

## East Midlands

# RSN NEWS

from the East Midlands Research Support Network

\*\*\* **October 2015 / No 26** \*\*\*

**Special Research Forum edition**



(Forum, by Stuart Miles: FreeDigitalPhotos.net)

### Welcome to News 26.

This edition is devoted primarily to reports of the 4th Annual Forum organised by the East Midlands Research Support Network Steering Group in Loughborough on 10<sup>th</sup>

October 2015 (what a mouthful!). I am grateful to my colleagues who produced the reports and, of course, to those who organised the event. In addition to the factual reports Wendy Morrison has written a vivid personal piece about what she gained from attending.

The newsletter also contains a piece by Amelia Hursey who has recently joined the staff of Parkinson's UK in London. She writes about her aim to increase opportunities for people with Parkinson's to 'participate' in research projects.

We also have a report from John Telford about the work of the RSN Development Team and various snippets of information about websites you might find interesting. Finally there is an invitation for you to get involved in producing this newsletter. Please consider it.

Caroline Maxwell, editor  
[caroline@paddockend.com](mailto:caroline@paddockend.com)  
or 01327 310901

### Inside this issue:

- **Research Forum 2015:**
  - Overview ..... 2
  - Mad Cows & PD ..... 3
  - Gestures and PD..... 4
  - Technology ..... 5
  - LOUD Therapy ..... 7
  - Personal view ..... 11
- **Report from RSN DT .. 13**
- **Growing Participation .15**
- **WPC webinars ..... 18**
- **Coming up ..... 19**
- **Steering Group ..... 19**

... and much more!



(Hand, by kibsri: FreeDigitalPhotos.net)

Parkinson's UK is the operating name of the Parkinson's Disease Society of the United Kingdom. A charity registered in England and Wales (258197) and in Scotland (SCO37554)

# Research Forum 2015

## Parkinson's and Communication: 4<sup>th</sup> Annual East Midlands RSN Forum

*An overview by Lionel Paulo written for the Leicester Branch Newsletter*

Saturday 10<sup>th</sup> October 2015 saw nearly 80 people interested in research into Parkinson's Disease meet at the Loughborough Link Hotel for the 4th Annual Forum staged by the East Midlands Research Support Network Steering Group.

A different theme is examined in detail each year and this time 'Communication' came under the spotlight. The Chair of our group, John Telford, opened proceedings by welcoming everybody and introducing the Chair for the Forum this time, none other than the mild-mannered mountain of a man from Nottingham Branch William Randall. Will told us about his Deep Brain Stimulation surgery and the very favourable results he has been enjoying since then before introducing us to the first speaker Dr Simon Paine.

Simon began with a series of slides explaining what a Neuropathologist does, showing us what the inside of a human brain looks like – the coloured microscopic pictures of neurons in particular looking like abstract art. Simon's enthusiasm and intellect shone through, allied to a plain English presentation that made things understandable to the audience, and an honesty with which he admitted there were no answers yet to some of the questions he was asked.

Up next was Dr Ellen Poliakoff of Manchester University, explaining her research into non-verbal communication and the difficulties Parky people can encounter when having off periods which reduce our voices to a whisper.



*(Human Brain, by ddpavumba:  
FreeDigitalPhotos.net)*

Alex Barker, Advice and Information Officer at AbilityNet, was next, tackling the world of computers and cell phones, programs and 'Apps' that youngsters effortlessly use while many of us are wary or even bewildered by all this hi-tech stuff. Alex showed us a lot of useful things we can get for free that assist with communicating or typing, along with items we have to pay for which give more options. His relaxed approach to these items making it all sound quite straightforward after all.

After lunch Dr Elina Tripoliti of University College London talked about the effects of Deep Brain Stimulation or DBS (Chairman Will Randall and Karen Gavin in the audience being two excellent examples of how effective it can be). This was followed by a brief description of some of the therapies that teach us how to talk louder and clearer, with video clips showing 'before and after' examples that proved their efficacy.

