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# Birmingham Clinical Trials Unit Parkinson's Disease Newsletter

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## PD Annual Collaborators' Meeting - First PD MED Results! 27 - 28th June 2011

The next PD annual collaborators' meeting is scheduled for June. It will take place at the Botanical Gardens in Birmingham.

The 27th will focus on the PD REHAB trial and 28th will primarily focus on the first PD MED results!

Invitations and further details will be sent in February/March, but please save the date for your diaries.

Please note - we have reserved a number of rooms for delegates with our booking, but owing to other events taking place in Birmingham that night (amongst others "Take That" are in concert) few other rooms are available. We would appreciate prompt responses to the invitations once they are sent out & to be informed asap if people no longer need their rooms - we will make every effort to ensure that all delegates have places to stay.



## PD MED News January 2011



**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.

### First PD MED results available this year!

The first PD MED results will be presented to the annual collaborators' meeting in June, we then plan to present them publically at the XIX World Congress on Parkinson's disease and related disorders in Shanghai in December 2011.

By the end of December 2010, all PD MED participants will have, at least, reached the 1 year timepoint. All the questionnaires and appointment reminder letters were sent out slightly early to maximise the amount of data we received before the data are frozen for analysis - if you have any outstanding queries, we would appreciate a swift response so that the data are as complete and accurate as possible.

The dataset will be frozen early in the New Year for analysis, this will generate a new round of queries as the data are cleaned. so we would appreciate a prompt response where possible.

We would like to thank you for your ongoing support of PD MED - without your tireless efforts we would not have this exciting data to help inform future practice.

Thank you for all your support

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## Total Return Rate.

100 - 99%	97 - 93%	93 - 85%	84% - or less
James Paget Hospital	St Martins Hospital (Bath)	Evesham Community Hospital	St Peter's Hospital
Darlington Memorial Hospital	Worcester Royal Infirmary	North Tyneside General Hospital	Colchester General Hospital
Abraham Cowley Unit	Birmingham Heartlands Hospital	Manor Hospital	Southampton General Hospital
Bedford Hospital North Wing	Delancey Hospital	Gloucestershire Royal Hospital	Royal Sussex County Hospital
Bridlington & District Hospital	Royal Bournemouth General	Luton & Dunstable Hospital	Kidderminster General Hospital
Bronglais General Hospital	Bishop Auckland General Hospital	Royal Devon & Exeter Hospital	Wansbeck Hospital
Brookfields Hospital	Sutton Cottage Hospital	City Hospital Birmingham	Brighton General Hospital
Hospital Of St Cross	Macclesfield District General	Bedford Hospital South Wing	Peterborough District Hospital
Kettering General Hospital	Leicester Royal Infirmary	Queen Elizabeth Hospital	City Hospitals Sunderland
Newcastle General Hospital	West Cumberland Hospital	Rookwood Hospital	Medway Maritime Hospital
Northern General Hospital	Eryri Hospital	QE The Queen Mother Hospital	Raigmore Hospital
Royal Victoria Day Hospital	Aberdeen Royal Infirmary	Llandudno General Hospital	Rotherham District General
Southend Hospital	Leicester General Hospital	Bishop Auckland General Hospital	Brookfields Hospital
Southern General Hospital	Borders General Hospital	Edith Cavell Hospital	Lymington Day Hospital
Staffordshire General Hospital	Taunton & Somerset Hospital	Frenchay Hospital	Addenbrooke's Hospital
University Hospital Coventry	Dumfries & Galloway Royal	North Devon District Hospital	Ipswich Hospital
University Hospital Of Wales	Watford General Hospital	Royal United Hospital Bath	NHNN
Victoria Central Hospital	Princess Of Wales Hospital	Bucknall Hospital	North Manchester General
Whiston Hospital	Arrowe Park Hospital	New Cross Hospital	Poole General Hospital
William Harvey Hospital	The Royal Oldham Hospital	QE Hospital (Kings Lynn)	Royal Hampshire County Hospital
Woodend General Hospital	Bronllys Hospital	Radcliffe Infirmary	Harold Wood Hospital
Yeovil District Hospital	Salisbury District Hospital	Warwick Hospital	Grantham & District Hospital
Torbay District General Hospital	West Suffolk Hospital	QE Hospital Birmingham	
	Hereford County Hospital	Walton Centre	
	Norfolk & Norwich University	Calderdale Royal Hospital	
	St Richard's Hospital	Fairfield General Hospital	

Unfortunately, given the relative numbers of participants recruited by different sites this translates in to lower overall return rates - see below. The small numbers of patients who have reached the later time points makes the return rate very sensitive to change so please return as many forms to us as possible or inform us of changes in circumstances so we can either arrange to collect the information from a participant's new doctor or not to expect to receive further information.

