

# Birmingham Clinical Trials Unit Parkinson's Disease Newsletter



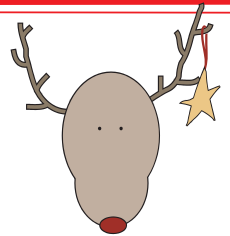
## Save the Date!

**PD Annual Collaborators' Meeting  
7 - 8th June 2010**

The meeting will again be held at the Botanical Gardens in Birmingham. The programme will include updates on PD REHAB, PD SURG and PD MED. Invitations will be sent out in the New Year



## PD MED News December 2009



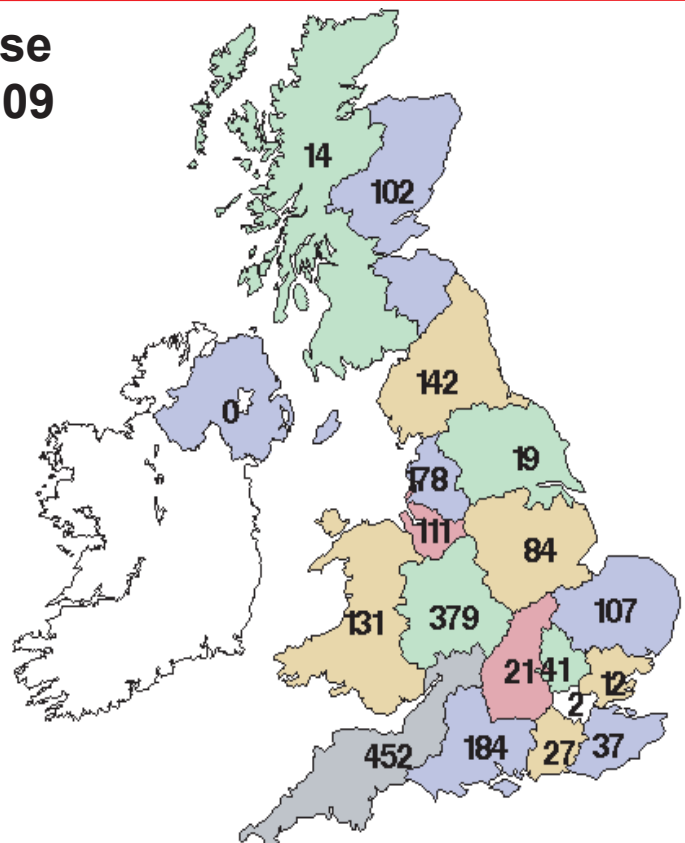
**PD MED** is a large, simple, 'real life' trial that aims to determine more reliably which class of drug provides the most effective control, with the fewest side-effects, for both early and later Parkinson's Disease.

**PD MED recruitment will close  
on the 22nd of December 2009**



### PRIZES

We will be offering prizes to the centre that has recruited the most later disease patients this year and the centre that recruits our 500th later disease participant. There will also be a lucky dip prize when a centre will be drawn at random from all the sites that have recruited participants in to the PD MED trial.



**Please note the University will be closed from  
23rd December 2009 - 4th January 2010**



## PD MED Form Return Rates

	Baseline (%)	6 Months (%)	1 Year (%)	2 Year (%)	3 Year (%)	4 Year (%)	5 Year (%)
PDQ-39	98	93	92	90	86	81	77
EuroQoL	98	93	92	89	85	81	76
Resource Usage	n/a	n/a	91	89	85	81	75
SF-36	97	93	91	89	86	84	84
Toxicity	n/a	92	90	88	85	80	75
Follow-up	n/a	n/a	93	89	84	82	71
MMSE	98	n/a	n/a	n/a	n/a	n/a	67

We will continue to follow up PD MED participants for 10 years, so it is important that we receive as much data as possible to assess the longer term effects of the medications prescribed in the PD MED trial. This is a unique opportunity to collect a significant set of data on a large sample of PD patients that will give us insight in to the lives of people with PD. Please continue to complete the follow up forms and MMSE (at 5 and 10 years). Some of the data from follow up forms can also be completed post hoc from the medical records - particularly information about medication. If your patient is no longer able to complete questionnaires or will no longer be seen in your clinic, we can adjust our data collection to only collect annual follow up forms or only collect the patient questionnaires - please inform a member of the PD team of these changes.



