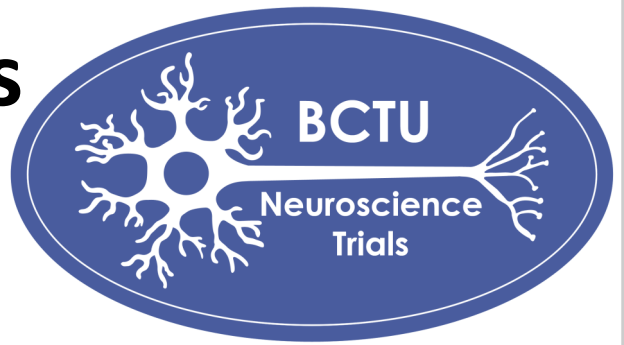


# Neuroscience Trials Newsletter

From the Birmingham Clinical Trials Unit  
May 2012



## **3<sup>rd</sup> Neuroscience Trials Team Newsletter - Francis Dowling**

Welcome to the third quarterly newsletter from the Neuroscience Trials Team. The team here are currently going through the storm before the storm: the PD MED paper is almost finished and will be submitted for publication soon. Also this quarter we are looking to further drive the recruitment of patients to the PD REHAB study before it closes to recruitment at the end of June. That's less than two months to go!

We are also finally getting close to opening all of the four preselected centres for the PD COMM pilot, which, incidentally, is going to have its full trial application reviewed by HTA this month. Interesting times.

I received many positive comments about the newsletter last quarter (and thank you for all of those) and this quarter I feel is no different. We've got a new map from Ryan Ottridge showing the sites involved in PD REHAB which will be on our website and interactive when the new format website launches. We have an article submitted by Chris Beards, one of our trial participants who has sent us a great article out of the blue on his experiences of PD: many thanks Chris. Finally, we also have an article from Linda du Preez, a Clinical Specialist Occupational Therapist from St. Leonards Community Hospital on her thoughts about trying to set up a ParkinsonsNet equivalent in the UK.

So, enough from me and I hope you have a great spring (or is it winter or summer I'm just not sure anymore).



## **PD COMM Pilot Update - Francis Dowling**

A great deal has happened since the last newsletter, we have three sites who have received full R&D approval (or are just about to receive full R&D approval): City Hospital, Birmingham; Fairfield Hospital, Bury; and the Royal Devon & Exeter Hospital in Exeter (expect to receive all your equipment very soon). We are still working on approvals for Southern General in Glasgow but we also have information on a potential new site in East Anglia at the Norfolk & Norwich University Hospital. Rounding off the site information, site visits have been taking place at both City and Southern General Hospitals and have been offered to the other sites involved in the pilot.

We'll be getting more information out about the pilot at the time of our collaborators' meeting in July and I'll be sure to continue the updates here in the newsletter.

## **Make a friend of Parkinson's - Chris Beards**

*A few comments about my experiences with PD over the last 20 years.*

If you have PD you will have to live with it. I don't think it's particularly helpful to fight it, rather do the best you can with it and try to make friends.

When I was diagnosed as having PD, I was already at a low ebb. I knew nothing about Parkinson's so it was not diagnosed or treated for a number of years during which time I was difficult to live and work with, irrational and undisciplined. I'd had many of the symptoms for several years; then the tremor started in 1992/3: this was the last piece of the puzzle and PD was diagnosed. I was just 50.

So, what did having PD mean to me? Well, firstly, it explained the wretched symptoms I and my family had endured for years; secondly, after nearly 25 years my employer said he could manage without me; and thirdly I wondered what it was actually going to mean to me both long and short term. What did life with PD hold in store?

I was given very good advice: not to take too much levodopa; this would have been a short term gain but could lead to problems later on – you have to try and keep a step ahead! No one could tell me what would happen as the disease progressed so you find out as you go along.

I have tried to live with it and not fight it, but be aware that there are chinks in its armour. You have to find them. This will release you to do things you'd thought beyond you. For example my handwriting became tiny and twisted – illegible. I learnt about the word processor, and so didn't give up the writing. If necessary I make special tools to do a job which is defeating me.

Try not to confuse PD with AD (Anno Domini) and put things down to PD when it's really just age and the passage of time. Stay alert: PD has had more practice than you!

You may think that tremor is inescapable but there is deep brain stimulation. If you get the opportunity, go for it: you may not like the idea but it works. I was very fortunate to have DBS nearly 10 years ago and there has hardly been a tremor since. Magic. You see there is a lot you can do. Over the years there does seem to have been a gradual reduction in physical capability, often of a step pattern; so things change slowly for a while and then quite quickly. This can affect your ability to climb ladders and ride a bicycle so you may have to give it up and go fishing!

You may need help to get washed and dressed, eating and drinking may present problems but you can sort them out!

Mobility aids help. I use a stick, a wheeled frame, a wheelchair and an electric buggy depending on the activity. Holidays are difficult to plan for – a crystal ball job! I go at short notice for a few days and this suits my carer too. I try to keep mentally alert... news, current affairs, puzzles, buying and selling on ebay... I really must get on...

One thing I can't help you with is the best carer, because I've got her. The NHS are wonderful too: Consultants, Surgeons, GP, Speech and Language, Physiotherapy, PD nurses, etc., etc.: nothing is ever too much trouble.

And do remember PD isn't the end of the line, there are other things too. Me? Profound deafness and cancer, but Parkinson's is my favourite...



### **PD MED Update - Francis Dowling**

Two important messages to get across for PD MED this month. First, we have recently submitted an application to the NHS Information Centre to gain access to data related to hospital admissions so we can do enhanced safety analyses on the PD MED study.

