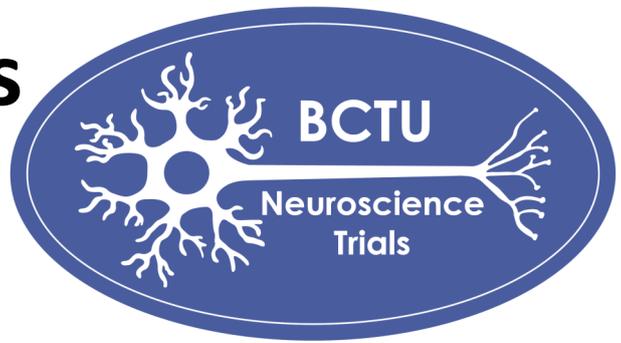


# Neuroscience Trials Newsletter

From the Birmingham Clinical Trials Unit  
October 2012



## October 2012 Edition - Francis Dowling

Welcome to your Autumn edition of the Neuroscience Trials Team Newsletter. As usual its all go go go here in Birmingham: we had our 13th annual PD Collaborators' Meeting at the Birmingham Botanical Gardens in July earlier this year, recruitment closed to PD REHAB at the end of June and we've also revamped all of our websites - but more on that later.



I'd like to thank our participants this issue for all the contributions sent in, you are putting all the medical professionals who work on our studies to shame with your prolific amount of written items. This month we're printing an article from Sylvia Greenland talking about there experiences with PD and her thoughts in response to Chris Beards' piece from our May newsletter. I received some other pieces which I just couldn't fit in to this issue, but don't fret: we will publish them and we are still deciding how they should distributed (either the quarterly newsletter or publishing them to our website), so please don't stop sending them - they are a morale boost for the whole team!

Stat cat made an appearance to help the team

For all our researchers, we have an article from Dr Kay Julier a research liaison manager from Parkinson's UK, with advice on how to get the word out about your research and promoting it to people with Parkinson's who have an interest in participating in research.



Pui welcomes collaborators to this years Collaborators' meeting

Speaking of which, I have a special message from Dr Tim Malone, member of the PD REHAB Trial Steering Committee, who wanted to reiterate to all the participants (patients and carers) of all our trials his thanks for their willingness and interest in research over the years, it's been invaluable. PD REHAB has over 70 participants who are also enrolled in one of our other studies.

Dr Malone continued to say about the BCTU "I think the care you have taken to involve and inform collaborators over the years has helped greatly in keeping us interested and involved and ultimately this has improved our care of patients with Parkinson's." Thanks Tim, I hope we can keep it up.

## To all participants - please reply if required

To ensure that we are not hassling any participants who are involved in one of our portfolio of PD studies, we would like to check if you want to receive this newsletter.

Please use the slip below if you **do not wish** to receive newsletters like these in the future and return it to the freepost address on the back of this newsletter;

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Please remove my name from the Neuroscience Trials Newsletters mailing list;

My name is ..... & my postcode is .....

## A friend in Parkinson's, indeed – Sylvia Greenland

It arrived in a large crisp white envelope that contained the Neuroscience Trials Team Newsletter from the Birmingham Clinical Trials Unit and a summary of information about the outcomes of the years we had all submitted to. There was also an outline of key points about the further set of trials that is to be funded next year. A lot of serious stuff and I, for one, appreciated at long last being given feedback about the results of the PD MED trials we had been taking part in.

But wait a moment – wasn't there something new here? Whence came this sentence at the end of the shiny newsletter, these two lines headed *contact details*, asking for more volunteers for the REHAB part of the trials and also asking for more articles and essays telling how it has been for members of the PD community who have learnt to live with their affliction?

I was immediately hooked and I read the accompanying "sample" article by Chris Beards with interest, gratitude and humiliation. Because for the ten years (yes, *ten* years) since my initial diagnosis of PD nobody had asked me how I felt about it and whether I thought I was making progress in the management of my illness. I had suggested every few months or so that we who were being done to might be able to offer some insights on our conditions, or even some clues as to how we came by the disease, but it seemed little was to be learned at this stage – yes, we did understand that "tweaking" the current studies with unplanned information would invalidate the procedures.

