www.angliameaction.org.uk/docs/professor-hooper-on-gibson-inquiry.pdf

A response and Appreciation of the Gibson Inquiry Report – Malcolm Hooper

[EXTRACTS]

5th December 2006

In making its recommendations the Report serves the needs of the poor, sick, disadvantaged and marginalised. It has also exposed so much that can only be viewed as calculated deception or gross incompetence within the medical, scientific, commercial, and political establishments. There is much that needs urgent follow-up.

The Report sets out an extensive and important Parliamentary Agenda which I hope the Enquiry team will pursue vigorously in both Houses of Parliament and beyond.

In particular,

1. The call for substantial funding (not less than £11million) for essential research programmes that will provide the biological basis for a better understanding of the ME-CFS, its causes, diagnosis and treatment.

The MRC comments, in this regard, are disingenuous and in my view insulting. The quality of the research from recognised MRC Research Professors such as Professor Jill Belch with Dr Vance Spence, and Dr Jonathan Kerr with Professor Stephen Holgate is of the highest order. I am also aware of other submissions that have not been recommended despite achieving a high score from committees charged with considering them.

The MRC has failed to show any scientific curiosity or serious clinical concern for the devastating, multi-system, multi-organ illness, called ME. This illness is causing great distress and presents many challenges to contemporary medicine and medical science, particularly, in relation to chronic illnesses that have emerged in the twentieth and twenty-first centuries. Well focussed and high quality research is urgently needed. It is a mark of the failure of the MRC that hard won research funding has had to come from the ME community itself, as a result of much sacrificial giving and the recognition of the essential need for research into the ME. The results from this research are very encouraging and have already exposed the limitations of official views about diagnosis, nomenclature, and classification.

The inflammatory aspects of ME have been confirmed and better delineated and are consistent with genetic studies showing activation of well-known inflammatory processes. The MRC needs to follow up these published peer-reviewed studies with more extensive ones.

2. There must be a well advertised call for substantial research projects into the biological causes and consequences of ME-CFS and ways of treating the illness.

3. The NICE guidelines are rightly heavily criticised and exposed as the formulation of limited understanding, concern and enquiry. They confine patients and clinicians who seek to help them to the very limited and rigid psychiatric regimes of CBT and GET. These must be changed.

A recent paper by Miller, *J Am Physicians and Surgeons* 2006;11:111-115, raises important questions about the independence and reliability of Cochrane reviews which NICE uses to develop its guidelines. The bias in NICE is at the heart of our criticisms of NICE.

4. The failure of the MRC and NICE to honour the call and challenge of the CMO's report to investigate the causes and biological aspects of ME is symptomatic of failures and the vested interests at the top of our management of scientific and medical and social systems for ME is recognised by the Enquiry.

5. There must be a major revision of medical training, teaching and advice to reflect the insights into ME-CFS recognised by the Enquiry. This in effect means recognition of the role enteroviruses play in ME. The Oxford Textbook of Medicine, 1987 edition, describes the neurological and cardiac damage caused by viruses as does Richardson, 2001, who also identifies their role in ME an understanding confirmed in the recent review by Chia, 2005.

6. The Enquiry identifies the lamentable failure of the benefits and insurance industries. There is urgent necessity for a complete overhaul of the benefits system and, possible legal actions.

The vested interests of the Insurance companies and their advisers must be totally removed from all aspects of benefit assessments. There must be a proper recognition that these subverted processes have worked greatly to the disadvantage of people suffering from a major organic illness that requires essential support of which the easiest to provide is financial. The poverty and isolation to which many people have been reduced by ME is a scandal and obscenity.

7. The recognition that young people and children area affected by ME needs much stronger emphasis particularly in regard to enforced absences from school. There is a need for this illness to be registered as a notifiable illness because of the massive dislocation ME causes to young peoples' education.

