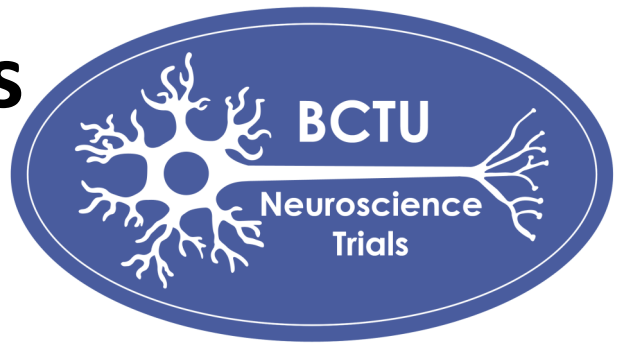


Neuroscience Trials Newsletter

From the Birmingham Clinical Trials Unit
December 2015



Merry Christmas in the BCTU office

December 2015 edition

Once again a very warm hello from all of us here in the Neurosciences team at Birmingham Clinical Trials Unit, and welcome to the final newsletter of 2015. We have had a great year, our PD COMM Pilot trial ended data collection — this data was crucial in securing funding for a full scale trial: the PD COMM Trial from the HTA. See our study update for more information on all of the trials.

We also have a very interesting article on pages 2 and 3 from one of our PD MED participants who gives us his experiences of being diagnosed and living with Parkinson's Disease. Please see page 3 for an update on the PD COMM Launch meeting and PD Trials update. This will be a very exciting meeting and so not to be missed.



We would also like to remind you that BCTU will be closed between Christmas and the New Year. We will be closed from 1pm on Tuesday 22nd December and reopen at 9am on Monday 4th January 2016. We will not be contactable via the phone but any emails will be replied to upon our return.

The PD REHAB paper has now been accepted for publication

The PD REHAB paper has been accepted for publication in JAMA Neurology and will be published first online on 19th January 2016, and then again in the print/online March issue. It will be made free to access on the JAMA Neurology website on 19th July 2016.



If you are not subscribed to the journal but would like to view the paper, it will be free for the week it is published online in January. JAMA Neurology online are able to feature one important article each week in this way and we are delighted that the Editor, Dr Rosenberg, has chosen PD REHAB. The journal team at JAMA Neurology will also feature the article in social media posts on 19th January 2016.

For any more information regarding the PD REHAB trial please see our website for any other information about PD REHAB.
(www.birmingham.ac.uk/pdrehab).



Living with Parkinson's - David Gibbings MBE, FRAeS

Diagnosis

I have led a full life, and a very enjoyable one. I knew what I wanted to do from the age of six on a day out to the 1938 Royal Air Force Display at Hendon. This was the defining moment when I knew that I wanted to fly. I joined the RAF as an Apprentice, went on to train as a navigator and came out of the RAF to join industry in the flight test business. I spent the rest of my working life flight testing aeroplanes and helicopters, including the Rotodyne and Lynx. I retired from Westland as Chief Flight Test Engineer, and continued working as a Flight Test Consultant, Artist and Historian.

My career ran smoothly, with good jobs and overseas lectures, including: USA, Berlin and Moscow. Then the first warnings showed up when my clever farmer wife, who is used to watching animal behaviour, spotted a few abnormalities and shakes. We saw our excellent GP, who took it all seriously, and we started the long trek to get a positive diagnosis. It took over 2 years to get this, including some private appointments. Yeovil is a centre of excellence regarding PD; I was immediately enrolled into their Day Hospital, with the good fortune to be under the care of Dr Kristi Baker MBE and Dr Rashid. Overall it had taken 2½ years to get a diagnosis.

Prompt diagnosis is vital. The present situation is unacceptable, this is not a criticism of the doctors, they can only work with the tools they have, but research needs to come up with a quick and positive answer would take some of the shock away and I do believe this contributes to the breakdown of confidence so often evident with PD sufferers. A new gym set up in Yeovil and as soon as they opened I started attending daily. To my surprise I enjoyed it, I had not expected to gentle social life centred around the coffee bar.

However, I was unable to keep up daily gym, but I continued with my consultancy work. In 2003, I was invited to present the prestigious 'Cierva' lecture to the Royal Aeronautical Society in London. This was a great success, and I was called upon to repeat it around the UK and in America. The Cierva lecture led to my first book on the Rotodyne, which won an award.

Throughout this time I was involved with a friend who was trying to collect and preserve Westland history. The Company Chairman agreed to digitise everything and form a proper collection, unfortunately he died and the task was mine. This task and the forthcoming Company Centenary has since kept me occupied.

In 2010, I was elected a Fellow of the Society of Flight Test Engineers. They only elect one per year and there are only twenty or so worldwide. Then the big surprise, I was awarded the MBE in the 2014 New Year honours. You don't get this level of recognition for what you have done in the more distant past and so it was recognition of work done in the shadow of Parkinson's.

Living and working with Parkinson's

Needless to say, it has not all been plain sailing, PD is a degenerative condition to be ignored at your peril. I met the condition head-on, with the battle cry 'Sorry Mr Parkinson I'm too busy, sod off!' I made a few mistakes, like refusing to start medication until the shakes made it obvious that I had to.