Finally came the panel discussion, chaired by Dr Lynn Bedford of Queens Medical in Nottingham. Simon and Ellen were unable to stay for this, so Alex and Elina were joined by Caroline Bartliff, Specialist Speech & Language Therapist, Specialist Assessment and Rehabilitation Centre at London Road Community Hospital, Derby. Caroline had a stall at the forum with various devices and programs all connected with communication. Evidently the speakers had previously satisfied most of the potential queries as there were very few questions asked before Will took over again to thank the audience for their interest and input, then wound up the day which had gone very well. What will be the theme next year?

## Reports of Individual Sessions

*Dr Simon Paine was the first speaker of the morning. Simon is a Consultant Neuropathologist at Queens Medical Centre in Nottingham where he is a colleague of Dr Lynn Bedford. He specialises in diagnosing diseases of the nervous system and brought along a fascinating model of the brain and some beautiful slides to illustrate his talk.*

*Simon reminded us of the structure of the brain then explained the changes that occur in the brains of People with Parkinson's (PwPs) and finally, while assuring us that there is no evidence that Parkinson's is infectious, pointed out some of the similarities between PD and Mad Cow Disease.*

*Here he gives a summary of his presentation:*

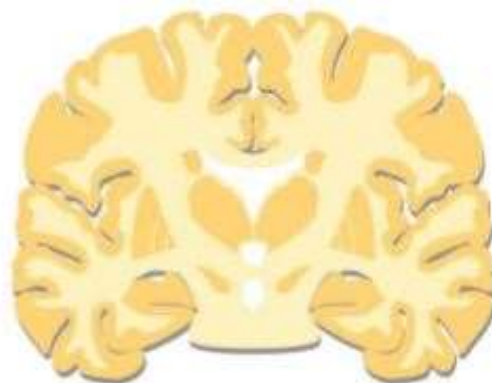
### Mad Cows and Parkinson's Disease

#### Dr Simon Paine, Consultant Neuropathologist

During my talk, I set (and hopefully answered!) three questions:

##### 1. What's in a brain?

Nerve cells, also called brain cells or neurones, (in grey matter) and their connections (in white matter).

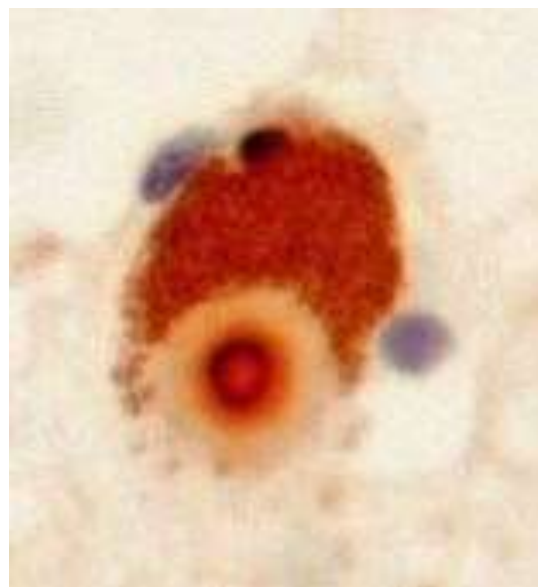


##### 2. What are the changes in the brain in Parkinson's disease?

Parkinson's disease is a complex disorder in which nerve cells are lost from particular brain regions (notably the substantia nigra) and abnormal protein accumulates in some of the remaining nerve cells (alpha-synuclein in Lewy bodies, right).

##### 3. Why might there be similarities between mad cow disease and Parkinson's disease?

Whilst there is no evidence to suggest that Parkinson's disease is infectious, there may be similarities between the way the changes in the brain develop in Parkinson's disease and a group of rare neurological disorders caused by prions.



# Perceptions and Non Verbal Communication in Parkinson's

**Dr Ellen Poliakoff, University of Manchester**

*How are gestures affected by Parkinson's? - Summary by Maria Rice*

This was a talk given by Dr Ellen Poliakoff, who is a senior lecturer in Psychology at the University of Manchester. She talked about the role of gestures in communication in persons with Parkinson's (PwP).

Hand gestures are a help when talking. They provide another level of communication. This interesting piece of research is trying to find out if PwP had lost or gained any gestures or if they exhibited any variations from a healthy control group.