Please note, if participants are no longer able to complete questionnaires, we will still expect to continue to receive annual follow up data from their clinician unless the participant asks us to stop doing so.

### Return Rate by Year

Year	1	2	3	4	5	6	7	8	9
Return rate%	94	93	90	87	80	74	71	66	66

Given the analyses are performed on a longitudinal basis, any extra data are very useful - even if you've previously missed a time-point or two.

### Missing forms

Lists of all the missing forms for each site have been sent to you in November so that any data that can be obtained post hoc is returned. Thank you to everyone who responded to this request - there was a clear increase in return rate following this exercise.

If you did not receive a list of outstanding forms from your site, can you please let David know by contacting [d.hingley@bham.ac.uk](mailto:d.hingley@bham.ac.uk) or 0121 415 9128 so that he can send a list of requested information to you?



# PD SURG NEWS

January 2011



## PD SURG results published in Lancet Neurology

### Other Publications

Emma MacIntosh has nearly completed the Health Economic analyses of the PD SURG data. She plans to submit the work for publication in the spring.

Work is also continuing on the other secondary endpoints including quality of life (for both patient and carer), psychometry and surgical endpoints. We will keep you updated with their progress.

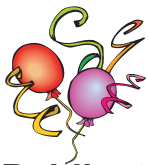
### Grant Extension

To ensure the secondary end points data are published and to continue the long term follow up of the PD SURG dataset, subject to the necessary approvals, we plan to extend the grant end date.

This will compensate for the extra time spent in the recruitment phase of the project and allow a much clearer picture of the long term effects of DBS.



## PD GEN - A DNA Bank



### PD GEN recruits 1,000th patient.

To celebrate the milestone, we will be sending a prize of chocolates & champagne to the Royal Devon & Exeter who provided the 1,000th patient sample.

### Publications

Data from the UK Genome Wide Association Study, GWAS, (in which PD GEN was the largest single contributor of samples) have just been published in Human Molecular Genetics (Hum Mol Genet. 2011 Jan 15;20(2):345-53). This study confirms that genetic variants in the region of both the alpha synuclein and Tau genes are associated with the development of sporadic PD. A meta-analysis of the original UK GWAS data along with those from 4 other large GWAS studies (over 5,000 PD cases and 12,000 controls, and investigating over 7.5 million genetic variants) has also been submitted for publication - we will keep you informed of progress.

### Sample usage

In Autumn 2010 we provided a further 400 PD GEN patient samples for ongoing studies as part of the UK PD Genetics Consortium, aiming to tease out exactly which genetic variants across the genome cause susceptibility to PD, and to analyse the mechanism of their effects. We have also provided PD GEN samples for 3 international research projects, specifically to investigate how genetic variants in the alpha synuclein gene influence survival in PD and also to study the effect of rare genetic variants in the disease. Once the PD MED data are unblinded (later this year) work can also start on pharmacogenomic analyses, linking the genetic data with response to specific therapies, potentially enabling personalised medicine for people with PD.

### Patients who are still eligible to provide samples

Lists of patients who are eligible to provide samples in to the PD GEN DNA bank were included in the site files that were recently sent to all sites. This is a list of all living participants in one of our PD Trials (PD MED, PD SURG or PD REHAB) who have not yet donated a sample.

Updated lists will be sent to each PI in April.



