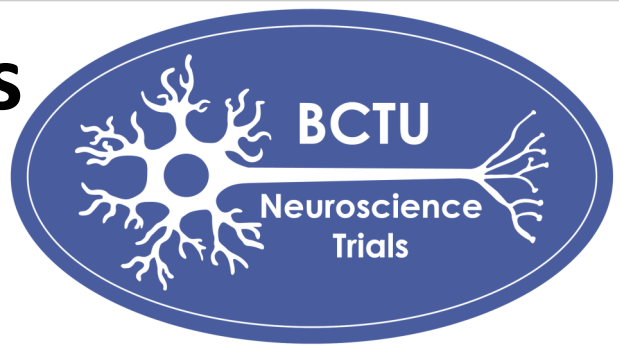


Neuroscience Trials Newsletter

From the Birmingham Clinical Trials Unit
September 2015



This owl has a clear advantage over the mice. They make themselves easy to catch by glowing in the dark!!

September 2015 edition — Lauren Genders

Hello and welcome once again to another edition of the Neurosciences Newsletter. We have lots of exciting news and some very interesting articles in this month's edition.

Over the summer the University of Birmingham has become the home to some very unusual birds and a couple landed just outside the home of BCTU. The city centre of Birmingham and the surrounding area has become home to a large art exhibition which features over 200 owls and little baby owlets. These owls have been scattered around the city and the public has been able to visit, so I thought why not have our own smaller owl spotting trail of our own! I have picked up a couple from around the University of Birmingham (the owls on the front page) and others from further afield.

I am aware that now you may just be looking out for the owls but please also enjoy our interesting articles. The first is from Dr Sharon Muzerengi who is currently looking into the process of going into hospital when you have Parkinson's disease. The second is an article from one of our PD REHAB participants who has given us the details of her Parkinson's experience. And then finally a roundup of all the trials, giving you all the most up to date information about all of the trials in the BCTU neurosciences team ahead of everyone else.

SAVE THE DATE!!

We are planning to have a joint launch meeting for PD COMM and a Trials update for PD MED results as well as status update and news for our other PD Trials on Thursday 17th of March in Birmingham. The main PD COMM launch will take place in the morning with parallel sessions for therapists, nurses and clinicians to either learn more about the nuts and bolts of the PD COMM trial or to hear an update on the ongoing PD MED trial analyses (PD MED later, Health Economics and Quality of Life) and news of the other trials (PD SURG, PD REHAB and PD GEN).

The collaborators meeting is a great opportunity for doctors, nurses and therapists who work across our trials to get together and discuss the new results and practices from around the country. With this in mind, please be aware that we may be contacting you for some data cleaning, so please be on the lookout for those letters!

More information will be following soon but we realise how busy you all are so wanted you to save the date for us. We are delighted that the HTA have funded a full scale phase III trial into Speech and Language therapy for People with PD.



*What do you call an owl with armour?
A knight owl!!!*

Hospitalisation in Parkinson's Disease— Sharon Muzerengi

In the last 18 months we have been conducting a project designed to look at various aspects of hospitalisation in people with Parkinson's disease. This is an important area to study because hospitalisation is one of the major cost drivers for the disease.

When people are admitted to hospital, details of their admission including the reasons for admission, investigations, and procedures performed, and administered treatment, are recorded and transferred to a central database. This information is then used by healthcare organisations and commissioners for making healthcare planning decisions.

It is therefore important that healthcare professionals record this information accurately because of its implications on allocation of resources.

Our project focusses on how accurate medical records for Parkinson's disease hospital admissions at a Birmingham tertiary unit are.

It is also known that when people with Parkinson's disease are admitted to hospital their medications are often incorrectly prescribed or missed and this can result in complications and prolonged hospital stay. So we are also looking at various ways in which people with Parkinson's disease can be managed in the community to prevent hospital admissions and for those who are admitted, interventions that can help improve their hospital experience. The results of the project will be published in the near future.



*A man at the cinema noticed what looked like an owl sitting next to him .
"Are you an owl" asked the man surprised
"Yes" replied the owl.
What are you doing at the movies?"*



Bud's Run and Bash 2015

Bud's run is back this year and they are hoping to once again hold a 5K or 10K run around the University of Birmingham grounds on the 10th October 2015. With a fun sprint track for any youngsters who wanted to join in.

After a fun filled day of running, bbq and sports massage marquee, Bud's bash will be held in the University of Birmingham's Great Hall. For an evening of music, charity auction and raffle.

Last year hundreds of athletes , along with family and friends joined together (even a few famous faces, Paula Radcliffe turned up!) to raise an amazing total of over £27,000 raised for Parkinson's UK. They are hoping that once again they can raise a fantastic amount for Parkinson's UK once again.

Owls feathers are meant to help them blend into their environment. Have you seen any of these nurses around your hospital?

If you are participating in or know of any fundraising for Parkinson's Disease in your area, why not write an article about it for the newsletter!



My Parkinson's Experience—Sally Bonfield

About three years ago, at 56, I began to realise that as I was walking my left arm wasn't moving as my right one was. Also as I was walking around at work, I was supporting my left arm with my right, although it didn't actually hurt, it felt better with support. It didn't seem to know what to do with itself!