*(Victory Hand Sign, by aopsan: freedigitalphotos.net)*

There are various types of gestures. They work together with speech but are related to the individual. They can be iconic, concrete semantic or metaphoric semantic which just means that they are tied up with what is spoken about. Concrete ones (we were given useful examples) are when we say "the water was rising" and we make a gesture with our hands. The SAME gesture which could accompany a statement like "House prices are rising" would be metaphoric. Other types of gestures include deictic, those are pointing gestures; beat and interactive gestures. The former used for rhythm and emphasis and the latter to pass the speaking role to another person.

There has been research which pointed to PwP having language difficulty with verbs. This may be to do with visualising the actions and their speech problems. Therefore, it is important to ask how gestures are affected in PwP. Since there was only one research paper on gestures before Dr. Poliakoff's work you may wonder what conclusions were arrived at. The only results were that PwP did not seem to use gestures as much as people without the condition. But since there were only 4 people taking part and the gestures did not accompany speech they seemed irrelevant to Dr Poliakoff's studies.

Dr Poliakoff's research compared 2 groups each of approx. 24 people, with and without Parkinson's. It was quite difficult measuring the gestures and it took 10 times as long to analyse and categorize the tapes as it did to record them. Therefore the number of tapes used had to be limited. Another difficulty in doing these studies was the knowledge that if participants were aware the researchers were looking at gestures the participants might not act naturally. With this in mind the participants were told that they would be observed but not that their gestures would be studied, this was in the hope that it would be a more naturalistic study.

The subjects of the research were recorded describing a session to the experimenter. The session contained pressing a large button and grasping a door handle. When analysed the following results were observed. There was no difference in the number of gestures or the types produced between the PwP and the control group. However there were fewer precise gestures when describing press and grasp.

In the next stage of the research, the researchers decided to look at more communicative descriptions. These were also more interesting. A PwP was asked to relate to an addressee a cartoon and how to build the Tower of Hanoi and to describe a plan of a living



area or house. These were recorded and the gestures were analysed. The questions being asked are: 'Does Parkinson's affect how a person's gestures aid communication?' and 'Does Parkinson's affect how well a person can understand gestures?' The conclusion was that co-speech gestures were an important aspect of communication and still being used by PwP with mild to moderate symptoms. They produced the same number of gestures as those without Parkinson's, but their form may have been affected. So in the future the researchers will continue to explore how gestures are affected by Parkinson's and how this may relate to other symptoms such as tremor.



(Thumbs Up and Down, by artur84: FreeDigitalPhotos.net)

The next project the researchers are planning will be about imitation and the potential benefits of mirroring movements and how this fits into Parkinson's. There will be a workshop on 8 April in Manchester when PwP can participate. Please contact [Ellen.Poliakoff@manchester.ac.uk](mailto:Ellen.Poliakoff@manchester.ac.uk) (0161 275 7333) for further details.

## Gadgets, Gizmos and Apps in the World of Communication

**Alex Barker, AbilityNet**

*By Lionel Paulo*

Alex Barker is an 'Advice and Information Officer' for a company called 'AbilityNet.' His father has Parkinson's so he knows the kind of problems we face. The aim of this company is to find ways and means of matching people who need to use communication technology (computers, phones, I-pads, texts, internet etc.) with appropriate systems that do the job required without a level of complexity that would confound them. And who are these people that need this knowledge? ALL OF US!

Communication and media technology has permeated every walk of life these days and the number of people who do not use any aspect of it has dwindled almost to zero. In future it will be more than likely that every one of us will use this technology in one format or another. Fortunately companies like AbilityNet exist to educate and assist us, and listening to Alex explain various programs and 'apps' in a matter-of-fact way made it all seem quite straightforward and nothing to be frightened of.

Alex started with some audience participation by asking how many of us had an apple or I-pad device, or an android device, or a windows device. Nearly everybody confirmed they had one or more of these devices already. Smartphones can be used for voice calls and texts but can also double up as personal organizers/electronic diaries and computers can enable us to produce written work to a high standard even if we have difficulties with typing or 'clicking' on items on-screen. Alex quoted the renowned wordsmith Mark Twain who emphasised how important it is to use words in the right context when he said: "The difference between the right word and the almost right word is the difference between lightning and a lightning bug".