It was about that time that I learned about *Madopar* in much the same way as Chris describes it. At one of the regular out-patient clinics we attended, where we were questioned and assessed and reassured, I had to face the fact that gradually, over the time to come, this stuff called *Madopar* or Levodopa to give it its proper name – would gradually prove less and less effective in keeping us mobile, and there was, at the present time, little prospect of any replacement. For this reason we were advised not to take too much Levodopa but it was hard, knowing that an enhanced dose for a few weeks would improve the ability to live a normal, pre-PD life for a short while.

I see from Chris' article that he dealt with the situation with sensible forward planning. I began to get into trouble because I found out, by trial and error, that overdoses of this *Madopar* stuff could have the effect of taking me on exciting dream-walks and also that most of my friends didn't understand what was happening to me and simply assumed I had managed to obtain a supply of illegal drugs to help me over the worst days of my PD. It was only when I'd been arrested in several foreign airports and subjected to in-depth interviews by important members of the PD team that I realised what was happening.

It took five or six of these so-named *psychotic incidents* for my family and probably my GP as well, to realise they must forbid me to travel alone, and must keep assiduous control of my legal drugs. It's been hard to cut down my doses of *Madopar* but now that I am on my new routine I feel a lot better, a lot less fuzzy in the head. I hope I have stopped frightening people in the middle of the night in strange places.

I know that, like Chris, I am not going to win this one, but the development of knowledge about what happened to me has made it easier to feel positive. We PD patients (volunteers) "enjoy" superb care from the NHS.

Could this be enhanced by the research centres that are accumulating such a wealth of knowledge about PD were to build on the questions asked by Linda du Preez by running a series of courses for newly diagnosed "volunteers"? Wouldn't it be a step forward from just measuring how well we are doing on the latest cocktail of drugs.

You will let me know, won't you?

# PARKINSON'S<sup>UK</sup> CHANGE ATTITUDES. FIND A CURE. JOIN US.

## **Let Parkinson's UK spread the word about your study – Dr Kay Julier**

However big or small, we can help find participants for your Parkinson's research study. By working with us we can help make sure you fill your study and some studies we've helped have even closed early as a result!

### **Promote your study online**

We use our website to let people know about studies recruiting in their area:

Visit: [www.parkinsons.org.uk/researchstudies](http://www.parkinsons.org.uk/researchstudies)

We keep the details short and sweet: a line or two about the study's purpose, where it's being run, who's eligible, the recruitment deadline, who is funding it and a copy of the patient information sheet.

Anyone interested contacts the study team directly.

We update the website each month to make sure studies are still recruiting. NRES have approved our approach so you won't need to get additional approval for us to feature your study on our website.

### **Tap into our network**

We can also promote your research study to our members and supporters through:

#### **Our Research Support Network**

Over 500 people are part of our Research Support Network. We tell our network about opportunities to take part in studies in their area and ask them to contact the site directly if they are interested.

#### **Our online research forum**

Posting the details of your study on our research forum is a great way to connect with people living with Parkinson's as well as to find participants. We can even give you a username and password so that you can answer questions or take part in any discussions about your research.

#### **Our local branches and groups**

We can also help you to access local Parkinson's UK branches and support groups. Local group members may not be online but they are often keen to hear about studies running in their area and may invite you to go along and talk about your study.

### **Find out more**

We support researchers in other ways too. To find out more have a look at our website: <http://www.parkinsons.org.uk/research> or contact us by email [research@parkinsons.org.uk](mailto:research@parkinsons.org.uk).



Professor "two shoes" shall remain nameless

## **Collaborators' Meeting 2012 - Francis Dowling**

The weather faired foul but the meeting was science sunshine all the way. In all seriousness it was a good day had by all, with an interesting examination of the epidemiological information pertaining to the PD GEN cohort, secondary analyses of the PD MED first trial report and a systematic review of the current speech and language therapy research. We also had talks from external speakers looking at cost effectiveness in the PD MED early patients from Seamus Kent as well as further analyses of the quality of life data in PD MED by Professor Crispin Jenkinson. Thanks go out to all the speakers and we hope to see even more collaborators' next year.

