

Birmingham Clinical Trials Unit Parkinson's Disease Newsletter



PD Annual Collaborators' Meeting 7 - 8th June 2010

This was another stimulating meeting and our largest ever with over 150 delegates from all over the country attending. Slides of the information presented, together with examples of completed PD REHAB therapist's forms, are available on the trial website:

<http://www.pdmed.bham.ac.uk/investigators/meetings.shtml>

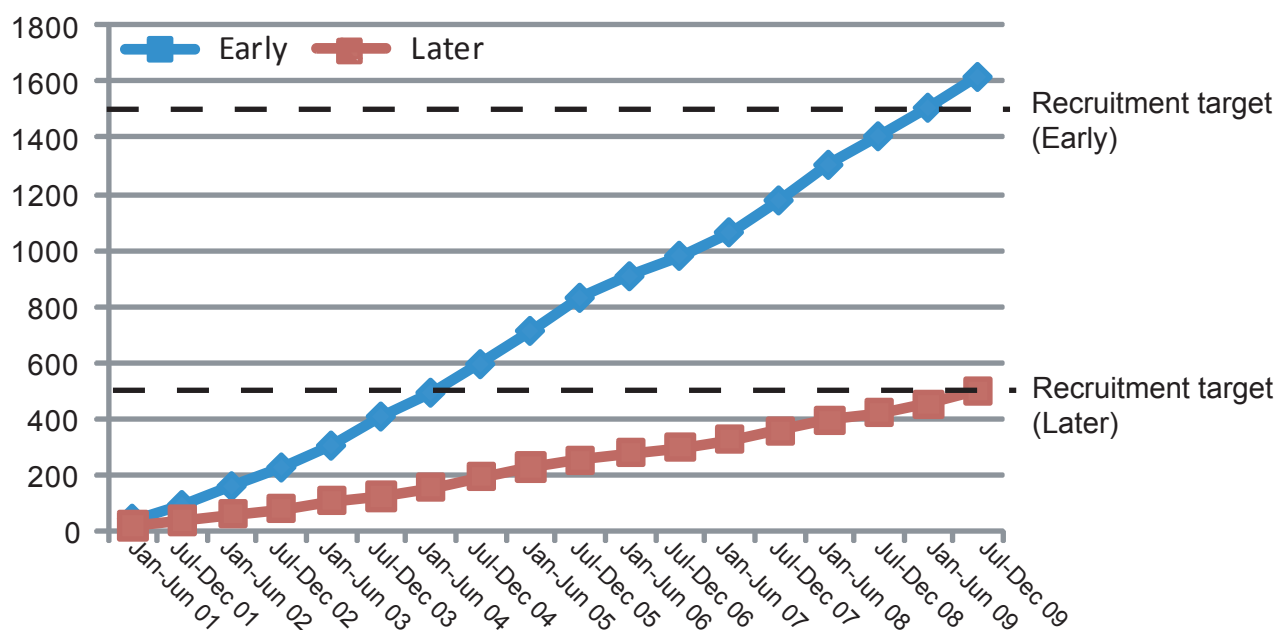


PD MED News August 2010



PD MED a large, simple, 'real life' trial that aims to determine more reliably which class of drug provides the most effective control, with the fewest side-effects, for both early and later Parkinson's Disease.

PD MED reaches its recruitment targets!



The recruitment phase of PD MED has now been completed but the trial is far from over, with 15 year median survival from PD diagnosis, it is essential that we obtain high quality long term follow up of this uniquely large cohort for really reliable results.

Thank you for all your support

PD MED Publications

- > A rapid response was published in the BMJ online highlighting the increased recruitment to PD MED in DeNDRoN compared to non-DeNDRoN areas: Reasons to be optimistic about the NIHR UK Clinical Research Collaboration - impact of DeNDRoN clinical research network on recruitment to PD MED trial Caroline E. Rick, Carl E. Clarke, Keith Wheatley, Neil P. Winkles, Smitaa Patel, Natalie Ives and Richard Gray. http://www.bmj.com/cgi/eletters/340/may17_1/c2375
- >The first results from the PD MED randomised comparisons will be published next year.
- >PD MED methods papers are currently being written and we plan to submit them to Biomed Central in September.
- >Abstracts of baseline data are being presented at World Parkinson's Congress in Glasgow and at the Parkinson's UK meeting in York.
- > Further publications are currently being planned including cost-effectiveness, quality of life and predictors of disease progression.

We are currently cleaning the data so will be sending out requests for information & clarification. The data analyses for the first publication will be run in 2011, so we would appreciate a timely response to enable us to get it all on the database.

The publication will be in the names of all people who have worked on the trials and for this we are collating lists of the collaborative group.

A list has been sent to the Principal Investigator at each site to confirm the local team. For sites who have not responded further requests will be sent out this month.



PD SURG NEWS

August 2010



PD SURG results published in Lancet Neurology

The first results of the PD SURG trial were published in the Lancet Neurology: June 2010, volume 9, pages 581 - 591. The publication was accompanied by media coverage in BBC Online Health, ITN Online, The Daily Mail, The Independent, Yahoo! UK & Ireland, the Scotsman and the Yorkshire Post. Professor Adrian Williams and one of our PD SURG participants were interviewed on the BBC news.