AbilityNet can help us with our communication needs by using its connections to several companies that are well known for their technology; for example Samsung, Microsoft, British Telecom and IBM, providing tech solutions for disabled people in all walks of life. It can help people who find difficulty with articulating their words, or those of us with a very quiet voice or a stutter. Text to speech programs can read out the contents of books and documents etc. Touch screens can be too sensitive for Parky people especially if we have tremors, in which case different technology based on switches can be used, or programs that help to control 'clicking' for you.

Cost is an important consideration for many of us so it is good to know that many apps are free and many 'assistant' programs are already a part of our operating systems built in to our Apple or PC computers. To find out how to adjust your computer go to [www.mycomputermyway.com](http://www.mycomputermyway.com).

'Google now' and 'Siri' can act as personal assistants responding to our voice commands (if our voices are clear) but are not fool proof – yet! Lots of free reminder software such as Google calendar can take the place of Filofaxes, helping organise our lives.

Of course, Alex pointed out that most free technology has only limited functionality so it may be necessary to pay out for apps you need with more options built-in. Fortunately there are many useful apps and programs that are inexpensive (£10 or less) and for items that are expensive funding can sometimes be made available to assist with the cost.



*(Social Network on Smartphone, by Stuart Miles;FreeDigitalPhotos.net)*

Programs such as 'Parkinson's easy-call', 'Google pill reminder' and 'Speak up for Parkinson's' were highlighted on Alex's slides, and solutions to a question from the audience were discussed – Alex noted that AbilityNet exists to find the right apps and programs for each individual's needs. Unlike the old idea of 'One size fits all', the aim today is to determine the person's needs and environment and tailor the technology to meet the specific criteria identified – and to adapt and evolve the technology used as the individual's circumstances and requirements change over time.

Alex concluded by giving us some links that could be very useful and they are listed below:

Alex Barker  
Advice and Information Officer,  
AbilityNet

<http://www.abilitynet.org.uk>

T: 0800 269 545

Follow us on Twitter: @AbilityNet | Facebook: <http://www.facebook.com/abilitynet>

Support us online: <https://mydonate.bt.com/charities/abilitynet>

# LOUD Therapy and the Effects of DBS on People with Parkinson's

Dr Elina Tripoliti, University College London

By Roger Elkin

This very informative and enjoyable session was presented by Dr Elina Tripoliti, a Consultant Speech and Language Therapist with University College London's Unit of Functional Neurosurgery where the primary objective is to further improve the outcome of neurosurgery and the quality of life of patients. The Unit achieves this through clinically treating speech problems arising from neurological diseases via medical and surgical approaches, together with research into understanding the role of basal ganglia-cortical connections on speech.

A total of 400 patients have undergone surgery in the Unit, whilst the effects of medications on speech has informed the research by following most patients over the last 12 years. Dr Tripoliti has published extensively on the effects of medication and stimulation over the long term.

Dr Tripoliti's presentation aimed for us to gain more appreciation:

- of the power of the voice and the force of conversation!
- to understand the effects of medication and surgery on speech
- to experience a taste of LSVT, the only evidence-based behavioral treatment for speech in PD.

When speaking, each of us uses more than 100 muscles which are specialised for speed rather than force and are capable of precise coordination in the performance of speech.

Parkinsonian speech can be typically characterised by

- tremor, rigidity and bradykinesia of the speech musculature
- reduced volume, fast rate and indistinct articulation.

Usually the sufferer does not recognise their own reduction in volume! There is no muscle weakness and consequently the condition can often be characterised by the **“my wife is deaf”** syndrome! Recognition that there is a problem is half the battle.

Elina went on to explain the general principles of Deep Brain Stimulation (DBS), discussing the different treatment options.

DBS target sites differ according to disease and symptoms, with established targets for electrode implants being the thalamus, internal pallidum or the subthalamic nucleus (STN) which is currently the preferred site for Parkinson's treatments. Other areas are under active investigation for DBS.

Speech is less responsive to STN stimulation than limb movements and clinical experience illustrates speech has a variable often negative response to DBS stimulation in PD patients.

There are issues and disagreement concerning the effects of bilateral STN stimulation on speech. These effects depend upon:

- Selection and number of patients
- Severity of the disease and dysarthria
- Speech measurement tools vs. Unified Parkinson's Disease Rating Scale

- Aspect of speech measured
- Time post surgery
- Availability of data before surgery and medication status.