PD team: Cally Rick / Neil Winkles/ Francis Dowling / Ryan Ottridge / Dani Scott Tel: (0121) 415 9129 / 9128 / 9127 / 9125 or email [pd-trials@bham.ac.uk](mailto:pd-trials@bham.ac.uk)



PD MED is funded by the NHS through its Health Technology Assessment Research Programme. It is supported by the Parkinson's Disease Society, the European Parkinson's Disease Association and the Parkinson's Disease Specialist Nurse Association



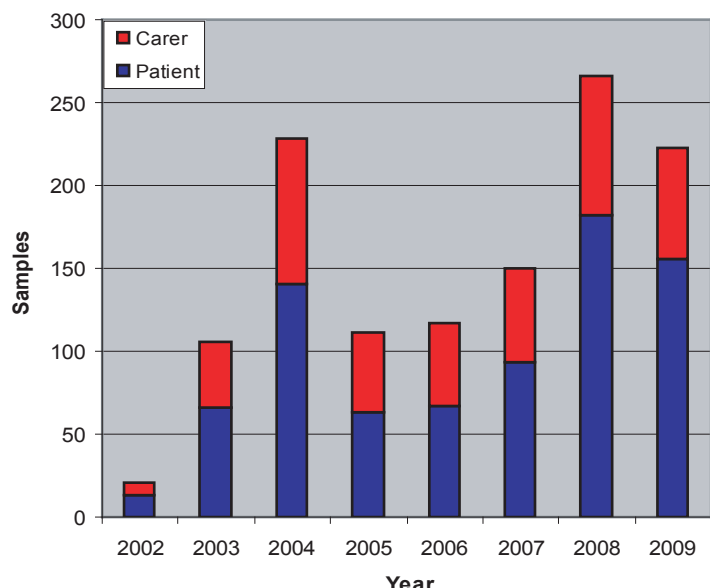
## PD GEN - A DNA Bank



**Please keep providing samples - Samples can be sent to us through the Christmas period - any delays will not destroy the DNA.**

The Welcome GWAS study needs 2,000 more samples for a replication set to confirm that the "hits" found in the first round were real and not false positives. Any samples you can provide for the PD GEN DNA bank may be used to support this important research.

Please note that data for 2009 does not include December.



## PD GEN–Substantial Amendment

A substantial amendment was approved by NRES to allow samples from PD REHAB participants and their carers to be included in the PD GEN DNA bank. This increase in the number of samples will increase the usefulness of the DNA bank.

If your site does not yet have ethical approval for PD GEN and you would like to provide samples, please contact the PD Team and we will help you get the requisite approvals in place. Note - the PD GEN DNA Bank is open to participants and their carers enrolled in the PD MED, PD SURG and PD REHAB trials.

If you are participating in PD GEN and would like us to update you on your complete participant list from the other trials and identify who has already enrolled in PD GEN, please let us know. For more information or PD GEN packs, please contact the PD Trial team.



## PD SURG NEWS

December 2009



### The PD SURG paper is currently being reviewed by the Lancet Neurology.

#### PD SURG Collaborators' meeting

The next PD SURG Collaborators' meeting will take place on 9th February 2010 at the Burlington Hotel in Birmingham. The focus of the meeting will be the broader results of the 1 year comparison including psychological data, adverse events and SAEs, quality of life measures and an update on the health economic analyses, plus some of the longer term results. If you would like to attend the meeting and have yet to receive an invitation, please contact the PD Trial office.

