



Participants' Newsletter

Issue 2. March 2007

In our last newsletter we asked for feedback and for contributions from participants and we can happily report that we have received both.

Many thanks to those of you who contacted us about the newsletter and a special thanks to G.T. Buchan, who sent us the poem printed overleaf.

Any similar contribution from participants who are receiving any of the trial treatments will be gratefully received. In the meantime, may we wish a healthy and **Happy New Year** to you all.

New PACE research centres begin recruiting

Three new PACE centres have recently started recruiting participants to the trial. They are at:

- The [John Radcliffe Hospital](#) in [Oxford](#), with co-leaders Dr Brian Angus, Professor Tim Peto and Dr Eleanor Feldman
- The [Royal Free Hospital](#) in [London](#) led by Dr Gabrielle Murphy and
- A second centre at [St Bartholomew's Hospital](#) in [London](#) led by Dr Maurice Murphy. This centre is being run jointly with the first [Bart's](#) centre. This makes six centres now recruiting to the trial.

The other centres are at:

- The [Western General Hospital](#) in [Edinburgh](#) and
- [King's College Hospital](#) in south [London](#).
- A seventh centre in [Bristol](#) will start recruiting in the spring. It will be based at [Frenchay Hospital](#) and led by Dr Hazel O'Dowd.

If you know of any friends or family who suffer from CFS/ME and who might be eligible and interested in taking part in the study and live close enough to one of these centres, please suggest they approach their GP for a referral to a PACE centre.

Professor White, the trial's chief investigator, said, 'These extra centres will significantly boost recruitment into the study so that we can more quickly answer the important questions the PACE trial is asking.'

Location of all of the PACE research centres



ISRCTN54285094

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



New, easier, website address for PACE

The PACE trial now has a shorter and easier to remember website address. The site can be found at www.pacetrials.org and has information on all aspects of the trial.

Comments and feedback on the site or on anything to do with the trial are welcome.

The trial can be contacted by email at pacc@qmul.ac.uk.

Alternatively, you can speak to the research nurse at your centre, to your SSMC doctor or, if you have one, to your therapist.

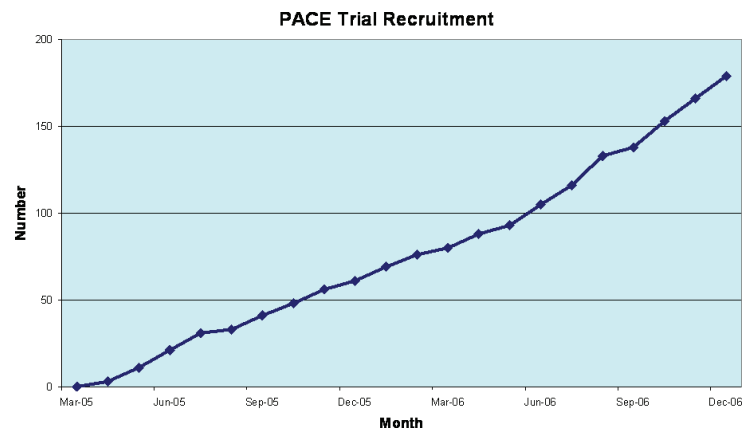
NICE draft guidelines emphasise importance of the PACE trial

Draft guidelines for the NHS on the assessment and management of CFS/ME, written by the National Institute of Health and Clinical Evidence (NICE), were published in November. The final version will be published on 25th April 2007. The PACE trial is referred to three times in the guideline, although not by name, particularly emphasising the need to test adaptive pacing therapy and the cost-effectiveness of the treatments.

NICE will be reviewing the guidelines around the time that the PACE trial will be finishing, so that the PACE trial results will have an immediate influence on treatment.

Recruitment set for sharp rise

The number of CFS/ME patients recruited to PACE rose steadily to 180 by the end of November 2006, as shown in this graph. The number is set to rise sharply as the number of centres, as reported overleaf, increases to seven.



Pacing, by G.T. Buchan

32 pairs of socks
40 colourful knickers
10 school polos
and
I haven't started yet.
Got to get this laundry High
down to Medium or Low
Little and often and daily
The PACING way to go.

The dog is looking
mournful
Wants a jolly three mile jaunt.
Front lawn needs some
mowing
And the office needs a sort.
First I'll have a sit down
Making sure I'm ergonomically
correct,
Then I'll get in a stew about
what I can do next.

Taking time out to recharge
Stop the activity drain
Shutting out the world a while
Re-activates the brain.
Not to think or hear or see,
Purposely you sit
Now, to set priorities
That's the tricky bit.

The dog is most
demanding
Twenty minutes is all I must do
I will throw the ball,
She can run from and to!
The lawn can be a meadow
Its currently the style
Carefully paced gardening
Even makes me smile!

Work, rest, play balance
To the office reluctantly I
trudge
Shifting tasks, shorter lists
Reduces all the drudge
Once you get the system
straight
PACING can be fun
And, it is no surprise,
You get the job done!

Boom and bust was the way
Frustration mingled with
Hope
Getting nowhere for so long
PACING is a better way to cope
I want to get more fun in
I want to run a mile or three
There are even some tickets
For a show I want to see
Then one day
I will give myself a treat
Put on my pack
Take a hike
To the top of Scarsdale Peak