 2005.]

"I have written to Michael Meacher MP to ask if he would sit on the inquiry as I feel his knowledge of environmental pesticide issues would be very useful in establishing the truth of matters.

Further to your message on my answerphone and request for names of those I would wish to see called as witnesses to the proposed inquiry, a preliminary list [includes]... Countess Margaret Mar (House of Lords); Martin J Walker (author of: 'Skewed...')..."[K Short, letter and e-mail to Dr Ian Gibson MP, 28th October 2005.]

[K Short, 2005.]



APPENDIX – 3**Prof. Malcolm Hooper's Document Presented to Ian Gibson MP on 4-Nov-2005.**
(Permission to Repost given by Professor Hooper):**Parliamentary Inquiry into ME/CFS; Outline Proposals****Preamble**

Following our recent telephone conversations it is clear that

- i.** Your proposed Independent Inquiry will need considerable time to consider all the evidence concerning ME/CFS and scrutinise it carefully.
- ii.** This is an ambitious undertaking. The Inquiry team will need to engage with a massive amount of both written and oral evidence.
- iii.** There is much division and even conflict between some official views of the illness and also among the ME/CFS community concerning major aspects of the illness and the history of developments over at least 20-25 years with individuals and groups adopting stances that vary from aggressive to despair about the truth never being told or admitted.
- iv.** The Inquiry team will need to be headed by a judge/QC and its members to be seen by all ME communities as truly independent. Already there has been concern expressed about possible membership of the Inquiry team. It is important that the full details of the membership be made public with any association members may have with parliamentary, regional ME/CFS groups, and clinical centres, especially those with adherence to an "establishment" view of the illness.
- v.** You have already judged the APPG to be an inadequate and failing Committee which ill serves the ME/CFS communities.
- vi.** Mr Des Turner who chairs the APPG and has been a member for over 8 years has already been the subject of concern and anxiety by some within the ME/CFS community because of his bias towards a psychiatric understanding of ME/CFS and the use of the term myalgic encephalopathy
- vii.** Your reasons for not inviting the Countess of Mar to join the Inquiry team – she represents a declared viewpoint- apply with equal force to Mr Des Turner who has a known declared viewpoint that runs contrary to that of many within the ME community.
- viii.** It is possible that his membership could prejudice the Inquiry from the start – something that should be avoided for such an important undertaking unless counterbalanced by someone of equal stature with an opposite view.

It is important that the Inquiry is aware of my role in the current concerns of the ME/CFS community. I have been involved with this illness through my work with the 1990-1 Gulf War Veterans many of whom have been diagnosed with CFS. Over the last 8 years I have been a member of the John Richardson ME Research Group that was founded by Dr John Richardson ably supported by Dr Irving Spurr who, following Dr Richardson's death in 2002 now leads this group. I have spoken to many groups locally and nationally and supported some individuals in a number of appeals and submissions for support and benefits and corresponded with some clinicians. I have tried to assess the scientific and medical evidence presented on all aspects of ME/CFS. I am, I believe trusted by many people with ME/CFS.

At the end of this short report I have listed people, in alphabetical order, who could make presentations to the Inquiry team of the important issues raised in this outline report. Many of them can contribute to more than one area of this report. The availability of Powerpoint facilities will facilitate speedy and efficient presentations.

I have kept the references to a minimum as these will be considerably expanded in written submissions and presentations.

Major Issues that need to be Addressed.

In my judgement and following consultation with members of the ME/CFS communities these are as follows.

- 1. Nomenclature, Case Definition(s), and Disease Classification-** ME (myalgic encephalomyelitis) is a multi-system, multi-organ illness presenting with multiple symptoms. Historically ME has been associated with a prior viral infection but progressively all clinical signs have been gradually removed from the case definition leaving only persistent fatigue lasting more than 6 months as the definitive symptom.
 - a. EV-ME (enterovirus Myalgic Encephalomyelitis) represents the classical form of the illness.
 - b. More recently the advent of the widespread use of pesticide has provoked symptoms akin to the classical viral illness. What is the connection between the common expression of these symptoms? Different subgroups of patients have been identified and distinguished but this is ignored in the UK- why is this?
 - c. The progressive removal of all clinical signs associated with the illness and the attempts to replace the term ME with CFS and even fatigue syndrome(s) which are classified as mental and behavioural disorders must be fully investigated by the Inquiry because it is here that there a lack of scientific credibility and where much anger and despair are felt by patients and those who support them.
 - d. The use of the alternative name, myalgic encephalopathy also abbreviated to ME, offers a meaningless term for classification and flies in the face of the inflammatory nature of myalgic encephalomyelitis. It is part of the confusion surrounding the understanding of ME.
 - e. The validity and basis of the psychiatric definitions of the illness also need to be thoroughly explored by the Inquiry team.
 - f. The role of the Chief Medical Officer's Report and the Medical Research Council in defining the illness and funding research and treatment centres also need close scrutiny.