There are two approaches to the prevention and treatment of speech problems:

- Surgical procedures to adjust and localise the implanted electrodes
- Clinical/behavioural
  - Lee Silverman Voice Treatment (LSVT) LOUD therapy
  - Electropalatography (EPG)
  - Music and Singing

**LSVT** fundamentals comprise voice loudness, ability to calibrate volume and the effort involved to control it.

Basically a “mismatch” occurs between the individual’s perception of speech and how others perceive it as being too quiet and indistinct.

LSVT LOUD therapy is an intensive approach of therapist led speech sessions four times a week for one month. This requires intensive high effort and is based on the premise ***‘If you don’t feel like you are talking “too loud” you are not talking loud enough!!’***

Dr Elina explained that LSVT treatment sessions were more feasible using the internet by employing a Web camera, Broadband connection and Skype. This has the advantage of no travel costs, no travel fatigue and the ability to participate from home! Preliminary results are proving successful.

A “brother” treatment is LSVT BIG where physiotherapists promote high amplitude movement in people with Parkinson’s aimed at reducing bradykinetic symptoms. Combining LOUD and BIG therapies could provide a complete physical and speech rehabilitation for people with PD.

The **Electropalatography** study of tongue movements during speech uses a specially made upper palate with 40 electrodes moulded to fit against a speaker’s hard palate to stimulate correct tongue movement. EPG provides dynamic feedback of tongue contact with the hard palate during speech and can thus improve articulation.

**Music and singing** can also be used as an adjunct to therapy. People could benefit from participating in choirs (like the ‘Sing for Joy Choir’ in London and the ‘Ronnie Gardiner Rhythm and Music’ (RGRM) method).– the value of music and rhythm has proven useful in neurological rehabilitation.

In conclusion Dr Tripoliti summarized that :

- Speech remains a complex problem in PD
- The effects of medication and stimulation on speech is variable
- LSVT therapy is an effective voice treatment for people with PD (see [www.lsvtglobal.com](http://www.lsvtglobal.com))



## Closing session and evaluations

*By Caroline Maxwell*

The final session of the day was a panel discussion in which members of the audience could put questions to the previous speakers. Dr Simon Paine and Dr Ellen Poliakoff had already left (researchers too, need to spend some time with their families!) so it was left to Alex Barker and Dr Elina Tripoliti with the assistance of Caroline Bartliff to pick up the questions.

There was discussion about the merits of differing apps, tablets and mobile phones. Two messages were clear; one was that you need to make sure the app you get is compatible with the operating system of your device. In other words an app designed for an android device will not necessarily work effectively on an iPad. The other important message was that just acquiring an app or a new device is not enough; you must use it; you must persist; it may take time to master how it works but your efforts will be rewarded. To begin with it is worth taking time to define what problem you actually want to solve then asking advice before acquiring a specific gadget. Don't expect miracles. It will take time to familiarise yourself with what your new technology can do for you and whether you are prepared to work hard enough to get the results. But in the end it will be worth the effort. For help and support look at the website <https://www.abilitynet.org.uk>

The final session ended with Will Randall thanking the speakers, the organisers, the hotel staff and everyone who had attended. As I left I was aware of numerous clusters of people enthusiastically chatting about the event and, I hope, exchanging contact details for future reference. It had been a lively and informative day and we could all go home with some practical hints on how to improve our communications. We now know that there is a wealth of gadgets, apps and devices out there just waiting for us to take advantage of them.

Only 19 of the 74 participants returned evaluation forms, but their views will be noted and are helpful for future events. The venue was popular but more space between the tables would be welcome. The talk by Dr Simon Paine was rated very highly and several participants reported an increased knowledge of DBS, more awareness of how Parkinson's affects gestures and how speech can be improved by therapies. The information available on various apps and gadgets was also appreciated. But my favourite response to the question on the form which asked "What have you learned?" was undoubtedly "not to visit Papua New Guinea". Rest assured that will be taken into consideration when planning our next forum.