Other Publications

Now that the main results paper has been published, we are focussing on the second tier of papers that will provide a much more detailed picture of the results from the PD SURG trial.

Work is being done on building the cost effectiveness models for the PD SURG data, examining the quality of life data, the psychological data and the neurosurgical data available from the trial. Longer term outcomes are also being studied, although these data are less clear as participants in the control arm were allowed to cross over after 12 months.

Dr Emma McIntosh has received a Career Development Award from Parkinson's UK to enable her to further develop research into the "Economics of Parkinson's Disease". The fellowship will allow Emma to build upon the existing data obtained from PDSURG and PDMED. Emma's top priority is the PD SURG trial to ensure that the cost-effectiveness data are ready for the next round of the NICE guidelines.

An abstract on apomorphine usage in the PD SURG trial will be presented at the World Parkinson's Congress in Glasgow and at the Parkinson's UK meeting in York.

We are continuing to clean the data for these analyses so will be sending out more queries to you, it would be much appreciated if you could respond in a timely fashion.

PD SURG Follow Up

Follow up will continue at least until 2015, when all participants reach the 9 year time point. We have excellent return rates up to 3 years, but then the rates start to drop off. We will be sending out requests for all forms that can be completed retrospectively to try to collect any available information.

Please keep us informed of any changes in status of your PD SURG participants - in particular we make every effort to avoid sending questionnaires to participants who have died as their families can find this distressing. We would also appreciate being informed if participants move so that we don't lose track of them.

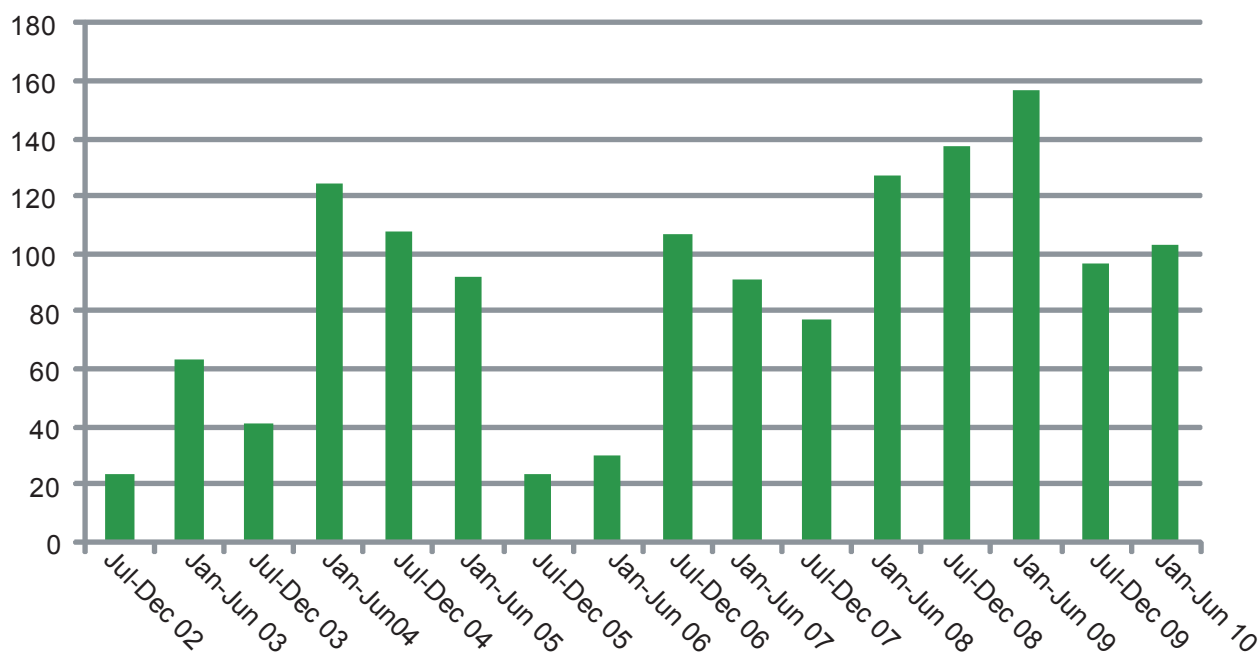
Please try to ensure that you return all follow up forms to us - if there is anything we can do to help you increase your return rate, please let us know.



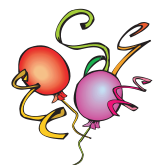
PD GEN - A DNA Bank



PD GEN Recruitment



To the end of July 2010, 1,404 PD GEN samples had been received: 902 from participants in the PD MED, PD SURG & PD REHAB trials and 502 control samples from their carers.



Prizes!

To celebrate the milestone, we are offering a prize of chocolates & champagne to the site that provides the 1,000th patient sample.

Sample Usage

We are currently putting together a second set of samples for the next round of the UK Genome Wide Association Study, GWAS, project, aiming to identify additional genetic variants in the region of 'hits' identified in the first round. A paper on the initial UK GWAS was submitted for publication in July 2010.

