

13th January 2013

Latest Independent on Sunday correspondence

On Sunday 25th November the UK newspaper, the Independent on Sunday, published an article,

"ME: bitterest row yet in a long saga" (1) which led to the publication of a letter signed by 27 signatories, which was published on the 2nd December (2).

Today, in response to this, the following letter has been published in the Independent on Sunday, in both the hard copy and on-line:

<http://www.independent.co.uk/voices/letters/ios-letters-emails--online-postings-13-january-2013-8449260.html>

Scientific understanding always depends upon sound evidence. According to Sir Paul Nurse FRS: "The John Maddox Prize is an exciting new initiative to recognise bold scientists who battle to ensure that sense, reason and evidence base play a role in the most contentious debates." For scientific understanding to prevail, the extensive biomedical evidence base of ME/CFS [myalgic encephalomyelitis/chronic fatigue syndrome] must now be recognised by all researchers in the field.

The idea that ME/CFS is due to a dysfunctional psyche is a hypothesis without an evidence base. The Maddox Prize was thereby awarded to the defender of a hypothesis with no evidence base rather than to someone who was upholding true scientific inquiry. Personal attacks against Professor Sir Simon Wessely do not advance the cause, but it is scientifically legitimate to direct criticism at the hypothesis both he and Professor White continue to espouse.

*The Countess of Mar
Professor Malcolm Hooper
Dr William Weir
House of Lords, London SW1*

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A longer version, too long for the printed edition, is expected to appear on the IoS website:

Sir,

Professor Peter White, on behalf of himself and his 26 co-signatories, has apologized to the three of us following the publication of their letter on 2 December 2012. He made it clear that he did not intend to imply that we were harassing Professor (now Sir) Simon Wessely. We were not harassing

him. None of us believes that harassment is a means of advancing scientific debate, and certainly not in promoting a greater understanding of the causes of ME/CFS.

In the IoS article of 25 November 2012 we were criticizing the award of the Maddox Prize to Professor Wessely because it is axiomatic that the progress of scientific understanding depends upon sound evidence. Sir Paul Nurse, President of the Royal Society, has said: "The John Maddox Prize is an exciting new initiative to recognize bold scientists who battle to ensure that sense, reason and evidence base play a role in the most contentious debates."

We are in complete agreement with Sir Paul. We would wish the scientific process to prevail, whereby the extensive peer reviewed biomedical evidence base on ME/CFS is acknowledged and used by all researchers in the field to advance the understanding of the disorder, and we have been calling for this for many years.

*There can be no doubt that the cause of ME/CFS is a contentious issue and that there remain many unanswered questions. Both Professor White and Sir Simon Wessely have promoted an hypothesis that ME/CFS is due to an abnormal illness belief; that it is perpetuated by dysfunctional beliefs and coping behaviours, and that cognitive behavior therapy (CBT) and graded exercise therapy (GET) are effective treatments for the condition. In an attempt to prove this hypothesis Professor White, principal investigator, and colleagues, including Sir Simon, conducted what has become known as the PACE trial, published in February 2011 in *The Lancet*, at a cost of some £5m to the taxpayer. No data on recovery rates and positive outcomes have been released and a FOI request to Queen Mary University of London revealed that: "The requested data relating to recovery rates and positive outcomes do not exist. That is to say that such analyses have not been done and there is no intention to do so. The reason for this is that the analysis strategy has changed from the original protocol."*

There has been no attempt by Professor White to correct the misapprehension in respected journals as well as the popular press that the PACE trial demonstrated recovery rates of between 30% and 40%. The release of all the data relating to the PACE trial would be the most telling indication of the efficacy of CBT and GET and would contribute very effectively to the evidence base that precise scientific enquiry demands.

In our view, the idea that ME/CFS owes its origins to a dysfunctional psyche is an hypothesis that lacks any scientific evidence base. We are therefore at a loss to understand why the Maddox Prize was awarded to the defender of that hypothesis rather than to someone who was upholding the spirit of true scientific enquiry.

Our main interest is in advancing the scientific understanding of the cause of a frequently devastating and debilitating condition which blights the lives of many thousands of people. We do not believe that personal attacks directed against Professor Sir Simon Wessely will advance the cause, but reserve the right to direct criticism at the hypothesis both he and Professor White continue to espouse. We believe that a proper scientific understanding of the cause(s) of ME/CFS will emerge in the fullness of time.

*The Countess of Mar
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(1) <http://www.independent.co.uk/news/science/me-bitterest-row-yet-in-a-long-saga-8348389.html>

(2) <http://www.independent.co.uk/voices/letters/ios-letters-emails--online-postings-2-december-2012-8373777.html>

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Continuing Correspondence Between Countess of Mar and Professor Peter White and Professor Sir Simon Wessely

Professor Peter White has responded to the Countess of Mar's letter published in the "Independent on Sunday" of 13th January 2013 :

From: "Peter White"
To: "MAR, Countess"
Subject: RE: Letter to the Independent on Sunday

Dear Lady Mar,
As a matter of courtesy and for your information, I attach the link to an IoS website posting from Sir Simon and myself, which was uploaded on Saturday.
Also for your information, I attach two of my most relevant papers that speak to the important role

of infection as an immediate cause of CFS.

Yours sincerely,
Professor White

<http://www.independent.co.uk/voices/letters/ios-letters-emails--online-postings-13-january-2013-8449260.html>

“John Maddox Prize: We would like to correct several errors of fact in the letter published on this website by the Countess of Mar and others. These authors state that we “..have promoted an hypothesis that ME/CFS is due to an abnormal illness beliefs,..” We have not; beliefs about an illness determine the ways people cope with it, but this has little to do with how the illness develops in the first place (its immediate cause), which our own research has shown can follow certain infections.

The correspondents also mention the PACE trial and state that “No data on recovery rates and positive outcomes have been released..” The results of positive (and negative) outcomes were published in the Lancet medical journal early in 2011. The results of recovery rates are due to be published in the medical journal Psychological Medicine within the next three weeks.

The authors state that “There has been no attempt by Professor White to correct the misapprehension in respected journals as well as the popular press that the PACE trial demonstrated recovery rates of between 30% and 40%.” Again this is not the case; Prof White and colleagues published the following in the Lancet in May 2011: “It is important to clarify that our paper did not report on recovery; we will address this in a future publication.”

The PACE trial has added to the now overwhelming scientific literature showing that two rehabilitative approaches of cognitive behaviour therapy and graded exercise therapy are moderately effective treatments of what is otherwise a chronic, debilitating and untreatable illness that blights patient's lives. This is good news that needs sharing. Professor Peter White Professor Sir Simon Wessely Queen Mary University London and King's College London”

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Professor White and Professor Wessely's response to the Countess of Mar

Here is the response to the Countess of Mar's letter from Professor White and Professor Sir Simon Wessely:

Dear Lady Mar,

Thank you for your recent email and letter.

We are disappointed that your response quotes sentences from various papers and presentations without context to seek to confirm conclusions already arrived at; conclusions we do not share. We cannot even agree the meaning of terms, let alone a more detailed analysis of the literature. As one example, perpetuating or maintaining factors of a medical condition are not the same as the causes of the condition. So, treatments tested and shown to be effective in the PACE trial do not address the infection that may have started CFS, but do help patients address particular barriers to their recovery, which are often nothing to do with an original infection.

With regret, we believe that continuing a correspondence will not bring our views closer together.

Yours sincerely,

Professor Peter White and Professor Sir Simon Wessely