## Communication devices

There are a wide range of devices to facilitate communication for people with Parkinson's. A selection was on display at the Research Forum in Loughborough with opportunities to find out more from Caroline Bartliff, Specialist Speech & Language Therapist. Useful communication devices include:

### **LSVT Clinician Edition**

The Lee Silverman Voice Treatment - LOUD is a treatment for speech disorders with Parkinson's

## **Sona-Speech**

Voice analysis software with real-time displays for visual feedback of critical speech/voice parameters

## **Apps for loudness feedback**

Decibel 10th (android and ipad)

Bla Bla Bla (ipad only)

**Speech Tools** (difficult to find when you search on the ipad, if they can't find it advise to select 'iphone only' option as it might then come up).

**Audio memo** or any record and playback app for extended talking or capturing speech. It enables self reflection on loudness - listening for the drop in decibel and putting that drive back behind speech.

## **Boardmarker activity pad**

Communication aid with a microchip so different layouts can be personalised for different contexts.

## **SL40**

A keyboard based communication aid which speaks the message typed in. Phrases can also be stored for quick access.

## **Allora**

Another keyboard based communication aid but this device also has a switch and scan function.



*(Smartphone with Social Media Icons, by kanate: FreeDigitalPhotos.net)*

For further information please contact Caroline Bartliff, Specialist Speech & Language Therapist, Specialist Assessment and Rehabilitation Centre at London Road Community Hospital, Derby - [caroline.bartliff@nhs.net](mailto:caroline.bartliff@nhs.net)

---

## **“Embracing technology for our health and wellbeing” - A survey that needs your answers**

Our recent Forum on Communication identified ways we can make our lives easier by using various apps, gadgets and devices. So it seems timely to draw your attention to this survey initiated by the National Information Board on behalf of the Department of Health. The aim is to gauge our attitudes to ‘embracing technology for our health and wellbeing’. I have not yet completed the form but the blurb promises it only takes 10 minutes and if we don't voice our opinions now they may not be heard later.

So for further information and to take part please visit:

<https://survey.efmfeedback.com/se/705E3EF520CFEE4D> or see the email to RSN members from Arwyn Davies on 26 October 2015.

Generally we think of the RSN and occasions like the Annual Forum as opportunities to exchange objective scientific information but here Wendy Morrison adds a new perspective and examines the emotional impact of this event. Ed.

## Some Personal Reflections around the Theme of Hope

By Wendy Morrison

Including the word 'support' in its title suggests that this is an important aim of the Research Support Network. So what follows are some thoughts, taking the recent Annual Forum as an example, of how supportive a role it plays. I offer no objective statistics or opinions - just my own very biased and personal view!

First then who might the RSN seek to support? The two groups that spring to mind are the researchers who are invited to speak and those, of which I find myself a reluctant member, whose lives are affected by Parkinson's. For researchers the opportunity to present, with convincing enthusiasm, their work, their conclusions and their predictions and in turn to listen to fellow researchers must be a potentially supportive experience; useful connections can be made.

But what about those of us invited as audience, each bringing with us our own needs and questions born of our own unique experiences? What, if anything, do I find supportive when attending such events? Two things: the first relates to how I feel and the second to how I think.

Like trying to adjust to any form of loss, living with Parkinson's requires considerable emotional juggling; therapeutic theory on grieving describes a progression through a range of feelings – ideally ending up in that illusive place of acceptance. But moving from, for example, denial then anger into the less traumatic place of acceptance is not a once and for all journey. Emotions come and go - sometimes on a daily basis; the pendulum may swing the other way - missing out acceptance altogether and settling for depression or even despair. Destructive though such feelings are they at least have the advantage of familiarity; there is no expectation of something better, no hope and so we protect ourselves from further pain. This neat but limiting trick seems to be what the John Cleese character in 'Clockwise' is referring to when one delay after another makes his much feared lateness more likely. In anguish he announces to his fellow traveller: "It's not the despair Laura. I can deal with the despair. It's the hope I can't stand!" Because with hope comes risk of disappointment.

To continue to hope requires, for me, interaction with people who retain the capacity for undefeated honesty. They may not be feeling 'fine'; they may express sadness or frustration and may feel unfairly embarrassed by, for example, the tremor they seek to hide. But they are brave - willing to share these feelings in the safe and exploratory atmosphere of an RSN conference. Their version of acceptance is active rather than passive. I have talked with such people who can still enjoy the present and imagine of coping with the future. And I have felt very much supported. They give me hope.