Important documents cataloguing these issues from our standpoint include

Canadian Consensus Panel Criteria for M.E. *J Chron Fatigue* 2003;11:7-115. This is a major milestone for the ME/CFS community and needs to be studied carefully- a useful summary of their proposals is found in some of the documents listed below.

Marshall EP, Williams M, Hooper M. What is ME? What is CFS?- Information for Clinicians and Lawyers, 2001. Available as a download from <http://www.meactionuk.org.uk/>

Hooper M, Marshall PD, Williams M. Response to CMO's Working Group Report, 2002 available at <http://www.meactionuk.org.uk/>

Hooper M, Marshall PD, Williams M. Response to MRC Research Advisory Group, December 2002 available at <http://www.meactionuk.org.uk/>

Hooper M and members of the ME (Myalgic Encephalitis) "The Mental Health Movement –Persecution of Patients", a briefing document for the Countess of Mar for a debate in the House of Lords, 22nd Jan 2004. Downloads of documents and the debate at

http://www.satori-5.co.uk/word_articles/me_cfs/prof_hooper_3.html- documents

<http://listserv.nodak.edu/scripts/wa.exe?A2=ind0401d&L=co-cure&F=&S=&P=1313>
for the debate.

Hooper M. Engaging with ME: towards understanding, diagnosis and treatment, 2003/4, – provides a useful overview of these and other issues concerning ME/CFS.

RCEP, Royal Commission on Environmental Pollution. Crop Spraying and the Health of Residents and Bystanders, Chair Sir Tom Blundell, September 2005 recognises the validity of multiple symptoms, multi-system, and multi-organ syndromes including ME/CFS, Gulf War Syndrome, and multiple Chemical Sensitivity syndrome.

Some local ME/CFS groups have produced their own literature on these issues

2. Diagnosis and Treatment.

- a. Despite early studies that recognised the organic nature of the ME/CFS The increasing emphasis on psychiatric definitions of CFS and its use as a catch-all term has led to a confusing and all-inclusive diagnosis, ignoring the need for subtyping of the illness, and the insistence on wholly inappropriate treatments being prescribed and in some cases forced on patients as a prerequisite for benefits payments.
- b. The Canadian criteria provide an abundance of clinical tests and signs that can be used in the diagnosis of ME/CFS and cover every aspect of the illness- the organs and body systems involved.
- c. MRI and SPECT scans are strongly favoured by many practicing physicians and research workers. More specialised techniques that can be used to diagnose patients are also emerging.
- d. Diagnosis requires a very thorough patient history and the knowledge of reliable evidence from research studies and clinical practice.
- e. It is important that clinical investigations are directed and conducted using the information provided by the Canadian consensus – necessary procedures include MRI and SPECT and allied scans coupled with diagnostic endocrine, immune system and cardiovascular studies.
- f. Supportive interventions need to be soundly based on both clinical and research studies. Rapid diagnosis will provide effective therapy that is less effective after long delays in diagnosis. The current 6 months period of sustained fatigue precludes early treatment and disadvantages the patient, especially the young.
- g. To include ME/CFS among somatoform disorders is seen by some psychiatrists as an abuse of psychiatry.

Key literature includes

Canadian Consensus Panel Criteria for M.E. *J Chron Fatigue* 2003;11:7-115.

Chia JKS. The role of enterovirus in chronic fatigue syndrome. *J Clin Pathol* 2005;58:1126-1126.

Hyde B, Goldstein J, Levine P. The Clinical and Scientific Basis of Myalgic Encephalomyelitis/Chronic Fatigue Syndrome, Nightingale Research Foundation, Ottawa, 1992. This is a major source of information and should be read. Copies can be provided if needed.

Per Dalen Somatic medicine abuses psychiatry. Download at http://art-bin.com/art/dalen_en.html

Richardson J. Enteroviral and Toxin Mediated Myalgic Encephalomyelitis/Chronic Fatigue Syndrome and other Organ Pathologies. Haworth Medical Press, Binghamton NY, 2001.

Richardson J. Four Cases of Pesticide Poisoning Presenting as "ME", Treated with a Choline Ascorbic Acid Mixture. *J. Chronic Fatigue* 2000, 6, 11-21.

Kaushik N, Fear D, Richards SCM, McDermott CR, Nuwaysir EF, Kellam P, Harrison TJ, Wilkinson RJ, Tyrrell DAJ, Holgate ST, Kerr. Gene expression in peripheral blood mononuclear cells from patients with chronic fatigue syndrome. *J. Clin. Pathol.* 2005;58:826-832.

