

## **Dr Ian Gibson's Parliamentary Inquiry into ME/CFS:**

### **Response by Prof Malcolm Hooper to Press Release and Terms of Reference.**

#### **Preamble.**

I spoke today, Friday December 2<sup>nd</sup>, for the first time to Ian Woodcroft who is providing secretarial support for the Inquiry. I was impressed by Ian's commitment and industry but concerned that he is already facing a mammoth task that threatens to overwhelm him. As I indicated in my Outline Proposals, 2nd Nov 2005, the Inquiry will be faced with huge amounts of correspondence and electronic evidence from large numbers of people. The job is too large for one individual so I would counsel more support for Ian who I realise is taking on this work in addition to his normal duties for Tony Wright.

#### **Terms of Reference**

I spoke to Ian to obtain clarification of the TORs which are the subject of considerable concern among ME sufferers, carers and supporters. My understanding was that the suggested TORs had not yet finalised.

It was, therefore, a big surprise to receive an e-mail of the Press Release which includes the TORs. These are not in agreement with our first discussions and have set limits on the Inquiry that greatly distress and alarm the ME community. There is no mention some of fundamental issues we discussed and no mention of the need for the voice of patients and carers to be an integral and essential part of the Inquiry's investigations.

May I suggest the following which I believe meets the requirements of a transparent, comprehensive, and open Inquiry such as you envisaged when we first met.

- To examine and clarify issues around disease classification and terminology which are essential for diagnosis, treatment, research studies and benefit and insurance claims.
- To increase public understanding and awareness of ME/CFS.
- To evaluate research evidence concerning the nature of ME/CFS especially in the light of the strongly contrasting views of the illness

1. The biological basis of the illness.
2. The psychiatric/psychological understanding of the illness
  - Examine key questions of diagnosis, treatment- including treatment centres, patients' needs and care, support for patients and carers.
  - Evaluate research funding and provision in the light of the previous and current research studies and deeper understanding of the illness

I am aware that the proposed TORs circulating on the Internet make reference to "research progress since the CMO's Working Group in 2002". This is far too prescriptive since the CMO's WG and the MRC which lies behind it are both part of the many problems currently experienced by the ME community. Both the CMO's WG and the MRC have ignored reams of evidence that was submitted to them previously and their reports and advice represent a huge degree of ignorance about the illness that some see as deliberate and partisan. To use such a cut-off point has already provoked outrage and charge of a sell out to the establishment which I would want to avoid.

A crucial point concerning terminology is the use of myalgic encephalopathy (ME) as an alternative to myalgic encephalomyelitis (ME) that is already muddying the debate as I explained in my e-mail of Nov 23<sup>rd</sup> concerning the EDM. [Unfortunately, due to the clock on my laptop needing to be reset this e-mail was dated September 2005.]

May I suggest that to avoid any confusion or accusations of complicity and duplicity with regard to the correspondence of the Inquiry that **ONLY** the following terms are used in full.

ME (Myalgic encephalomyelitis), CFS (Chronic Fatigue Syndrome), PVFS (Post Viral Fatigue Syndrome). These terms are the only ones found in the WHO ICD-10 classification of the illness and the only ones with valid scientific and legal definition and meaning. The Press Release does not include ME in full as myalgic encephalomyelitis, as I had recommended, for clarity and the avoidance of doubt, to Ian Woodcroft in our telephone conversation.

### **Members of the Inquiry Team.**

This is another fundamental issue. In my judgement it is imperative that the names, affiliations, possible vested interests and allegiances of ALL the members of the Inquiry are known as soon as possible. This will make the work of the Inquiry transparent and provide vital information to the wider ME community.

### **Evidence from International Authorities who are working on Myalgic Encephalomyelitis.**

It is important that the Inquiry hears the views of internationally respected researchers who have worked for many years in this field. To that end we would advocate a video link that would allow at least the following to present evidence to the Inquiry.

From the USA

Professor A Komaroff, University of Harvard, USA.

Dr Nancy Klimas, University of Miami, USA.

Professor L Jason, De Paul University , Chicago, USA.

Dr K De Meirleir, Vrije University, Brussels, Belgium.

For this to be planned effectively the date(s) of the Inquiry need to be set as soon as possible and technical assistance will be needed.

In the interests of the transparency we have both espoused and following the publication of the press release I am arranging for this reply to be posted on various ME web sites.

Malcolm Hooper

3<sup>rd</sup> Dec 2005

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