



PD GEN Newsletter

November 2007

Expansion in PD GEN recruitment

Recruitment to PD GEN has accelerated in the last 6 months thanks to the support of the Dementias and Neurodegenerative Diseases Research Network (DeNDRoN). DeNDRoN research nurses have speeded up obtaining blood samples in the 50% of England that has Local Research Networks. Over the next 6 months, Comprehensive Research Networks (CRN) will be created throughout all areas of England. For those of you without DeNDRoN support, watch out for your local CRN developing so that you can apply early for the support you need. Now would be a good time to discuss this with your Research and Development Department who may know more about what is happening about CRNs in your area.



New technician – normal service will be resumed shortly!

We apologise for the delays in getting PD GEN packs out to some areas. The demand has been so great that the existing system could not cope. Professor Morrison has appointed a new technician who will be responsible for sending out the packs in a more timely manner and processing the samples.

Collection sites

The protocol and thus the ethics approval for PD GEN allows investigators and their medical and nursing colleagues to collect blood samples from patients and carers anywhere in the hospital environment where they will be covered by NHS indemnity. The protocol also allows for collection by the general practitioner.

Collection of samples by research nurses in the patient's home is NOT covered by the protocol or ethics approval and it is unlikely that NHS indemnity would cover such a practise. The PD GEN Management Committee considered including this collection method in a protocol amendment but, on the advice of colleagues who have been through a similar process with MND, we decided that this would be an unnecessarily long and complex process. It seems more efficient to bring groups of patients to centralised clinics to take PD GEN samples rather than to visit patients individually.



Central banking of PD GEN samples

You may be aware that the PD GEN samples are transferred from the Molecular Neurology Unit, University of Birmingham, to an MRC-funded central repository in the University of Manchester called the UK DNA Banking Network. It is from here that samples will be distributed to investigators who have approval from the PD GEN Management Committee to use the samples. The MRC has recently announced continued support for the UK DNA Banking Network. They are also seeking a multi-agency collaboration to create a much larger centralised repository to include a greater proportion of UK DNA sample collections.

Diary Date: PD MED Collaborators' Meeting, Birmingham 8-9th May 2008

Next year's PD MED Collaborators' Meeting will be held as usual in the Botanical Gardens in Birmingham. It will be a little earlier in May and will include the PD SURG Collaborators' Meeting. This will be the first presentation of the initial results of the PD SURG trial, so it will be very exciting. Book the date in your diary now!

Centre	Patients in PD MED/PD SURG	Samples in PD GEN	Patient Samples	Carer Samples	Percentage of PD MED/ SURG patients entered
Dumfries & Galloway Infirmary	5	8	4	4	80%
Torbay Hospital	15	22	12	10	80%
Yeovil Hospital	38	39	26	13	68%
Bronllys Hospital	12	11	8	3	67%
Royal Devon & Exeter Hospital	182	215	120	95	66%
Arrowe Park, Wirral/Victoria Central Hospital	34	37	21	16	62%
City Hospital, B'ham	103	81	55	26	53%
Staffordshire General Hospital	2	1	1	0	50%
St Peter's Hospital	6	5	3	2	50%
Colchester General Hospital	6	6	3	3	50%
Watford General Hospital	21	18	10	8	48%
Fairfield General Hospital	125	77	47	30	38%
Queen Elizabeth Hospital, B'ham	33	19	12	7	36%
Rotherham General Hospital	3	2	1	1	33%
Aberdeen Royal Infirmary	49	27	16	11	33%
Hereford County General	32	16	10	6	31%
Birmingham Heartlands	7	3	2	1	29%
Princess of Wales Hospital	42	16	12	4	29%
QE, B'ham – PD SURG	64	29	18	9	28%
Leicester Royal Infirmary/Leicester General Hosp.	72	30	17	13	24%
St Richards Hospital, (Chichester)	17	6	4	2	24%
Southern General Hospital	9	4	2	2	22%
Walton Centre (Liverpool)	23	7	5	2	22%
Llandudno Hospital (also Ysbyty Gwynedd, Eryri Hospital)	46	14	8	6	17%
West Cumberland Hospital	19	4	3	1	16%
New Cross Hospital (Wolverhampton)	20	5	3	2	15%
Walton Centre – PD SURG	40	11	6	5	15%
Delancey Hospital/Gloucestershire Royal	25	4	3	1	12%
Queen Elizabeth, Queen Mother Hospital, Margate	12	2	1	1	8%
Frenchay Hospital – PD SURG	53	6	3	3	6%
King's College, London – PD SURG	26	0	0	0	0%
Macclesfield General Hospital	9	0	0	0	0%
Total		717	432	283	

Can we help?

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