## Trial Updates - Francis Dowling



PD MED is closed to recruitment but is still collecting information from both medical professionals and participants with PD. Please continue to send us forms, the long term follow up is crucial for the accuracy of future results and establishing best medical practices in patients with Parkinson's. Thank you for all ongoing support with this important question.

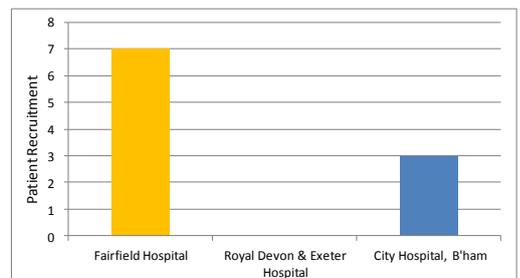
**Important notice** - The first results from the PD MED treatment comparisons have now been released. These show that the differences between the drug classes being compared are small and that all of the treatments being compared are reasonable options for people with PD. Results appear at least as good with the older drugs as with the newer, more expensive drugs. But, longer follow-up is needed for definite conclusions. PD is a condition that affects people for many years and, so far, fewer than half of the patients in PD MED have three years or longer follow-up. So, it is important that participants in PD MED stick to their allocated drug class as far as possible so that PD MED will provide definite answers on what drug class provides the best control of disease symptoms, with the least side-effects, over both the first few years and over the longer term ([www.birmingham.ac.uk/pdmed](http://www.birmingham.ac.uk/pdmed))



PD REHAB has closed to recruitment. With the most successful recruitment to date for the Neuroscience Trials Team, the PD REHAB study recruited to date and to time even though the study started 3 months later than originally planned. The study recruited 763 people with Parkinson's from 38 centres across the UK. Thanks must go out to all the involved participants and medical professionals who made this possible. Good job! ([www.birmingham.ac.uk/pdrehab](http://www.birmingham.ac.uk/pdrehab))



The PD COMM Pilot is now open to recruitment at 3 centres in the UK: Fairfield Hospital, Royal Devon & Exeter Hospital and the City Hospital in Birmingham. We hope to be opening 2 other centres soon. So far we have recruited 10 participants into the PD COMM Pilot study against our target of 60 in the 5 months the study has been open. ([www.birmingham.ac.uk/pdcomm](http://www.birmingham.ac.uk/pdcomm))



PD GEN is still recruiting patients and carers who have joined either PD MED, REHAB, SURG or COMM. We have collected 2062 samples, 1380 from patients with Parkinson's and 682 from their non-blood relative carers.

This is currently the largest collection of PD DNA samples in the UK. The samples have contributed to the Genome wide association study, the largest PD Genetics study to have taken place to date, as well as other studies trying to improve our knowledge of the genetic influences in PD. Please take a look at our website for further detail. ([www.birmingham.ac.uk/pdgen](http://www.birmingham.ac.uk/pdgen))



PD SURG has seen progress in some of the further analyses being done recently. The team took a poster presenting initial work on the life spans of the internal power generators that power deep brain stimulation (DBS) devices – one of the major costs in surgery for Parkinson's – to the Movement Disorders Society conference in Dublin in June, and it is hoped that this will be a precursor to more advanced work on how different settings affect battery life. This could eventually lead to DBS being more cost-effective. The team also took a poster looking at the STIMULUS algorithm, a new hypothesis for predicting which patients are most likely to most benefit from DBS. ([www.birmingham.ac.uk/pdsurg](http://www.birmingham.ac.uk/pdsurg))

### 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:

Newsletter contact - Francis Dowling, Freepost RRKR-JUZR-HZHG, BCTU, Robert Aitken Institute, University of Birmingham, Vincent Drive, Birmingham. B15 2TT.

Email: [PD-Trials@bham.ac.uk](mailto:PD-Trials@bham.ac.uk) Phone: 0121 415 9127