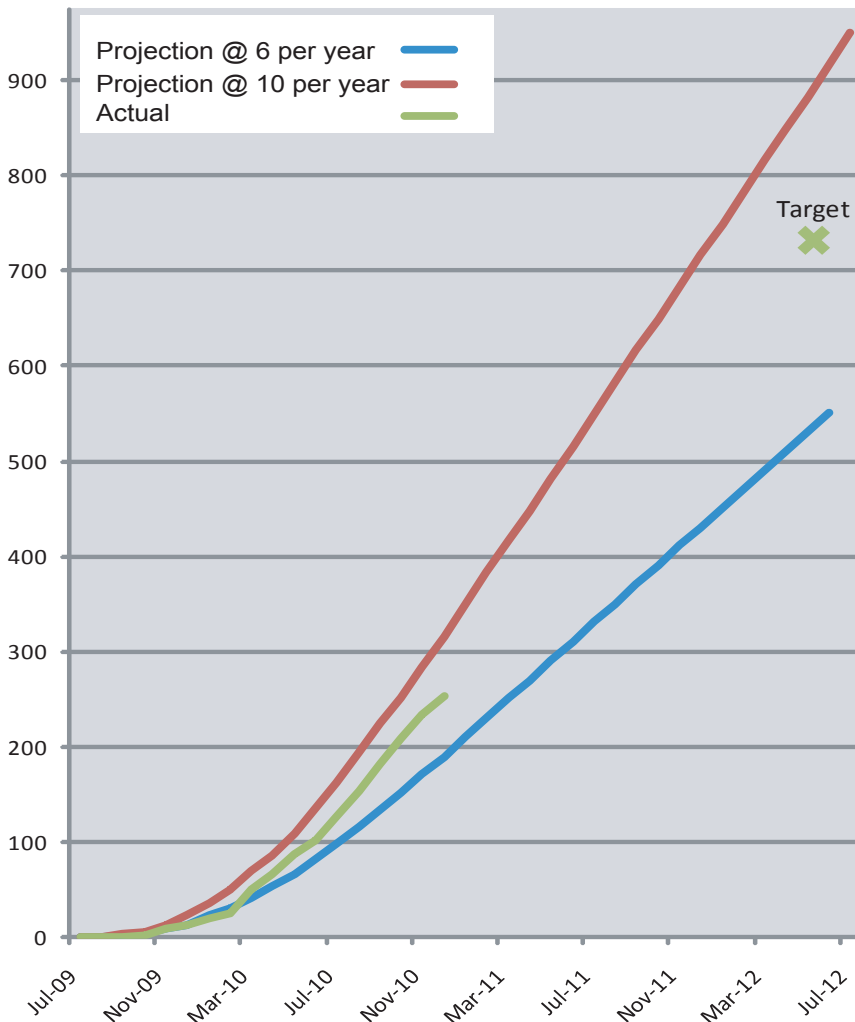
# PD REHAB News



January 2011

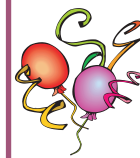
A Randomised Controlled Trial to Assess the Clinical- and Cost-Effectiveness of Physiotherapy and Occupational therapy in Parkinson's Disease.

## PD REHAB has recruited over 250 participants!



As of the end of December 2010, 254 participants have been recruited in to the PD REHAB Clinical Trial. The Royal Devon and Exeter Hospital is currently our top recruiter with 39 participants, followed by Taunton & Somerset with 20, Macclesfield with 18, Darlington with 15 and City Hospital Birmingham, Gloucester Royal Infirmary and the Royal Bournemouth all with 14 participants. We are still on target to recruit on time, despite starting slightly later than planned.

### Prizes!



To celebrate the milestone of reaching 250 participants, we will be sending a prize to the team at St Helen's Hospital who recruited our 250th participant. Just 500 more to go!

### Site Visits

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](mailto:pd-trials@bham.ac.uk).

### Meetings

We have recently had a Therapists' Meeting in Birmingham with over 50 attendees. Slides from the presentations are available on the PD REHAB website: [www.PDREHAB.bham.ac.uk](http://www.PDREHAB.bham.ac.uk).

The PD REHAB sessions at the Annual Collaborators' Meeting will take place on 27th June, the morning will be a general session and the afternoon will be split in to 2 sessions, with a separate session for the therapists. Professor Bas Bloem has agreed to give the pre-dinner talk on the evening of 27th June.

**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)**

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