8. The very strong emphasis on the Canadian Criteria is welcome as these provide extensive clinical guidelines for use in clinics and by General Practitioners and Consultants. The significant and authoritative clinical experience and advice from both Drs Carruthers and Hyde have been acknowledged and commended – a big step forward.

9. The Canadian Guidelines and Criteria also address the vexed question of differential diagnosis that is key to treatment, care, and benefits.

A note of caution concerns the general comments about the work in the USA. Some of this is high quality and ground breaking but there is also a powerful lobby that supports the

biopsychosocial/somatisation views so wholeheartedly and misguidedly embraced by the UK medical fraternity and insurance industries. Drs Strauss and Reeves in the States endorse this approach and advocate both CBT and GET. The CDC toolkit cannot be recommended whilst the CDC (Fukuda) research criteria for ME/CFS are now known to be flawed, Kennedy, Spence et al 2004, Jason et al, 2005, and need to be replaced by more specific and focussed criteria such as the Canadian ones.

10. An important concept described in the Canadian Guideline is that of triggers and aggravators. It is apparent from the work of Kaushik et al, 2005, that the dysfunctional genetic damage also includes enhanced susceptibility towards organophosphate pesticides. It is well known among ME sufferers and their carers that exposure to various chemicals including anaesthetics, and further vaccinations can aggravate and/or initiate a profound deterioration in the illness. This needs much closer investigation.

11. The Report rightly stresses the neurological basis of ME in the WHO's classification of the illness and underlines the failure by medical authorities at the highest level in the UK to act unequivocally in accordance with this information. The USA offered an alternative reclassification of CFS that removed it from chapter G.93.3 but placed in a new chapter. This is at present only provisional and remains to be agreed or rejected by the WHO. On balance the present classification is preferred although I would advocate the complete removal of CFS (chronic fatigue syndrome) from any WHO classification category leaving fatigue 9or chronic fatigue) as a symptom of ME and many other illnesses eg. thyroid deficiency, cancer, COPD, primary biliary cirrhosis, etc.

12. The treatment of ME is complex and varied but some treatments using vitamins, supplements, and dietary changes have been found helpful. It is important that prescription of these materials is allowed under the NHS where clinical judgement recognises their importance. These include some essential fatty acids, especially fish oils, vitamin B12, folates, and compounds that support mitochondrial function, Myhill and McLaren-Howard, 2005 and gluten/dairy free dietary materials.

13. The comments concerning Professor Wessely's refusal to give evidence to the Inquiry on account of 'harassment' are unconvincing and trivial when viewed in the light of the amount of harrassment and loss imposed by officialdom as a result of the 'Wessely School' of psychiatrists whose vigorous and persistent promulgation of CBT and GET, not to mention involvements with the false prosecution of cases of Munchausen Syndrome by Proxy which have resulted in so much distress for patients and carers.

Overall

The Report of the Inquiry should be warmly welcomed as it offers a number of new beginnings that if initiated and pursued offer ME suffers and their carers real hope and effective help with the understanding, diagnosis, treatment, and the care their illness demands.

Parliamentarians, scientists, clinicians and benefits agencies please take note and efficiently and purposefully make the changes demanded by this report.

Only a full Government Inquiry can address all these issues satisfactorily and this must be established as advocated by the Gibson Enquiry.

Dr Gibson and his Inquiry team are to be congratulated on their report and the splendid work of his voluntary Parliamentary research staff deserves a warm vote of thanks for their efforts that brought this demanding Inquiry to such a satisfactory conclusion. Well done everyone.

5th December 2006

FULL PROFESSOR HOOPER RESPONSE TEXT AVAILABLE HERE:

http://www.meactionuk.org.uk/Hooper_response_to_Gibson_Report.htm

---

The Gibson Enquiry

Read a detailed summary of the report here

View the full report here **or download the .pdf file** here

View the Press Release here **and**

A few facts about the Report here

Professor Malcolm Hooper's Response here

---

www.angliameaction.org.uk/docs/professor-hooper-on-gibson-inquiry.pdf