



Professor Simon Gaskell  
President and Principal  
Queen's Mary University London  
Mile End Road  
London E1 4NS

March 15, 2016

Copy to: Records and Information Compliance Manager, QMUL

Dear Mr Gaskell,

RE: PACE TRIAL ANONYMOUS DATA RELEASE

We note the statement on the QMUL website, 18 December 2015  
(<http://www.qmul.ac.uk/media/news/items/smd/168729.html>):

“We are currently seeking further ethical and scientific advice, as well as the advice of patients, on how best to provide independent decisions about appropriate access to relevant data in a way that balances the rights of trial participants, and future progress of the trial analysis and follow up, with the public interest in releasing trial data.”

The three Dutch ME and CFS patient organizations, ME/CVS Stichting Nederland, ME/cvs Vereniging and Steungroep ME en Arbeidsongeschiktheid, believe it is in the best interests of patients, including those in the Netherlands who we represent, for the anonymized PACE trial data to be released, enabling everyone the opportunity to check and reanalyse the data.

We add our voices to the other patient-representing organizations from the UK, Ireland, Belgium, the Netherlands and the US, in asking you to release the anonymized PACE trial data and to withdraw your appeal against the Information Commissioners order that you release part of this data.

Sincerely,  
The collaborating patient organizations

Yvonne van der Ploeg, Treasurer  
ME/cvs Vereniging  
[contact@me-cvsvereniging.nl](mailto:contact@me-cvsvereniging.nl)

Mary Rietdijk, Chief Executive  
ME/CVS Stichting Nederland  
[info@me-cvs-stichting.nl](mailto:info@me-cvs-stichting.nl)

Dick Quik, Chairman  
Steungroep ME en Arbeidsongeschiktheid  
[info@steungroep.nl](mailto:info@steungroep.nl)

Correspondence address:  
Oostdijk 12A  
1844LP Driehuizen  
the Netherlands