PDQ-39	
Assessment	Percentage
Baseline	96.99
1 Year	88.24
2 Year	85.42
3 Year	67.2
5 Year	59.89

SF-36	
Assessment	Percentage
Baseline	95.8
1 Year	78.62
2 Year	84.7
3 Year	58.44
5 Year	59.54

UPDRS	
Assessment	Percentage
Baseline	97.54
1 Year	85.59
3 Year	60.26
5 Year	48.24

EuroQoL	
Assessment	Percentage
Baseline	96.99
1 Year	87.96
3 Year	66.24
5 Year	59.32

RU	
Assessment	Percentage
1 Year	84.31
2 Year	65.18
3 Year	71.7
5 Year	64.97

Annual Follow Up	
Assessment	Percentage
1 Year	90.14
3 Year	72.04
5 Year	57.65

**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 REHAB News



December 2009

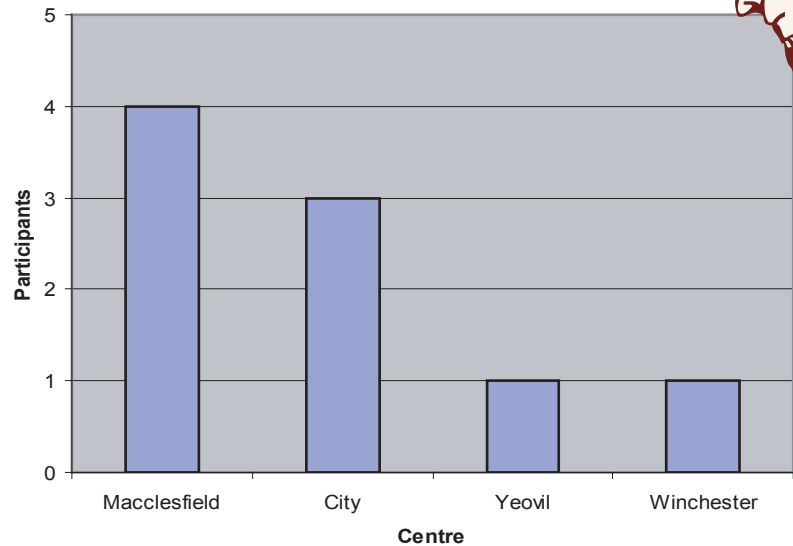
A Randomised Controlled Trial to Assess the Clinical- and Cost-Effectiveness of Physiotherapy and Occupational therapy in Parkinson's Disease.



## PD REHAB has recruited its first participants!




Congratulations to the teams at Macclesfield General Hospital, City Hospital Birmingham, Yeovil District Hospital and Royal Hampshire County Hospital for recruiting our first participants. If you are having problems with our website, participants can also be randomised by telephone: 0800 953 0274 between 9am - 5pm (please note the University will be closed from 23rd December 2009 - 3rd January 2010).




### Substantial Amendment

We will be submitting a substantial amendment in the New Year - if there is anything you would like to change in the forms or feel is missing that would be helpful, please let us know. For example we will be adding a letter of invitation to potential participants in the amendment. We cannot guarantee to make all proposed changes but will consider all suggestions.

### Meetings

 The PD REHAB Therapists meeting took place in Birmingham on 20th November. Over 100 delegates attended the meeting to discuss the provision of occupational therapy and physiotherapy for PD REHAB trial participants. Slides from the day are available on the PD REHAB website.

 The next PD Trials Collaborators' meeting will take place on 7 - 8th June 2010, at which Bas Bloem will give the pre-dinner talk. Invitations to the clinicians, nurses and therapists will be sent out in the New Year.

### BCTU

The website for the PD REHAB trial is now operational and contains updated information about the trial and links to useful websites: [www.pdrehab.bham.ac.uk](http://www.pdrehab.bham.ac.uk).

An online forum has been set up to provide support and advice for Therapists in a confidential setting. Please register through the link on the PD REHAB website and the trials team will activate your account.



**If you would like any further information about PD REHAB, please contact:**  
**Carl Clarke - [c.e.clarke@bham.ac.uk](mailto:c.e.clarke@bham.ac.uk), Cath Sackley - [c.m.sackley@bham.ac.uk](mailto:c.m.sackley@bham.ac.uk)**  
**Cally Rick - [c.e.rick@bham.ac.uk](mailto:c.e.rick@bham.ac.uk)**