I eventually went to my GP who referred me to a neurologist. Meanwhile I'd also seen an article in the newspaper about someone with Parkinson's and that one symptom was often struggling to get change out of a purse, which I often did, like a little old lady!

After the neurologist examined me and I told him about my arm, he asked me if I had any idea what it could be. I told him I felt it could be Parkinson's and he immediately agreed with me. He told me to start on Co-Beneldopa straight away, to inform DVLA and 'did I have any questions?' As I was slightly shell shocked all I could think was 'is it terminal?' He was very pleasant and kind. 'no you die with it not from it!' Very reassuring I'm sure!

He said I'd probably had it for about 5 years, which when I thought about it I probably had. So I rushed back to work and an hour after my diagnosis I was on playground duty at school, with my coffee and whistle surrounded by 150 children thinking 'what on earth can I do about this?' Well of course there's not much you can do is there? You get on with your life and make the best of a bad job.



*What do owls sing when it is raining?
Too wet to woo!*

In fact it was all kept in proportion for me by the fact that I'd only just lost one of my best friends to pancreatic cancer at 49. He died a horrible death within a few months of his diagnosis. My illness was a minor irritation in comparison. Since then, I have actually taken early retirement due to ill health. I couldn't handle the stress of school, a bad Ofsted inspection, resulting in Special Measures, observations, more and more red tape. It made me realise how I had been struggling with work for some time, although I hadn't realised how the illness was affecting me at work.

I do sometimes find I struggle if I am in a large group of people I find myself sitting wide-eyed, like a rabbit caught in the head lights. Is this common?

Most of the time I feel quite positive about my Parkinson's and try not to dwell too much on what the future has in store. It doesn't seem worth worrying about what might happen.

Study Updates



PD COMM Pilot has now finished follow up with all of the participants now reaching the 12 month time point. We have now received 100% of the clinical forms as well as everyone's voice recording (for those who had them). We would like to thank you all for your hard work in making the data collection as successful as possible. We are also data cleaning so will be sending out queries on a rolling basis. The data is currently being analysed by stats so hopefully we will be able to supply you with the results soon. As you have heard the PD COMM team have submitted an application to the NIHR HTA to fund a full scale nationwide trial. The HTA have agreed the final trial design. We have already identified 40 sites to roll the trial out across the country, with a planned start date of early 2016. We will keep you up to date with the progress of the application in our newsletters but in the mean time you are able to keep up to date with the trial on the PD COMM website. (www.birmingham.ac.uk/pdcomm).

Study Updates cont.



The PD MED LATER data is currently being analysed and has already given us some very interesting results. We very much value your dedication to the trial and all of you that were able to bring forward your clinic visits so we can have as much data as possible. As soon as we have finalised the results you will be the first to know. The PD MED EARLY data in The Lancet is now available for open access so you are all able access that now. For those of you who may have missed it in our last newsletter, the results of PD MED have now been published in The Lancet (see here for the abstract ([http://www.thelancet.com/journals/lancet/article/PIIS0140-6736\(14\)60683-8/abstract](http://www.thelancet.com/journals/lancet/article/PIIS0140-6736(14)60683-8/abstract)) or type 'PD MED Lancet' into a search engine). We are still collecting the follow up information from patients, carers and their clinicians so please continue to send your booklets back in. The long term follow up is crucial for the accuracy of future results and establishing the best medical practice for patients with Parkinson's. The team has submitted a no cost extension so we can carry on until October 2016. If you would like to find out some more information of the PD MED study and keep up to date with the trial, please visit our website. (www.birmingham.ac.uk/pdmed)



The PD REHAB manuscript has been rejected by a number of high ranking journals including The Lancet and the British Medical Journal. One reason seems to be the null result (i.e. publication bias in action). It has recently been submitted to the Journal of the American Medical Association. We will let you know once we have any news. The final HTA report has been signed off and will also be published after a print version. In the meantime please see our website for any other information about PD REHAB. (www.birmingham.ac.uk/pdrehab).

PD GEN has now finished collecting samples. We would like to thank you all for your hard work in giving and collecting samples. Thanks to your dedication, PD GEN is one of the largest PD DNA banks in the world. The samples are stored in the Molecular Neurology Laboratory at the University and are available for applications for research. Samples have already been used in many global research projects to try and determine genetic factors involved in Parkinson's disease. The PD GEN epidemiology data is now been published. The first paper appeared in Parkinsonism and Related Disorders: (<http://www.ncbi.nlm.nih.gov/pubmed/25577023> or type 'Systematic review and meta-analysis of hydrocarbon exposure and the risk of Parkinson's disease' into a search engine). If you want any more information or want to keep updated with all that is happening in PD GEN then please check our website (www.birmingham.ac.uk/pdgen).



The newsletter needs your help!

I hope that you have enjoyed reading your copy of the BCTU Neurosciences Trial newsletter. If you would like to write an article for the next edition I would be very happy (and grateful). Articles can be on any aspect that you find interesting, and can be as brief or extensive as you want. Subjects from your experiences as a patient with Parkinson's Disease or as a carer to if you are a research nurse doing your own research into Parkinson's Disease.

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Dr Whooot!!