

Parliamentary Debate: 'The PACE Trial and its effect on people with ME'

This debate was held at Westminster Hall on February 20th 2018. It was initiated by Glasgow North West constituency MP Carol Monaghan. The government spokesperson tasked with responding was Caroline Dinenage, Minister for Care.

Quotes.....

"Does my hon. Friend agree with my long-term family friend Maureen Bivard that the cover-up, and the way in which the PACE trial was carried out, amounts to a miscarriage of justice for patients?"

Alison Thewliss MP

"I think that when the full details of the trial become known, it will be considered one of the biggest medical scandals of the 21st century."

Carol Monaghan MP

The ME Association chose this as their banner headline: www.meassociation.org.uk/2018/02/government-funded-me-cfs-trial-one-of-greatest-medical-scandals-of-21st-century-20-february-2018/ Well done Maureen!

View the debate

On Westminster parliament TV www.parliamentlive.tv/Event/Index/cf2fde9d-f327-4bf4-8e72-1fc6124b8998 or <https://tinyurl.com/ya3gln95>

.... On You Tube <https://youtu.be/UwCEvnXZTIA> - this goes directly to the debate, whereas the above has prior and subsequent business also; plus You Tube has some interesting comments and observations posted by viewers.

Read a transcript <https://tinyurl.com/y8uk7pvv> or <https://hansard.parliament.uk/commons/2018-02-20/debates/990746C7-9010-4566-940D-249F5026FF73/PACETrialPeopleWithME>

Read an analysis of the ministerial response.... www.meaction.net/2018/02/26/read-about-the-westminster-hall-debate-on-the-pace-trial-and-its-effects-on-people-with-me/

MPs who spoke (*in order of occurrence*)

Carol Monaghan, Glasgow North West (SNP)

Jim Shannon (Strangford) (DUP)

Mr Jim Cunningham (Coventry South) (Lab)

Alex Sobel (Leeds North West) (Lab/Co-op)

Rachael Maskell (York Central) (Lab/Co-op)

John Howell (Henley) (Con)

John Lamont (Berwickshire, Roxburgh and Selkirk) (Con)

Layla Moran (Oxford West & Abingdon, LD)

Alison Thewliss (Glasgow Central) (SNP)

Nicky Morgan (Loughborough) (Con)

Luke Pollard (Plymouth, Sutton and Devonport) (Lab/Co-op)

Helen Whately (Faversham and Mid Kent) (Con)

Paul Blomfield (Sheffield Central) (Lab)

What Next? the wider context

“I consider this debate to be a starting point rather than an end point”

Carol Monaghan, quoted in Scottish Newspaper ‘The National’ Feb 20th 2018

www.thenational.scot/news/16033656.SNP_politician_to_lead_debate_on_poor_treatment_for_ME_patients

“All these changes unequivocally demonstrate that there has been significant erosion in support for the fake claims promoted by the CBT/GET ideological brigades. Besides the flaws in PACE, it has become apparent that many of the other studies from the biopsychosocial crowd are rife with ethical and methodological missteps. That’s on top of the fact that they are all open-label trials with subjective outcomes, which would present an insurmountable obstacle to obtaining reliable and valid results even without all the other violations of scientific principles.”

David Tuller (journalist) 5th March 2018

<https://tinyurl.com/ycxwufz> or www.virology.ws/2018/03/05/trial-by-error-news-about-my-plans/

Contacting Your MP

Firstly, if you have been harmed by following NHS advice, including attempting ‘PACE’ trial style exercise or ‘behavioural therapy’ aimed at exercise, please let your MP know your story, copying in Carol Monaghan.

Even if you are too ill to tell the whole story, a simple message saying who you are and that you have been worse since attempting NHS recommendations, would be much better than silence. Feel free to write by post, e-mail, or phone your MP’s office. Many MPs have assistants, at parliament and/or at their constituency office, who may be able to support in taking down the details.

Secondly, whether or not you have a personal story to tell, you may be able to help with this campaign by providing your MP with a copy of a briefing paper recently produced by the excellent on-line working group of patients that is ‘Science For M.E.’ This paper was written specifically to tie in with the level of interest being shown in this topic among UK politicians. It is just over 5 pages long plus references.

Most ‘Science for M.E.’ participants have a background in science and mathematics. The authors of the briefing paper, including Tom Kindlon, Sean Kirby and Graham McPhee, have published over twenty papers and letters of expert commentary on the PACE trial and related matters in peer-reviewed journals such as The Lancet and the British Medical Journal.

“This is a great document to share with MPs. Good stuff.”

A PDF of the document can be downloaded here: www.s4me.info/docs/PaceBriefing3.pdf

Alternatively can be downloaded from Dropbox: www.dropbox.com/s/t6n35z7wtv0mwhe/PaceBriefing3.pdf

Finally - don’t forget to thank your MP if they participated in the debate. There’s a list of participating MPs on the previous page.

