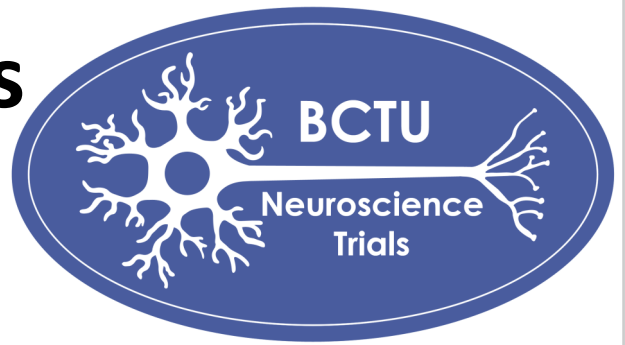


# Neuroscience Trials Newsletter

From the Birmingham Clinical Trials Unit  
January 2018



## **January edition—Published Paper!**



Hello everyone and welcome to another newsletter from the Neurosciences Trials team at BCTU. We have had a fantastic start to this new year—the PD COMM Pilot paper has been published in Pilot and Feasibility Studies Journal! We are very happy to share in the hard work that each and every one of you has contributed to all of our research. We could not do this without you. We are also very pleased to say that if you would like to read the paper it is available free at <http://rdcu.be/EtF0>.

Coming up in this edition we have an overview of the PD COMM Speech and Language Therapist day that we held in December for all our SLTs on the trial. Also you will hear from Ravi Dhaliwal about her and Pui Au's trip to the Parkinson's Disease Nurse Conference. We also have a poem from one of our PD MED participants experience with his Parkinson's. As well as our update on how PD COMM full trial is progressing.

## **Shaping the Neurologist of the future**



Just in case publishing PD COMM Pilot results and being a key part of changing the NICE guidelines (Feb 2017 edition) for Parkinson's wasn't enough. We are also very happy to let you know that the PD MED trial results have been included in the new edition of Bradley's Neurology in Clinical Practice, which is one of the main Neurology textbooks used by Neurologists in training.





## PD COMM Update— Lauren Sturdy

### Recruitment Sites

1. Basildon University Hospital
2. Blackpool Victoria Hospital
3. Birmingham City Hospital
4. Birmingham Heartlands Hospital
5. Buccleuch Lodge
6. Central Middlesex Hospital
7. Diana, Princess of Wales Hospital
8. Dumfries Galloway Royal Infirmary
9. Fairfield General Hospital
10. Forth Valley Royal Hospital
11. Gloucester Royal Hospital
12. Great Western Hospital
13. Guy's and St Thomas' Hospital
14. Harrogate District Hospital
15. Hereford County Hospital
16. Homerton Hospital
17. Leeds General Infirmary
18. Llandudno General Hospital
19. Macclesfield District General Hospital
20. Musgrove Park Hospital
21. Norfolk & Norwich University Hospital
22. Norfolk Community Hospital
23. Queen Elizabeth University Hospital
24. Royal Devon & Exeter Hospital
25. Royal Preston Hospital
26. Southmead Hospital
27. Torbay Hospital
28. Withybush General Hospital



As I am sure you are all aware we are behind in our recruitment to PD COMM. We do know that recruitment can be hard and that you are all extremely busy, however we need more participants in the trial. If there is anything we can do to help you please let us know and we will be happy to support you in anyway we can. For instance, please contact us if you need any more members of staff to be trained in LSVT. We have a few places available on the LSVT LOUD Training days in London on June 1st-2nd.

We are also excited to say that we are going to have a prize for the 100th participant recruited. We will be sending a prize to both the nursing team and the SLT team (even if it's a control participant!) so carry on recruiting and you never know, it could be you. Remember the more you recruit the more likely you are to win the prize.

You will hear more about the SLT day later on in the newsletter but as a sneak peak one of the topics discussed was the need for large scale randomised clinical trials and how they are more robust than smaller trials or individual case studies. As this is the largest clinical trial researching speech therapy in Parkinson's you are helping to gain the evidence that will change practice in the future.

**Parkinson's Disease Nurse  
Specialist Association (PDNSA)  
Conference 17<sup>th</sup> October 2017—  
Ravi Dhaliwal**

We were very kindly invited to have a stall at the PDNSA Conference in Warwick last October. Two members of the Neuroscience Team, Ravi Dhaliwal (Data Manager – pictured right) and Pui Au (Trial Administrator) had the opportunity to attend the day. Our main purpose was to promote the PD COMM trial to the nurses



who perhaps may not have heard of it by handing out leaflets and to provide some help and support to those who are already taking part. This is currently a crucial time in recruitment and we wanted to see if we could get more people involved to help this.

We were amazed at the positive response we received from the nurses about the trial and were really excited to see so many people wanting to find out more information about the trial and how they can get involved. We have worked with many of the nurses on other trials such as PD MED, and so it was lovely to finally meet face-to-face with people we have been working with for such a long time. It was also lovely to meet people from other charities such as the Young Onset Parkinson's Disease (YOMD) and Parkinson's Disease UK.

Finally, we would like to say a big thank you to the PDNSA for inviting us and being such wonderful hosts!

**A Parkinson's Poem by Kenneth Cleal**

Parkinson's is a peculiar illness, it's like you've got two lives.  
One day you feel so very bad, the next day you want to jive.  
I keep telling jokes like I always have, because it makes me feel so good.  
Then I'm on a very good day, and feeling like I should.

When I get bad muscle tension, I can hardly walk or move.  
So I sit down in my reclining chair, until I can get back in the groove.  
When I'm good I do all sorts of jobs, because it gives me great pleasure.  
Because I was a Carpenter, I get out my tape, a piece of wood and then I begin to measure.

When you have Parkinson's, you have to be very very strong.  
Because if you're not positive, everything seems to go wrong.  
I always look on the bright side, because that's the way I am.  
I won't change for Parkinson's, and let it get the upper hand.

When I get bad days, it sometimes makes me feel very upset.  
But then I think of all the people I love and all the wonderful people I've met.  
You have to look on the bright side, because that's the way I am.  
I won't change for Parkinson's, and let it get the upper hand.



## **PD COMM Speech and Language Therapists' (SLTs) Day**

We had a great day at the SLT day in December, where therapists from all over the UK came along or joined us via our first live webinar. We all thoroughly enjoyed it and we hope you did too. In the morning we had a couple of great sessions, starting off with Professor Nick Miller who discussed the communication changes in Parkinson's Disease (PD) and the SLT interventions that are best. Dr Christina Smith then quizzed Dr Caroline Rick on everything one would ever want to know about pragmatic trials. With Professor Carl Clarke ending the morning with a clinical overview of PD and its medical treatments.

After a great lunch of chatting and networking we sat down and listened to Amy Curran, Specialist SLT from Manchester University NHS Foundation Trust, giving her experiences of working on the PD COMM trial. She gave us some great tips for smooth running, mainly that communication is key within the hospital between the SLT, nurses and doctors. After Avril Nicoll gave us an update on the social media for the trial and updated us on the PD COMM community. Please see the trial twitter account below and tweet to let us know how your getting on.

We then split up into groups and all thought about the different aspects of working on PD COMM that could make up either a 'wall of worries' or a 'bridge of benefits.' Lastly Max Hughes spoke on the importance of completing and returning trial paperwork. I think we can all agree that we never like it when we either send or receive queries about missing data and so Max's main point was to remember to complete every question which should reduce the number you receive.

### **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 person with Parkinson's or as a carer to if you are a research nurse or therapist doing your own research into Parkinson's.

### **Contact Details**

Please supply your articles, stories or experiences to: Newsletter contact  
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