

Dear Editor,

We are writing with deep concerns about Kate Kelland's recent [article](#), *Special Report: Online activists are silencing us, scientists say*.

Despite Kelland's framing, the debate is not about a psychological versus a purely biomedical concept of myalgic encephalomyelitis (ME), but **pseudoscience versus science**. The men Kelland champion in her article have produced [poorly-designed research](#) that has drawn criticism from the scientific community.

Kelland's article omits the 100+ scientists who have [called](#) for an investigation and **retraction of the PACE trial study** based on its numerous methodological flaws.

Kelland's article omits the 40+ researchers and academics who supported the temporary **withdrawal of the Cochrane review** of graded exercise therapy for ME/CFS based on concerns about methodological flaws in cited studies, explicitly stating that their decision was in no way due to "patient pressures".

The article fails to report that [people with ME see their health deteriorate](#) after undergoing graded exercise therapy (GET), the therapeutic approach endorsed in the PACE trial. A survey from the UK with over 1000 respondents reported that **over 80% experienced worse health outcomes following GET**. Yet due in no small part to inflated reports of success by the original authors, the PACE trial continues to serve as frontline evidence to support the treatment of people with ME today.

Furthermore, there is growing [evidence](#) that people with ME/CFS experience physiological abnormalities to exercise, including reduced blood flow to the brain and heart, reduced oxygen uptake in hemoglobin, reduced oxygen utilization, and abnormal gene expression.

It took the Lancet 12 years to **retract** the [paper](#) supporting a link between **autism** and the MMR vaccine, which has done **inestimable damage**. The methodological flaws of the PACE trial have likewise done irreparable damage to people with ME: stalling biomedical research, quashing funding, contributing to stigma in the clinic and at home, and leading to dismal health outcomes for people with ME. The PACE trial paper is now flagged by **PLoS One** with an 'expression of concern'.

In a recent **UK House of Commons Parliamentary debate**, more than 40 MPs passed a motion to support increased funding into biomedical research, and the suspension of graded exercise therapy. The **Danish Parliament** recently announced that it will

unanimously support using the **World Health Organization** (WHO) classification of ME as neurological.

The **US CDC** has removed GET and CBT from its recommendations for treatment and stated that graded exercise may cause harm. The **US AHRQ** downgraded the evidence for GET and CBT and recommended that Oxford -- the broad diagnostic criteria used to recruit people for the PACE trial -- be retired. Meanwhile, exciting projects focused on epidemiology, etiology, and treatment push forward at [Harvard](#), [Cornell](#), [Columbia](#) and [Stanford](#), with all-star scientific teams. The **US NIH** funded its first [research centers](#) to study ME. And the [UK Biobank](#) to study genetics of ME launched, gathering the data of thousands. [Read more](#) about ME research.

A **sea-change in science** has led to a shift in the way researchers and clinicians understand ME. And it goes without saying that this is an unsettling situation for people who have staked their careers on the safety and efficacy of GET and CBT for people with ME.

All this renders Kelland's recent [article](#), *Special Report: Online activists are silencing us, scientists say*, biased reporting. In addition, Ms. Kelland and Reuters have contributed to harm by promoting a potentially deleterious treatment as safe, and by framing a disabled population as violent by default.

We urge Reuters to reconsider this stance and hope they will reach out to us or other people with ME with any questions they have about ME's history, the science behind the condition, and developments in research groups around the world.

Sincerely,

[#MEAction Network](#)