



25% M.E. Group

Advocacy & Support Group for Severe M.E. Sufferers
Services: Support; Newsletter; Fund Raising; Information
Charity No: SC034265

PATRON: Dr Byron Marshall Hyde MD
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Prof Malcolm Hooper PhD. B.Pharm. C.Chem. MRIC

MEDICAL ADVISOR:
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10th February 2016

Dear Sir/Madam

Re Access to raw unpublished data for PACE trial

As has been expressed by other charities, groups and individuals. 'The Freedom of Information (FOI) request for release of so far unpublished data from the PACE trial, along with the refusal of Queen Mary University of London (QMUL) to comply with this request, is currently causing a great deal of concern and comment from people with ME'.

We are a charity supporting severely affected ME sufferers. Over the last few years we have been increasingly sceptical of the claims made by the authors of the PACE trial regarding the beneficial effects of CBT and GET in this condition. This is because so many of our members have tried CBT and found it unhelpful, and that those of our members that have tried GET have by and large found it positively harmful.

We accept that the PACE trial did not involve severely affected patients, but nevertheless find the lack of efficacy and indeed harmfulness of these modalities for our members to be adequate grounds for scepticism.

We note that recently there has been increasing academic criticism of the PACE trial and its claims, and that various academics have asked for access to the data in the trials so that these can be subject to further scrutiny. We would like to add the voice of our Charity to these requests, and therefore ask your organisation (as the organisation with overall responsibility for the authors) to authorise release of the data to those requesting it.

Sincerely

Simon Lawrence

Chairman

25% ME GROUP (for severely affected ME sufferers)

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If you are able to make a donation, please make cheque payable to '25% M.E. Group'. Thank you