

Hello everyone,

As you may have heard, it appears that a major news organisation in the UK is planning to publish an article about ME that is likely to be negative about the impressive work by David Tuller, DrPH that has exposed flawed ME research, and may also paint advocates with ME negatively.

A journalist friendly with the Science Media Centre interviewed David for the article, and that is David's interpretation of the article based on the questions posed by the journalist.

The article has NOT been published yet so we don't actually know its final content. David Tuller has written about the interview and responded with some rebuttals on his blog ([here](#), [here](#) and [here](#)), which, hopefully, will force the editors to consider the facts of the situation and publish an article that is more accurate. However, we expect that this article will be published soon.

#MEAction UK volunteers have been discussing our response to this article once published, and we feel that the best response is NOT to engage. We want to get across the message that this narrative is no longer worth our attention, and that we are not going to promote it as valid by debating its blatantly erroneous premise.

The other reason NOT to engage is that we don't want to give the article prominence on social media. Whenever someone discusses a post or links to a post on social media, it raises the importance of that subject. Social media algorithms don't distinguish between negative or positive feedback - it just perceives that people are talking about the subject and so boosts its visibility. Again, we encourage the community NOT to comment on, share or reshare the article so as not to give it limelight on social media.

The Bristol Cable was impressed by how quickly and efficiently the ME community can share an article around the world - online amplification is a form of power we possess which we can also withhold. If we withdraw our online conversation on an article it is an equivalent of going out on strike.

#MEAAction will likely publish a statement on our website rebutting the article IF the article turns out to be biased and inaccurate, but we **DON'T** suggest that you share our article on social media, either, again not to draw undue attention to the article.

If you would like to comment below the actual article itself on the news organization's website (NOT on social media), we suggest sticking to these points and **not** attacking the journalist, editor or scientists involved directly.

- **The scientific community has issued strong criticism to the PACE trial.**

Over [100 independent international scientists](#) have signed an open letter calling for an investigation and retraction of the trial based on its numerous methodological flaws.

- More than [40 researchers and academics](#) have shown support for Cochrane temporarily withdrawing the review of exercise therapies for ME/CFS, based on substantive concerns about the methodology of the review and its studies.

- **Scientific evidence shows that people with ME have physiological abnormalities to exercise***, which is consistent with overwhelming [reports](#) from patients saying that their condition has deteriorated after undergoing graded exercise therapy, which the PACE trial promotes.

* Patients have been found to have reduced anaerobic threshold, errors in energy metabolism (Fluge and Mella, 2016; Armstrong et al., 2015, Naviaux, et al., 2016), and exercise studies that show, among other abnormalities, reduced blood flow to the brain and heart (Neary et al., 2008; Peterson et al., 1994), reduced oxygen uptake in hemoglobin (Miller et al., 2015), reduced oxygen utilization (Snell et al., 2013, Vermeulen & Vermeulen, 2014), and abnormal gene expression (Light et al., 2009) that cannot be explained by deconditioning. Gene expression post-exercise -- Light's group found different gene function after exercise in patients, including in genes related to immunity, metabolism, and the nervous system. Genes with increased expression included those responsible for regulating function of the heart, cell death, and inflammation.

- **Scientific studies contradict the premise of the PACE trial: that ME is caused by deconditioning.** [Evidence](#) from cardiopulmonary exercise (CPET) testing, muscle biopsies, and metabolomics strongly contradict that ME is caused by deconditioning. Multiple peer-reviewed studies show demonstrable differences when comparing people with ME and sedentary controls. The idea that the illness is itself a result of deep-seated fears leading to a lack of exercise is not supportable given the current evidence.
- People with ME are speaking out against the PACE trial since **we have the most to lose from doctors prescribing treatments based on flawed information.** The focus on one flawed trial has stalled the progress of scientific investigation into the underlying, biological mechanisms of this disease that is ravaging our lives. The truth is that we are desperately interested in advancing rigorous scientific investigation into this disease.