Richardson J, Myalgic Encephalomyelitis: Guidelines for Doctors. *J Chronic Fatigue* 2002;10:65-80.

Jason LA, Corradi K, Torres-Harding S, Taylor RR, King C. Chronic fatigue syndrome: the need for subtypes. *Neuropsychol Rev* 2005;15:29-58.

Peckerman A, Lamanca JJ, Dahl KA, Chemitiganti R, Qureishi B, Natelson BH. Abnormal impedance cardiography predicts symptom severity in chronic fatigue syndrome. *Am J Med Sci* 2003;326:55-60.

Benefits and Insurance Claims and Assessments.

These have been the source of great anxiety, anger and despair among many ME/CFS patients.

- h.** The influence of the psychiatric lobby on both medical and insurance assessments is extensive and serious with some patients being compelled to undergo psychiatric and psychological programmes of cognitive behavioural therapy (CBT) and graded exercise therapy (GET). Evidence is accumulating that CBT offers no significant improvement over the short or long term, whilst GET is positively harmful for some patients.
- i.** CBT and GET studies are particularly confused by patient selection that meets criteria that are extremely broad and unfocussed with regard to ME/CFS.
- j.** Dr WRC Weir has extensive experience in preparing reports for insurance and benefits cases and can speak with authority about the difficulties experienced by many ME/CFS sufferers in making clinically supported claims.

3. The Science of ME/CFS.

Very exciting research studies are now appearing that unambiguously demonstrate that ME/CFS is a complex organic illness with an increasingly identified pathology. An essential requirement for any research studies is an accurate diagnosis of both patient and control groups. This emphasises the importance of the above comments on disease classification, case definitions, and diagnosis.

- a.** MERGE – this group works in conjunction with the world renowned cardiovascular group at the University of Dundee (Ninewells Hospital). A major figure is Dr Vance Spence a medical researcher who suffers severely with ME. They have published papers on the CDC defined patients and distinctions between different groups of patients (Gulf War Syndrome (GWS), organophosphate (OP) poisoning, and ME/CFS) with a common symptomology, unique cholinergic responses in ME patients, oxidative stress in ME patients, and have initiated and funded research studies on genes and ME/CFS, muscle activity, pain and fatigue. Their summaries of research in this field are scientifically accurate- see above.
- b.** Gene research, in a well defined group of ME/CFS patients has found major upregulation of genes associated with the immune system, mitochondrial function, and neuropathy target esterase, NTE. This study shows that changes in immune responsiveness are a feature of ME/CFS- something indicated in the studies when the illness first emerged. Mitochondrial dysfunction provides a physiological basis for the debilitating and overwhelming fatigue suffered by ME/CFS patients whilst the changes in the NTE gene provide an intriguing link with OP poisoning and nerve agent exposure found in GWS.
- c.** Dr Abhijit Chaudhri formerly at Glasgow and now at Oldchurch hospital has investigated CFS/ME using functional magnetic resonance and found changes in choline levels in the brain. A study confirmed by Professor Puri.

d. Professor Basant Puri at Imperial Medical School has also investigated other magnetic resonance changes in the brain. Other investigators have found changes in the volume of gray matter in varying regions of the brain.

There are major research groups in Europe, Canada and the USA also investigating ME/CFS who have made significant contributions through publications and conference presentations covering the areas of immunology, muscle and central fatigue, endocrinology, cardiology, and neurology.

Major literature sources include

Puri BK, Counsell SJ, Zaman R, Main J, Collins AG, Hajnal JV, Davey NJ. Relative increase in choline in the occipital cortex in chronic fatigue syndrome. *Acta Psychiatr Scand.* 2002;106:224-6.

Puri BK; (2004) "[The use of eicosapentaenoic acid in the treatment of chronic fatigue syndrome.](#)" *Prostaglandins Leukot Essent Fatty Acids* volume 70 issue 4 pp. 399-401 (issn: 0952-3278).

Puri BK; Holmes J; Hamilton G; (2004) "[Eicosapentaenoic acid-rich essential fatty acid supplementation in chronic fatigue syndrome associated with symptom remission and structural brain changes.](#)" *Int J Clin Pract* volume 58 issue 3 pp. 297-9 (issn: 1368-5031)

Cox IJ; Puri BK; (01/04/2004) "[In vivo MR spectroscopy in diagnosis and research of neuropsychiatric disorders.](#)" *Prostaglandins Leukot Essent Fatty Acids* volume 70 issue 4 pp. 357-60 (issn: 0952-3278)

Chaudhri A and Behan PO. In vivo magnetic resonance spectroscopy in chronic fatigue syndrome. *Prostaglandins Leukot Essent Fatty Acids* 2004;71:181-3

Hyde B, Goldstein J, Levine P. *The Clinical and Scientific Basis of Myalgic Encephalomyelitis/Chronic Fatigue Syndrome*, Nightingale Research Foundation, Ottawa, 1992. This is a major source of information and should be read. Copies can be provided if needed.

