

## **Initial Thoughts – Gibson Inquiry From Dexhaven 27 November 2006**

Thanks to One Click, you have obviously continued to work tirelessly in the last weeks, and it is very much appreciated. I just had a quick read through the report, and thought I'd send you my first impressions. I have just typed some stuff, as I wanted to put down my first impressions.

1. The report obviously calls for another 'independent scientific inquiry'. "The Group calls for a further Inquiry into the Scientific Evidence for CFS/ME by the appropriately qualified professionals."

OK. Firstly, they have heard from most of the main scientific people involved in the field. There are presentations on their own website to prove it. They have already, by their own admission, heard from the most qualified people.

Secondly, I thought that the chair of the group was a 'scientist', so why the further need for discussion? If I can understand the basics of what the science says then why the need for another inquiry? They are called 'Group on Scientific Research into Myalgic Encephalomyelitis (M.E.)', and so THEY ARE the inquiry that they are calling for. The very things this group are saying should be determined in another inquiry are the very things they should have achieved in this inquiry.

Thirdly, from all the evidence presented it is entirely possible to make a judgement call. It does say in the report that biomedical research has been ignored, and that the current psychosocial model is useless. So why do we need another inquiry to tell us the same thing again? I get the distinct impression that the last year has been a huge waste of time if this group cannot (or does not want to) make any firm conclusions. I would also note that this 'inquiry' demonstrates the ineffectiveness of government, and the huge waste of time and money involved engaging with any political body.

2. The report confirms that there are clear links to other conditions. "the rest having a variety of other already recognised illnesses." "Their exclusions are useful as they begin to extrapolate an idea of CFS/ME separate from other related or similar illnesses."

The contents of the report are very 'light', considering all the evidence presented, and the conclusions are also lacking in substance. I think it is entirely possible that the enquiry should make the conclusion that it is necessary to ensure that patients are not suffering from other conditions, before being diagnosed with CFS/ME.

I would go further, and say the report does not want to admit that there has been a negligent attitude towards people who exhibit certain symptoms. Unfortunately the report doesn't make clear enough that the majority of symptoms linked with ME are also present in many other conditions, and therefore people demonstrating these symptoms are not being investigated for equally serious conditions  
i.e.

Addison's disease

Anaemia  
Anxiety Disorders  
Chronic Hepatitis  
Coeliac disease  
Diabetes Mellitus  
Diastolic Filling Dysfunction  
Lyme disease  
Major Depression  
Malignancy  
Multiple Sclerosis  
Myasthenia Gravis  
Parkinson's disease (Including early onset/young onset)  
Polymyalgia Rheumatica  
Rare myopathies  
Sarcoidosis  
Sjögren's syndrome  
Sleep Apnoea Syndrome  
Somatoform disorders  
Systemic Lupus Erythematosus

**3.** The report seems to make several conclusions about the nature and diagnosis of CFS/ME, without actually making any recommendations.

The idea of using the 'Canadian Criteria' for diagnosis is a good one, however the report fails to make the recommendation that it should absolutely be used.

The report makes clear that the current psychosocial model isn't appropriate, however fails to suggest another in clear terms.

The report seems to give the message that nothing can be done until we know more about the condition, however doesn't make any suggestions for the present, except for more research. I agree that there is a need for more research, however I disagree that nothing can be achieved at present. Using the 'Canadian Criteria' would be a start, and also excluding all other possible conditions would be prudent for patients.

The report in general terms fails to help any person at present, and further, seems to ignore the fact that there are people in need of action now. There have been many CFS/ME diagnosed patients, that have later been diagnosed and treated with other conditions. This shows the need for suitable protocol to be put in place now, so that patients facing the symptoms (akin to, or identical to M.E.) are given the best chance of recovery.

"However, while those with Lyme Borreliosis exhibit many similar symptoms to CFS/ME the Group believes they are two separate afflictions." This is an obvious statement, and doesn't even need to be written. However it is also clear that when suspecting one, you should suspect the other. Again the group fails to make any recommendations for protocol.

The report in general fails to present anything, except a summary of the information already widely known. When looking at an inquiry report such as this, it is only possible to conclude that they are intent on summarising the information given to them, and definitely not interested in actually conducting a proper inquiry with actual conclusions or recommendations.

**4.** Overall the inquiry seems to want more research into specific areas, whilst at

the same time calling for another inquiry into these areas by "appropriately qualified professionals."

This seems to invalidate not only the inquiry participants, but also the members of the group, by stating that they are not "appropriately qualified professionals".

How can it be possible then for this under qualified group to make specific decisions about where the research should be targeted, and in the same document state that they aren't qualified to make that kind of decision. Let us be frank, the inquiry was given all the evidence they need to reach a conclusion. The inquiry should be justified in calling for research into specific areas. The inquiry could only reach that conclusion, given the research presented them. Why then, after some truly excellent presentations, has the inquiry failed to recognise the key areas of research needed.

Why does the inquiry not recommend any of the research projects, previously submitted to the MRC by members of the presentation group, or even highlight the fact that all of the current promising research has been funded through charitable donation.

5. It's all there, yet nothing has been given the detail it deserves.

Whilst the group must be commended on their wide-ranging choice of presenters, and participants in this inquiry, it is also clear that the 'group' have been unable to review and perhaps understand the information given to them. The report presented is clearly of a 'primary school' level, and fails to present the level and quality of information they have received. The whole report is lacking in detail, lacking in conclusions, and lacking in direction.

If this 'group' hasn't realised that they 'must do better' (as I'm sure any teacher would comment), they hopefully soon will. I don't think I am being too harsh when saying this, as 12 months of inquiry has resulted in this poor outcome. I think an important indicator of just how useless this report (and I suspect this inquiry) will be, is the following entry: -

### **"3.0 The Science – Symptoms and Potential Causes - Dr Vance Spence**

Dr Spence presented on a number of biomedical areas that had shown a need for further investigation. These included blood flow to the brain, orthostatic intolerance and oxidation."

Having seen Dr Spence's' presentation notes, and transcript, I think a little more detail would be called for. Especially as this report condenses a lot of very important work into two sentences, which are extremely vague. This would be like speaking of Einstein as "Some guy who invented a formula or two, mostly about relative things."

It seems that the inquiry was given all the information needed to make some comprehensive decisions and conclusions, and they have instead decided to produce a very bad 'book report'.

### **SUMMARY & CONCLUSIONS**

There are many flaws in the report, and probably the inquiry, however I think I can sum it up with this analogy from a child's school report card: -

\*Inquiry spends a lot of time staring out of the window, and is disinterested in

this subject. Inquiry's work is not at a good enough standard for an year eight pupil. The inquiry's latest efforts have been marked as a fail, as it is clear that despite efforts being made to teach inquiry, and supply inquiry with the best information, inquiry demonstrates little aptitude/willingness for academic work. I hope to see a greater improvement in the next term.\*

I think the report, and the conclusions of this inquiry, show that there is little hope of the current situation being taken seriously. This report further demonstrates the attitude of government process towards people with M.E. - they just don't care. There are many possible reasons why this inquiry has failed, and I'm sure many conspiracy theories abound. However, whatever the reasons for this failure, and whatever the motivations of the group to fail in their tasks, one fact still remains:

People with certain medical symptoms are neglected by the government, and the NHS. This is human rights issue, and it will be acknowledged. Despite the efforts of the M.E. Community to provide the inquiry with information they can act upon, they have joined the ranks of the people who are determined to ensure the ongoing suffering for those labelled with CFS/ME.

**- ends -**