



Participants' Newsletter

Issue 1. June 2006

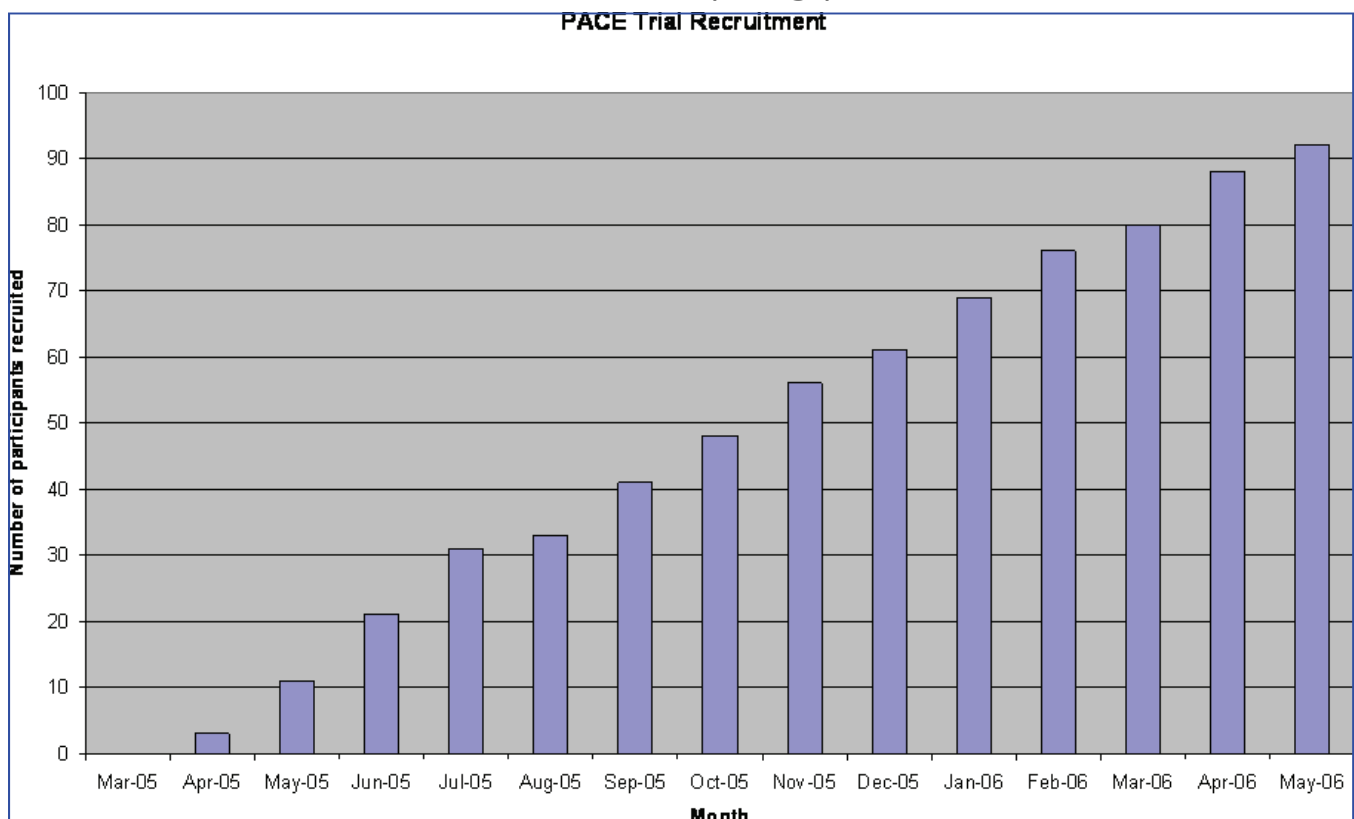
This is the first newsletter to be sent to participants in the PACE study and the first thing we would like to say is a big thank you to each of you for taking part in this, the largest ever study to be carried out into the comparative effectiveness of different treatments for CFS/ME. By May there were 92 people receiving treatments as part of PACE (see the graph below) and our first 11 participants have now completed their 12 month assessment. Congratulations and a special thank you to them.

A new centre, Oxford, joined St Bartholomew's and King's College hospitals in London and the Edinburgh centre in recruiting into the study in May. June will see the Royal Free Hospital, London, and a second centre at St Bartholomew's also begin recruitment.

There are now some 70 people working on PACE, including occupational therapists, physiotherapists, psychologists and CFS/ME specialist doctors, as well as research staff to gather all the information and analyse it. The information is being entered onto a large and secure database, designed and maintained by an independent clinical trial unit at King's College, London. Three committees run or oversee the study, two of which are completely independent of the people running it.

Our comprehensive new website, www.wolfson.qmul.ac.uk/pace, will give you more information about the study.

Please send any feedback on the website or any aspect of the study to pace@qmul.ac.uk.



ISRCTN54285094

The PACE Trial is a Multi-Centre study run across six UK Centres, and is jointly funded by:



What is it like to take part in the PACE trial

We have already received some informal feedback on the experience of participating in the study. Please remember you can let us know about your experience of the study by writing comments, good or bad, as part of your final assessment, or by talking to your research nurse/assistant, therapist or doctor. Comments so far have included: "I really think it is good to be part of something that will make a difference to so many people." "We need this research to know the best treatments." "The staff were so professional that I felt well taken care of." "It has helped being able to have some of the sessions by telephone."

FINE trial tests treatment at home

NICE guidelines on their way

The National Institute for Clinical Excellence is due to publish its first draft guidance on the management of CFS/ME later this year.

This guidance will be used by the NHS to decide on which treatments to offer patients.

To help this process, York University is about to publish a systematic review of all treatments for CFS/ME. This review is likely to conclude that the PACE study is vital to understand which treatments are most effective and whether certain treatments best suit different individuals.

Fine (www.fine-trial.net) is a "sister" study to PACE currently being carried out in the north west of England. It will show how effective a "pragmatic rehabilitation" programme, provided by nurses in a patient's home, is. The programme has the major advantage of allowing people who are too unwell to attend a clinic to nonetheless receive treatment

Our website is intended to keep all our participants up to date on the trial



New PACE website launched

Our new website contains a wealth of information on the trial, including answers to some of the most frequently asked questions and electronic versions of the patient information sheet and the clinic patient

leaflet.

www.wolfson.qmul.ac.uk/pace is intended to keep all our participants up to date on the trial and we will be adding relevant information to it in the future. We would love to hear what you think of it. Please do let us know if there is anything else you would like to see on the site.