



Charity Nr 1114035

# *Invest in ME*

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## **To The Editor of the Lancet – The PACE Trial**

To: Dr Richard Horton Editor The Lancet

14 November 2015

Dear Dr Horton,

As you may be aware the PACE Trial (*Comparison of adaptive pacing therapy, cognitive behaviour therapy, graded exercise therapy, and specialist medical care for chronic fatigue syndrome (PACE): a randomised trial*) has come under further scrutiny recently – this time by scientists and journalists who have looked at this trial from an unbiased viewpoint.

You may recall that we contacted you several years ago [1] but received no reply.

Previously you have commented about the PACE trial where you have described patient advocates as “a very damaging group of individuals”, who “have distorted the debate” [2].

Whatever your views may be now concerning ME patients, as advocates of better education regarding ME/CFS, Invest in ME would suggest that the current authors of the recent analysis of the PACE Trial [3, 4] cannot be described as “damaging group of individuals” but rather as accepted authorities casting real, objective analysis over research which the patient community has not wanted, has not needed and which has become a template for how not to perform research.

To many, the PACE Trial has become synonymous with poorly conducted and biased research. Yet the PACE trial is more than an abject failure – it is an embarrassment.

In addition it is also now damaging.

It is damaging to science.

It is damaging to other researchers who are put off entering ME research – not because of distortion by patients – but rather because the lack of quality that this trial embodies and which casts doubt on every other piece of ME research being funded

It is damaging to the public perception of this disease.

Most importantly it is damaging to patients, their carers and families – those whose GPs accept the PACE trial as being of good quality evidence of the efficacy and safety of CBT and GET as treatments for ME/CFS, as the study was published by the Lancet.

It is the patients who matter and who should be served by the £5 million pounds or more that has been given for this research from a publicly funded body.

The blame for initiating this trial and the lack of ongoing monitoring of this trial, must be laid squarely at the door of the Medical Research Council who have utterly failed in meeting the requirements for research regarding myalgic encephalomyelitis.

However, it is the Lancet that published the PACE Trial and implicitly continues to support it by the silence from the editorial staff.

This letter was originally created to request that the Lancet retract the PACE Trial paper in full, without reservation.

However, before we had dispatched this letter, a new development arose.



# *Invest in ME*

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A letter signed by many notable scientists was sent to you [5] requesting that an independent review of the PACE Trial be made with no UK and no psychiatric presence.

We therefore feel there are two clear choices for the Lancet to consider – the independent review of the PACE Trial – or the complete retraction of the paper.

We understand that, having fast-tracked the publication of the original PACE trial, it will be difficult for the Lancet to admit that this research is of no value in treating ME/CFS.

The Lancet's own web site states its core editorial values - "When you publish with The Lancet you're joining a community that believes that everyone has the right to the highest attainable standard of health and that care should be equitable and just".

This is clearly not the case with the flawed PACE Trial.

As we stated in our previous letter to you, there is no excuse for ignorance with regard to any disease – especially ME/CFS which has been so maligned by misinformation, lack of funding and vested interests employed by the insurance industry.

The Lancet has a duty to report honestly and fairly. And it owes the patients and the public an admittance that flawed research will not be tolerated – and certainly not promoted as being worthy of carrying support from the Lancet name.

If your role really is "to let in the light" and "be a sharp surgical instrument to cut out the dross" [6] then it is inherent on you to see through the farce of the PACE Trial and move on.

We ask you to consider now the consequences of maintaining support for the PACE Trial and instead act for the benefit of patients – those on the receiving end of poor research and orchestrated media attacks by ignorant or bigoted journalists.

There is a clear choice now – an independent review of the PACE Trial or a full retraction.

The alternative is to continue this farce – to the detriment of patients.

In order to help resolve the inadequacies of the past we therefore again invite you to Invest in ME's annual research conference next year – IIMEC11 the 11<sup>th</sup> International ME Conference in London in June. Invest in ME would also facilitate a meeting for you with some of the researchers who will be presenting at the conference and our 6<sup>th</sup> Biomedical Research into ME Colloquium.

In all failures there is an opportunity to improve. The PACE Trial may have completely failed but this opportunity can be taken to learn from this failure and to make things better.

Yours sincerely,

The Chairman and Trustees

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## **REFERENCES**

1. Invest in ME Letter to the Editor of the Lancet <http://tinyurl.com/ocpq5fe>
2. Richard Horton interview Australia - <http://tinyurl.com/3dg468w>
3. David Tuller's full articles:



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<http://www.virology.ws/2015/10/21/trial-by-error-i/>

<http://www.virology.ws/2015/10/22/trial-by-error-ii/>

<http://www.virology.ws/2015/10/23/trial-by-error-iii/>

4. Professor James Coyne [http://blogs.plos.org/mindthebrain/2015/10/29/uninterpretable-fatal-flaws-in-pace-chronic-fatigue-syndrome-follow-up-study/-](http://blogs.plos.org/mindthebrain/2015/10/29/uninterpretable-fatal-flaws-in-pace-chronic-fatigue-syndrome-follow-up-study/)
5. "An open letter to Dr. Richard Horton and The Lancet  
<http://www.virology.ws/2015/11/13/an-open-letter-to-dr-richard-horton-and-the-lancet>
6. Thomas Wakley, founded The Lancet with the statement that "A lancet can be an arched window to let in the light or it can be a sharp surgical instrument to cut out the dross and I intend to use it in both senses".