After 2010, I had restricted my driving to local, and had a 'Smart Car' which I loved. I had gone on to Madopar and disaster struck when I fell asleep at the wheel and nearly had a head-on. I am not into 'Russian Roulette', so ended my driving, my independence and my lovely Smart Car. Not being able to drive is worse than the disease itself, and this was made worse by the fact that I have developed a lung condition, which makes it hard to walk more than 100 yds. I still remain defiant and active.

Survival with PD is a full time job, my personal approach is to attack it on all fronts. Most importantly keep your mind active through Sudoku, crosswords, genealogy, Open University, art, computers and local committees. It may not be true, but I believe that it is all in the mind.

Equally important is; Exercise, Exercise, Exercise! Join a gym while you are still fit and take Pilates classes so that you can work independently later. Tai Chi is a God's gift to PD and it has a spiritual side, like a lot of these things, it will only work if you believe in it. I personally believe that you have to be a bit 'bloody minded', and consider yourself at war with PD.

I have also been fortunate in having an ability to draw and paint to a standard where I have enough confidence to go public. Not surprisingly, most of my successes are 'aviation paintings'. Over the last forty years I have sold most of my output and illustrated a few books. Parkinson's hasn't stopped me doing that yet. So here is my next point: if you believe you have even the hint of any ability or talent, and I believe we all have, develop it, you may just surprise yourself. It's all about self-esteem, and it is a bumpy road, which isn't easy on either you, or your carers.

I decided quite early that I was going to proclaim that I had Parkinson's loud and clear. People are immediately sympathetic; some a little bit too cloying for comfort and it's difficult not to be an irritable old devil. They are only being kind, my wife tells me!

I would add a word of warning. A lot of people when first diagnosed with PD seem to cave in, it may even be the majority. My 'all in the mind' approach will not work for them. In any case it's not necessarily true and a bit cruel, there is a narrow line between being a role model and being over bearing.

Carers, just remember, self-esteem is important and for heavens sake avoid the 'Does he take sugar' approach. Believe me it takes courage to accept wheel chair assistance at the airport.

A final thought

I make an effort to tell the world that I have Parkinson's, I believe that the more of us who do this helps awareness. I would like to suggest a small discreet flash of Parkinson's blue about 5mm x 15mm on one lapel. This of course needs to be well publicised, and needs an equivalent for the ladies, nothing too garish or large, but if you've got it, flaunt it!



Thursday 17th March 2016 PD COMM Trial Launch and PD Trials Collaborators' Meeting

We have some more details regarding our joint PD COMM launch meeting and Neurosciences Trials update. It will be taking place on Thursday 17th March at the Council House in Birmingham City centre. Invitations will be sent out in the New Year, but please save the date.

In the morning we are going to have sessions for therapists, nurses and physicians which will give you an oversight of the PD COMM trial. In the afternoon there will be 2 parallel sessions: 1. Therapist led session for the PD COMM SLTs and interested nurses and 2. An update on the trials within the Neurosciences portfolio, this will include the ongoing analyses of the PD MED trial (PD MED later, Health Economics and Quality of Life) as well as news from our other trials (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. We also enjoy meeting you all and putting a face to a name and vice versa find out who it is that send you all those letters! With this in mind, please be aware that we may be contacting you for some data cleaning for the PD MED Trial and PD COMM Pilot, so please be on the look out.

We will be sending out more information soon but we realise how busy you all are so wanted you to save the date for us. We will have a small budget for people who are unable to gain travel funding elsewhere (mostly for therapists and nurses).

We are delighted that the NIHR HTA have funded a full scale phase III trial into Speech and Language therapy for People with PD.

Study Updates



PD COMM Pilot has now finished follow up as all of the participants have reached 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 the Stats team so hopefully we will be able to supply you with the results soon, as soon as we have the results you will be the first to know. In the mean time you are able to keep up to date with the trial on the PD COMM Pilot website. (www.birmingham.ac.uk/pdcomm).



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. The protocol has been submitted to the Research Ethics Committee and we are waiting to hear back from them. We aim to open the trial at 40 sites and begin recruitment in Spring 2016. Sites who have previously expressed an interest in the trial will have received an invite email with information about the trial. We look forward to working with you on this trial so please do get in touch with us. We will keep you up to date with progress of the trial in our newsletters.



The PD MED LATER data is being analysed and has already given us some very interesting results. The PD MED later paper is currently being written. As soon as we have finalised the results we will let you know. We have very much valued your dedication to the trial. This December we have now entered the 15th year of PD MED so we would like to take the opportunity to thank you all for completing the Patient and Carer booklets and for continuing to send us the information back in the follow up forms. We are still collecting the follow up information from clinicians, patients and carers, so please do be on the look out for those envelopes! The long term follow up is crucial for the accuracy of future results and establishing the best medical practice for patients with Parkinson's. We submitted a no cost extension request for PD MED and are happy to announce that we have been successful which means the PD MED has been funded until October 2016. 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). If you would like to find out some more information of the PD MED Trial and keep up to date with the trial, please visit our website. (www.birmingham.ac.uk/pdmed)



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).

I still need articles!

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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