



## Solve ME/CFS Initiative

Leveraging patient-centered  
research to cure ME/CFS

September 1, 2016

Erik Engstrom  
CEO, RELX Group  
1-3 Strand  
London, WC2N 5JR, UK

RE: ME/CFS coverage in your publication, *The Lancet*

Dear Mr. Engstrom,

On behalf of the Solve ME/CFS Initiative and as a patient with Myalgic encephalomyelitis (ME), commonly known as Chronic Fatigue Syndrome (CFS), I am writing to bring your attention to a matter of vital importance to the ME/CFS community, the PACE Trials and your publication, *The Lancet*.

I am writing to ask that you continue the good name and reputation of *The Lancet* within the ME/CFS scientific community by facilitating an open discussion of the PACE trials and committing to publish an independent review of the trial data now that a First-Tier Tribunal has ordered the data to be released.

As you may know, ME/CFS is a complex, neuro-immune disease with no known cause, treatment, diagnostic tool, nor cure. It is estimated that up to 20 million people worldwide are stricken with ME/CFS from ages 10 to 80 of any race, gender, or socio-economic class and this disease leaves its patients with lower quality of life scores than lung cancer, stroke, and rheumatoid arthritis. (Source: Beyond Myalgic Encephalomyelitis/Chronic Fatigue Syndrome: Redefining an Illness IOM 2015 And, The Health-Related Quality of Life for Patients with Myalgic Encephalomyelitis / Chronic Fatigue Syndrome. PLoS One. 2015; 10(7): e0132421. Published online 2015 Jul 6.)

The PACE Trials concluded, in contrast to over 4,000 other scientific publications, that this disease was psychological in nature. The Pace Trial evaluated a series of treatments which it claimed was successful in helping patients with ME/CFS. However, with poorly defined definitions of the disease and inaccurate reporting measures, these conclusions are actively causing harm to patients.

The ME/CFS community has made several appeals to Dr. Richard Horton, editor of *The Lancet*, and, at this time, those appeals remained unanswered. We do not fault Dr. Horton or *The Lancet* for initially publishing the PACE Trial results. But, various concerns and errors in the study have since been uncovered and published in many public forums. We ask that *The Lancet*, provide a continued forum for debate and discourse regarding the Pace Trials and continue to ensure the "best science" receives exposure. To learn more about the details of the communications between the ME/CFS community and Dr. Horton, I invite you to read the reporting on the matter by David Tuller and Dr. Vincent Racaniello at The Virology Blog ([www.virology.ws/mecfs](http://www.virology.ws/mecfs)).

I ask that you please continue to provide a constructive space for good science to prevail.

Sincerely,

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CC: Dr. Zaher Nahle  
Board of Directors, Solve ME/CFS Initiative  
David Tuller, DrPH

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