Jason LA, Corradi K, Torres-Harding S, Taylor RR, King C. Chronic fatigue syndrome: the need for subtypes. *Neuropsychol Rev* 2005;15:29-58.

Kaushik N, Fear D, Richards SCM, McDermott CR, Nuwaysir EF, Kellam P, Harrison TJ, Wilkinson RJ, Tyrrell DAJ, Holgate ST, Kerr. Gene expression in peripheral blood mononuclear cells from patients with chronic fatigue syndrome. *J. Clin. Pathol.* 2005;58:826-832

Richardson J, Myalgic Encephalomyelitis: Guidelines for Doctors. *J Chronic Fatigue* 2002;10:65-80.

Richardson J. Enteroviral and Toxin Mediated Myalgic Encephalomyelitis/Chronic Fatigue Syndrome and other Organ Pathologies. Haworth Medical Press, Binghampton NY, 2001.

Richardson J. Four Cases of Pesticide Poisoning Presenting as "ME", Treated with a Choline Ascorbic Acid Mixture. *J. Chronic Fatigue* 2000, 6, 11-21.

"Breakthrough" produced by the Charity MERGE (Myalgic Encephalomyelitis Research Group for Education and support) provides useful summaries of research studies for people with ME/CFS and doctors and carers who support them. Available at www.merereasearch.org.uk

4. Research Funding.

a. The evidence shows that very considerable sums have been allocated to support research studies aimed at validating the psychiatric approach to and understanding of ME/CFS, in line with national policy. Excellent research programmes seeking to investigate the organic basis of the illness have been refused funding and research has only been able to proceed through funding raised by the efforts of patients and their helpers and supporters.

- b. The policy and assessment of research proposals by the MRC need to be examined and questioned.
- c. The role of the MRC RAG and NICE in establishing the current research agenda also needs to be examined.

5. Patient Groups Testimony, Experience, and Need.

It is important that the voices of patients are fully heard- a failure of the CMOs working group. To that end I would suggest that

- a. The 25% Group lead by Simon Lawrence and Greg Crowhurst. This group encompasses the 25% of people with ME/CFS who are very seriously ill and are either housebound or bed bound. Whilst the incidence of ME/CFS is hard to gauge it is estimated that 1 in 250 have ME/CFS with between 1 in 1250 falling in the 25% Group.
- b. Young people with ME/CFS are of particular concern and Dr Nigel Speight with Jane Colby of TYMES trust are the best people to tell their stories and the demands faced by families with sick children.
- c. Two representative patient groups with, where possible, their accompanying physician be invited to meet with the Inquiry Team and present their evidence and stories,
Mrs Pauline Donaldson and Professor TJ Daymond Sunderland and South Tyneside ME Support Group.
Mr Geoff Bock-Brown East Anglia ME Support Group that covers Norfolk, Cambridge and Suffolk.
Many other groups will wish to contribute and it is important that these two groups are seen as representative of many and not just speaking for themselves
- d. Two patients from Dr Weir's clinic.
- e. RiME- Research into ME has a fine collection of case histories that the Inquiry team need to read or heard.
- f. CFS Research Foundation has provided research funding for an important genetic study- their testimony in writing or orally is important.
- g. MEActionuk run by Stephen Ralph provides an invaluable archive of major documents and papers- see www.meactionuk.org.uk

The inquiry should be advertised widely with invitations to all groups involved with ME/CFS to participate and present their evidence.

6. Proposed list of people to make oral and written presentations to the Inquiry.

Dr Abhijit Chaudhri* a neurologist with a longstanding special interest in ME/CFS, formerly at

Glasgow, now at Oldchurch Hospital, Romford, has published several papers and lectured extensively on ME/CFS

Jane Colby* – TYMES Trust for young people with ME/CFS.

Gregory Crowhurst Secretary and carer, 25% Group works closely with Simon Lawrence

Prof Malcolm Hooper a trustee of John Richardson Research Group - scientist and writer and author of numerous articles on ME/CFS and related multisymptom/multi-system/multi-organ disorders.

Professor Basant Puri* Imperial College School of Medicine – a psychiatrist with special interest in brain function and illness

Dr Nigel Speight*. A paediatrician with a longstanding interest in the treatment and care of children and young people with ME/CFS. Much used in legal cases involving children and parents as carers.