Second, we need to reiterate the importance of form completion. The longer the study continues the more accurately we can establish best medical practices for PD patients. The only way to do this is by the continuous flow of completed forms from both hospital consultants and individual patients. Please keep up the good work.

## **Is there merit in a UK ParkinsonNet?- Linda du Preez**

I was inspired by the talk Bas Bloem gave at the PD Trials Collaborators' Meeting in June 2011. I was particularly interested in the ParkinsonNet concept that Bas spoke about:

*"ParkinsonNet - a professional regional network within the catchment area of hospitals."*

*The ParkinsonNet Concept: Development, Implementation and Initial Experience  
Movement Disorders Vol.25 No.7 2010*

I understand that ParkinsonNet covers 60 regions in the Netherlands and aims to ensure *equity and quality* of care and rehabilitation offered by Allied Healthcare professionals to people with Parkinson's in the Netherlands.

My two questions following the meeting were:

1. "Is there any merit in the idea of a PD REHAB network of therapists, together with a network of those who participated in the Parkinson's UK annual audit 2011, being used as building blocks for a UK ParkinsonNet?"
2. "Could this network of therapists be taken forward to make a link for further research and training or a UK yellow pages of service provision for people with Parkinson's?"

I went to the trial team with my questions, who in turn spoke to Cath Sackley and reported that the questions would be brought up at the next trial management meeting.

It is perhaps a strange coincidence that 60 Trusts took part in the national audit by Parkinson's UK and that ParkinsonNet covers 60 regions in the Netherlands. I feel it would be wonderful to see the hard work of networking and recruiting individual therapists and teams for both the research work of PD REHAB and the work of Parkinson's UK in their national annual audits built upon for the benefit of patients and the end goal of quality care provision.

We would need people to champion this and funding is always an issue but with the current drive to develop integrated care closer to home with services wrapped around the needs of users, is now the time for a business proposal? Possibly the specialist therapy advisory groups could link in with those interested in taking the concept further...



### **PD SURG & PD GEN Updates - Ryan Ottridge & Pui Au**

Things are moving along nicely with secondary analyses of the PD SURG data: the Health Economics analysis is nearly complete and should be submitted for publication this year and the BCTU team are taking two posters to the Movement Disorders conference in Dublin this June, which will lead on to a full publications at a later date.

The first poster uses the PD SURG data set to test whether the STIMULUS algorithm or proportion of the day spent in the "off" state can predict who is most likely to benefit from Deep Brain Stimulation. Better predictors of surgery results would allow patients to make more informed choices and reduce the risks of surgery for people who are less likely to receive benefit from it.

The second poster reports the lifespan of the batteries used to generate DBS stimulators. These vary in the PD SURG trial from over 8 years to less than one, so a better understanding of the correlation between stimulation levels and lifespan may provide the information to increase their longevity. Since battery replacement is one of the major expenses in Deep Brain Stimulation this would be an important step in bringing down its costs and also reducing the frequency of surgery for the patients.



PD GEN is still open for recruitment of patients and carers who have previously joined one of our PD trials. So far, 1324 patients and 661 carers have kindly donated their blood samples to this DNA bank.

Alongside the blood sample taken we ask patients and carers to complete a short epidemiology questionnaire and these are currently being analysed at the University. The first findings will be presented at this year's Collaborators' Meeting in July.



## **PD REHAB Update**

**- Ryan Ottridge**

### **Recruitment Sites**

- 1) Aberdeen Royal Infirmary
- 2) Central Middlesex Hospital
- 3) City Hospital Birmingham
- 4) Cumberland Infirmary
- 5) Darlington Memorial Hospital
- 6) Dorset County Hospital
- 7) Eryri Hospital
- 8) Fairfield General Hospital
- 9) Gloucestershire Royal Hospital
- 10) Grantham & District Hospital
- 11) Harrogate District Hospital
- 12) Hereford County Hospital
- 13) Hull Royal Infirmary
- 14) Leicester General Hospital
- 15) Lincoln County Hospital
- 16) Macclesfield District General Hospital
- 17) Mount Gould Hospital
- 18) Newmarket Community Hospital
- 19) Norfolk & Norwich University Hospital
- 20) North Devon District Hospital
- 21) Peterborough City Hospital
- 22) Poole General Hospital
- 23) Princess Of Wales Hospital
- 24) Queen Alexandra Hospital
- 25) Royal Blackburn Hospital
- 26) Royal Bournemouth General Hospital
- 27) Royal Devon & Exeter Hospital
- 28) Royal Hampshire County Hospital
- 29) Royal Preston Hospital
- 30) Salisbury District Hospital
- 31) Southampton General Hospital
- 32) St Helens Hospital
- 33) Taunton & Somerset Hospital
- 34) Torbay District General Hospital
- 35) Walton Centre For Neurology & Neurosurgery
- 36) Weston General Hospital
- 37) William Harvey Hospital (Ashford)
- 38) Yeovil District Hospital



### **PD REHAB RECRUITMENT TO END: 30<sup>th</sup> JUNE**

In April the Data Monitoring Committee reviewed the data collected so far and were pleased with the progress made. There is a potential concern regarding crossovers and dropouts but this is below the limit allowed for and is being monitored closely.

We are pleased to say that as things stand the trial will close to recruitment on schedule, at the end of June. Please consider all potential participants for the trial: hopefully we can exceed our recruitment targets!

### **I still need articles!!! Please help**

#### **Contact Details**

If you're interested in sharing with our community of Doctors, Nurses, Therapists and Patients, please supply your articles, stories or experiences to:

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