We have had further requests for samples from other researchers around the world and are actively working with them.

Any samples you can provide will be an important addition to the DNA bank and will support ongoing research in to PD.





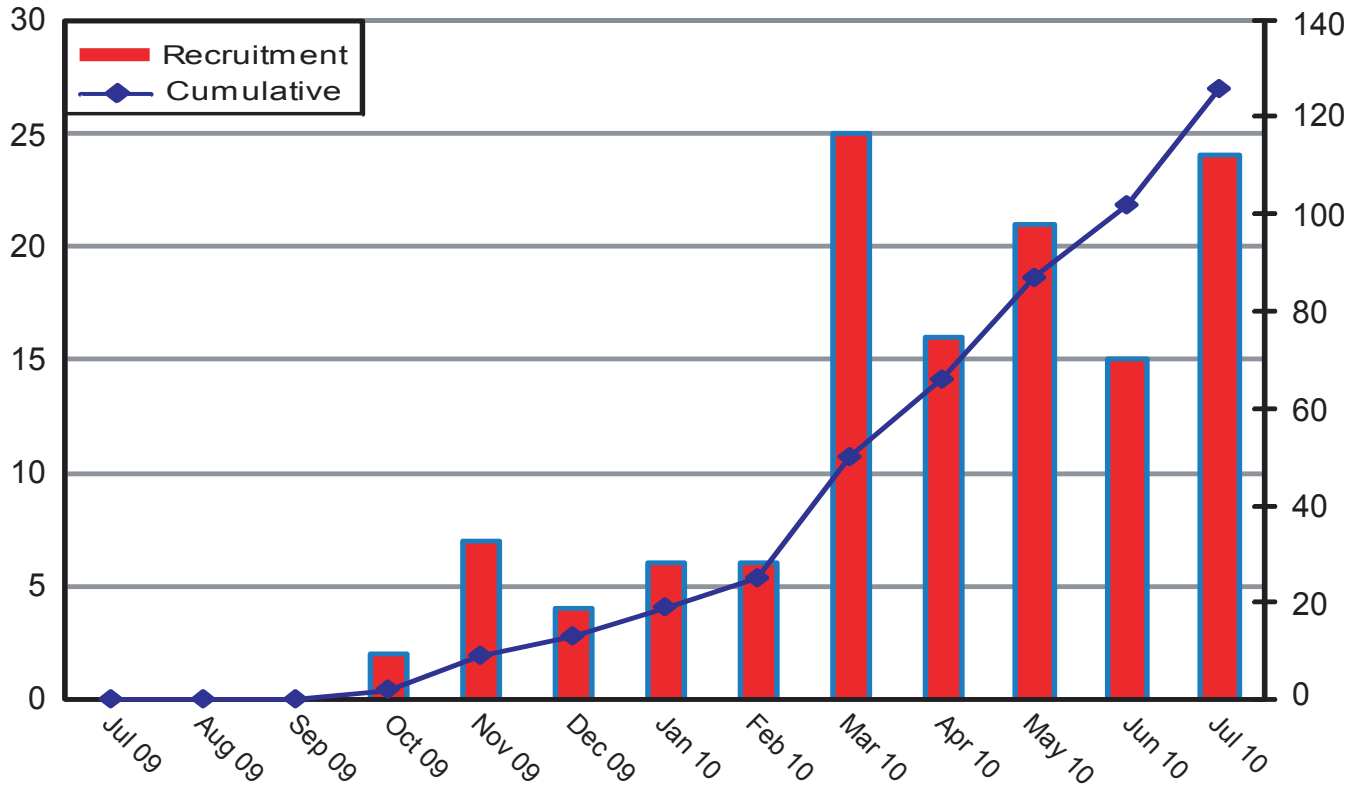
PD REHAB News



August 2010

A Randomised Controlled Trial to Assess the Clinical- and Cost-Effectiveness of Physiotherapy and Occupational therapy in Parkinson's Disease.

PD REHAB has recruited over 100 participants!



The Royal Devon and Exeter Hospital is currently our top recruiter with 17 participants, followed by Macclesfield & The Royal Bournemouth on 11 and City Hospital Birmingham, Lincoln and Taunton & Somerset on 10 participants.

Site Visits

are available to all sites once the requisite approvals are in place. These visits are designed to discuss with the local team how the trial will be run locally & to address any outstanding concerns. If you would like a site visit, please contact the trials office on pd-trials@bham.ac.uk.

Therapists meeting

is scheduled to take place on 26th November in Birmingham. Please save this date for your diaries. Further details & the programme will be circulated as soon as they are available. If you have any particular areas of interest or suggestions can you please let us know?

Substantial Amendment

We have received ethics approval for a substantial amendment giving rise to protocol version 9. This amendment will not affect the day to day running of the trial except that a letter of invitation will be available. Updated therapist logs were reviewed by the therapists who attended the annual meeting and final small changes have been made. New documentation will be sent out shortly.

**If you would like any further information about PD REHAB, please contact:
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