

Gibson Report Press release 26th November 2006

“The Parliamentary Group on Scientific Research into Myalgic Encephalomyelitis (ME) today releases its Inquiry Report “Inquiry into the status of CFS/ME and research into causes and treatment”. The report also known as the Gibson Inquiry has been ongoing for almost a year.

The Group is an offshoot of the All Party Parliamentary Group on ME and the members are as follows

Dr Ian Gibson MP (Chair)

Dr Richard Taylor MP (Vice-Chair)

Ms Ann Cryer MP (Secretary)

Rt Hon Michael Meacher MP

Dr Des Turner MP

Mr David Taylor MP

Lord Turnberg

The Countess of Mar

Baroness Cumberlege

Over the past year, the Inquiry has received written submission of evidence from medical experts, scientists, patients and patient groups across the UK and internationally. The Inquiry also held 5 oral hearings details of which are on the website www.erythos.com/gibsonenquiry.

The Group undertook this Inquiry after meeting with patient groups in 2005. CFS/ME is arguably one of the most contentious illnesses in medicine today. Even the name is a point of contention. Patient Groups refer to themselves as the ‘ME Community’ and consider CFS to be a term invented by psychiatrists who do not believe their condition exists. Meanwhile the situation in the UK is that due to a lack of research there are only symptomatic treatments available and indeed these have proved useful in some controlled trials.

It is treated with Cognitive Behavioural Therapy (CBT), Pacing, where the patient paces their energy and Graded Exercise Therapy (GET). These treatments are useful to people with a number of long term debilitating illnesses but are usually prescribed as well as medical treatment not instead of.

The Gibson Inquiry argues that we must invest massively in research into biomedical models of this illness. It is still unclear whether CFS/ME is one illness with a spectrum of severity or whether it is two separate illnesses. The most severely affected are least affected by the existing symptomatic treatments. And indeed many of the most severely affected find GET massively worsens their condition. Researching the possibility of sub groups is essential so sufferers can get the best treatment.

One problem with investigating CFS/ME is that the ‘Oxford Criteria’, the guideline for selecting patients for research trials, is very vague and focuses on fatigue rather than the numerous other symptoms of CFS/ME. As such, the knowledge we do have of the illness may have been gleaned from people who did not genuinely have the condition.

NICE has just finished consulting on their draft guidelines for treating CFS/ME. These guidelines have been widely criticised by patient groups and by the APPG on ME. Chair Des Turner described them in a meeting last week as ‘not fit for man nor beast’ Dr Ian Gibson MP of the Inquiry described them as ‘useless’.

ME patient groups have questioned the independence of reviewers in previous Inquiries and believe that the psychosocial school has received an unfair historical advantage in term of funding for research.

The Inquiry calls on the government to rectify this historical bias toward a psychological model and commission a genuinely independent panel of medical experts consisting of virologists, immunologists, geneticists, biochemists etc who can assess the international and UK evidence objectively.

The inquiry also calls on the MRC to encourage research projects into a biomedical model.

The government invested £8.5 million in treatment centres around the UK, these centres should also be used as a for research programmes. The UK is supposed to be currently focusing efforts on science technology and innovation. However the UK is falling behind the rest of the world when it comes to CFS/ME and it is the patients in the UK who are paying the price.

There is also a benefits issue. While the illness remains undefined and perceived by many as psychological, patients find it almost impossible to receive higher rate DLA despite in many cases being severely incapacitated, house bound and in need of 24 hour care.

Dr Ian Gibson MP Chair of the Inquiry says

“At last there is an Inquiry which identifies the seriousness of CFS/ME. For too long the patient voice has been left out of the debate. I hope that our Inquiry will highlight the difficult issues surrounding this illness and the urgent need further research. There is a wealth of published and evidence based research on this subject, some in the UK but mostly internationally. Canada and the US are leaving us way behind on this issue. We are a Group on ME and even in our group there has been conflicting opinions on the evidence. One thing is sure, we have a fantastic opportunity here with our Inquiry and the new NICE guideline to really begin to recognise this illness for what it is to look for causes and new treatments and to really build consensus amongst doctors and patient groups”