

9<sup>th</sup> December 2010

Dear Mr Willetts

On the advice of Gillian Ross in your Enquiry Unit, as research assistant to Professor Malcolm Hooper I am writing to inform you that he has received no response to his complaint about the MRC PACE Trial as you assured him would be the case in your letter dated 8th November 2010 (reference: 2010/0085082PODW).

Briefly, the history of this significant complaint is as follows:

1. Because no response to an initial complaint to the MRC itself about the PACE Trial was received, on 11th February 2010, Professor Hooper lodged a formal complaint with the then Minister for Science and Innovation responsible for the MRC, the Rt Hon Lord Drayson.
2. Lord Drayson replied by letter dated 8th March 2010 (reference: 2010/13270POLD) advising that the complaint should be addressed to Dr Morven Roberts, the MRC's Clinical Trials Manager.
3. Professor Hooper's complaint was therefore lodged with the MRC on 30th March 2010 and was addressed personally to Dr Morven Roberts. A print-out of the signature for its receipt at the MRC was obtained.
4. By 18th June Professor Hooper had received no acknowledgement or response, which many people saw as discourteous behaviour on the part of Dr Morven Roberts, so the MRC was contacted by telephone and the enquirer (myself on behalf of Professor Hooper) asked to speak to Dr Morven Roberts. I was variously told that Dr Morven Roberts was not Clinical Trials Manager; that there was no-one of that name at the MRC; that I would not be given the name of the person who was Clinical Trials Manager; that Dr Roberts was Clinical Trials Manager, and that Dr Roberts was in a meeting, whereupon the person at the MRC to whom I was speaking informed me that she was going to put the phone down with no further discussion, which she did. The episode was a quite extraordinary response to a simple request to speak to the Head of a department of a publicly-funded body about a legitimate complaint to which no acknowledgement had been received for almost 12 weeks.

5. That same day, 18th June 2010, Dr Morven Roberts sent an email to Professor Hooper (which was incorrectly addressed to "Professor Cooper") saying: "I understand you have recently tried to contact me in regard to your complaint lodged with me as Clinical Trials Manager about the PACE trial. I can let you know the MRC are working through the large document you have sent and will respond in due course".

6. Nothing further was heard from Dr Morven Roberts, so on 7th October 2010 Professor Hooper wrote to the current Secretary of State responsible for the MRC, the Rt Hon Dr Vince Cable MP.

7. Dr Cable did not acknowledge or respond to that letter, but on 8th November 2010 you did reply, courteously apologising for the delay in doing so and promising a thorough response by the MRC. In your letter, you said "You have taken the correct course of action in raising your concerns with the MRC....I have been assured that you will receive a response from the MRC within the next month".

8. That deadline has now passed and no response has been received from the MRC.

It is now ten months since this major complaint was first raised and, given the seriousness of the issues set out in his complaint, Professor Hooper is sure you will agree that such a delay is wholly unacceptable.

The ramifications of his complaint are legion and if, as expected, the PACE Trial results are interpreted as being supportive of behavioural interventions including exercise strategies for the alleged target group (people with ME/CFS), they may have the potential to cause irreversible iatrogenic harm on seriously sick and vulnerable people in the UK, estimated in 2002 by the Chief Medical Officer's Working Group Report to number 240,000 (which far exceeds the 83,000 people estimated to suffer from the similar neurological disorder multiple sclerosis).

The Chief Principal Investigator of the PACE Trial himself, psychiatrist Professor Peter White, is on record as stating as long ago as 1992: "Do not exercise if clinically active infection is present" (Invicta LiNC-UP, Belfast Castle, 15th April 1992).

The evidence continues to mount that ME/CFS is a chronic inflammatory neuroimmune disorder, including the recent evidence of an association of a retrovirus (XMRV / MLV) with ME/CFS, this family of retroviruses being only the third known to man, the other two being HIV (which causes AIDS) and HTLV (which causes leukaemia and lymphoma).

Professor Hooper asks that you hold the MRC to account over this very important issue as quickly as possible.

Yours sincerely

Margaret Williams