



Ignorance is not an option.

The Editor of the Lancet recently participated in an Australian radio broadcast which included proponents of the PACE Trials. The comments by Dr. Horton indicate a lack of knowledge about this disease and about the biomedical research which has taken place and is continuing, even though it receives none of the funding which psychiatrists have received to promote their flawed research.

Invest in ME responded.

We publish this letter to allow as much open debate as possible and to show that there is a possibility to change things for the better for people with ME and their families - if the will and the education is available.

<http://www.investinme.org/IIME%20Letter%202011-04%20Lancet.htm>

Letter to Editor of the Lancet

19th April 2011

To: Dr. Richard Horton Editor The Lancet

Dear Dr. Horton,

Recently you have commented about the PACE trials.

You have described patient advocates as a very damaging group of individuals, who have distorted the debate.

Invest in ME is a UK charity which seeks to educate about Myalgic Encephalomyelitis (ME/CFS).

We are advocates of better education regarding ME/CFS.

We are organising and hosting our 6th Invest in ME International ME/CFS Conference at One Birdcage Walk, Westminster, London, on 20th May 2011. The conference has been given full CPD accreditation.

We would not wish the editor or staff of the Lancet to be criticised for holding unhelpful illness beliefs with regard to ME/CFS.

So, in the spirit of open debate, the chairman and trustees of Invest in ME respectfully invite you to attend the conference on 20th May as guest of Invest in ME.

The conference presents the biomedical research which is being performed by world-class scientists from USA and Europe - research which the Lancet is seemingly unaware of, in that it never seems to mention any of it.

At this year's conference you will have the opportunity of hearing from world-renowned experts on ME/CFS including

- one of the most experienced paediatricians in the world discussing a 25-year follow-up of ME/CFS patients;
- a former Stanford doctor discussing translational research into ME/CFS;
- the clinical and research experiences of an infectious diseases specialist concerning enteroviral research in ME/CFS;
- the proteomics of cerebrospinal fluid in ME/CFS;
- the possibilities in the UK for genome sequencing,
- immunological and virological analysis of ME/CFS;
- B-cell depletion therapy and clinical trials of Rituximab in ME/CFS;
- the clinical experiences of diagnosis, treatments and trials in ME/CFS from Europe's most experienced ME/CFS researcher; and
- the latest news of XMRV research and ME/CFS, including results from Germany.

It ought to be important for the Lancet to be acquainted with current biomedical research into this disease especially as the Lancet has not distinguished itself in being objective in its reporting of ME/CFS. Apart from the conference on 20th May we will also be organising and hosting a pre-conference evening presentation in Westminster on 19th May. The presentation is entitled Science, Politics and ME and will have respected scientist, academic and politician Dr Ian Gibson and the respected US journalist Hillary Johnson presenting transatlantic views of the influence of politics on research, media and healthcare.

You are cordially invited to that evening as guest of Invest in ME. In addition to the above Invest in ME would also like to facilitate a meeting for you with some of the researchers who will be presenting at the conference. We can organise this on the 19th May in London at a venue arranged by the charity. Here you would be able to discuss with scientists who have and are performing biomedical research into ME/CFS and research upon which the Lancet really ought to be reporting.

We understand that, having published the PACE trials document - a study which most ME/CFS patient organisations view as deeply flawed and a complete waste of money, it is difficult for the Lancet to admit that this document is of no value in treating ME/CFS.

However, 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.

We note from your web site that the founder of the Lancet, 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".

Patients suffering from this awful disease certainly need a campaign to cut out the dross which we see only too clearly in the way ME/CFS is presented by false research such as the PACE trials - and healthcare staff really do need to see the light.

We welcome you to our conference events in London in May to listen to the biomedical research and demonstrate whether the Lancet still maintains that it is a reformist medical newspaper known for its campaigns. We look forward to welcoming you at the conference in May,

Yours sincerely,

The Chairman and Trustees
Invest in ME
UK Charity Nr 1114035