(Hopes – Heart Signpost, by Vlado: [FreeDigitalPhotos.net](http://FreeDigitalPhotos.net))

Onto the second type of support – that which works on the way I think, by offering me information. I can listen objectively to speakers - as to any other interesting presentation. Or I listen and strive to relate what I am hearing to my own situation. Such understanding is as close to empowerment and control as I can get.

Sometimes, as with Neuropathologist Dr Paine's presentation, what I hear and see is at least partly familiar to me. For example, the impulse-conducting, interconnecting dendrons of grey matter which showed up beautifully on his stained slide - looking very much like a piece of modern art! I had also heard previous accounts of how brain cells, in just one tiny region of the brain, become filled with protein folded in such maladaptive ways so as to interfere with their functioning. As a consequence the cells cease producing precious dopamine and die.

Why do these cells die? Dr Paine suggested a possible causal link with infectious, microscopic agents called prions found on the surface of cells in degenerative brain conditions - like Parkinson's and CJD. I had not expected Mad Cow Disease to be part of the Parkinson's story.\*

Also new to me was work described by the second speaker, Dr Poliakoff - involving the analysis of conversational gestures by people with Parkinson's. Her research has shown the quality and accuracy of such non-verbal communication can be affected resulting in an impaired capacity to imagine and to reflect back accurately to others. I found what sounds like the potential loss of empathy very disturbing.

And so, do I really want to be informed, to strive to understand? The other option - that deep, deep hole in the sand is safe from elusive hope but free of effort. The work ethic demands more! Having rejected the ostrich solution I am grateful to those working in research and even more so to those whose effort takes the demanding, but quietly hopeful, form of mountaineer Ralph Fiennes 'I just keep putting one foot in front of the other and trudging forward.....'. In my case with the support of the RSN!

*Note \* Dr Paine did reassure us there is NO evidence that PD is infectious. Ed.*

## Getting Involved with this Newsletter

Do you enjoy reading this newsletter? Do you have any ideas for possible articles? Would you like to be involved in producing future editions?

As my Parkinson's Disease progresses it is becoming more difficult for me to find the time and energy to continue editing the newsletter. So the next edition, News 27, will be my last. I have enjoyed being involved. I have learnt a lot both about Parkinson's and about producing a newsletter but the time has come for me to step aside. So the editor's chair will be vacant. Would you like to have a go at being the new occupant?

The way it works at present is that I keep my eyes and ears open for potential articles such as reports of conferences or lab visits, developments in the national organisation, new research initiatives, personal accounts of being involved in research projects and so on. I approach people to write these articles, giving them approximate word counts, some idea of the level of detail and of course the deadline which would usually be about four weeks ahead. The articles trickle in. I read them and make suggestions, usually to improve clarity or to reduce length.

Once I'm satisfied with the content I send it all to Chris Johnson who has been responsible for the layout of the newsletter since it began . Chris also is ready to take a break from these responsibilities so we are looking for somebody who could take over his role. This involves arranging the various articles and other newsletter items in a clear and attractive way and adding appropriate pictures and illustrations. You will need a good knowledge of Word, Publisher or a similar programme; attention to detail and visual sense; and depending on experience 1-2 days every two months for producing the newsletter, and additional time to be involved in the East Midlands RSN such as meetings, events etc. This job is very satisfying because you have tangible results.

Once the content and layout is finalised Lionel, the Steering Group Secretary and 'Holder of the Lists' takes over. Lionel adds his inimitable letter and distributes the finished newsletter to everyone on his list.

It is likely that there will be other steering group roles to fill before long but meanwhile please consider trying your hand at producing this newsletter. Please contact me Chris or Lionel for more details.

Caroline Maxwell. 01327 310901 all email: [Caroline@paddockend.com](mailto:Caroline@paddockend.com)

## The Bigger Picture

### What the RSN Development Team is doing

*By John Telford*



*The RSN Development Team (Photo Parkinson's UK)*

The RSN Development Team is a group of volunteers and staff who monitor how the RSN is developing and initiates actions to promote Parkinson's research. It meets three or four times a year and the last meeting was on October 16th. Below are some of the things we dealt with.

The RSN also has a staff team who help execute the charity's policy on research promotion especially with regard to the wider membership.

Amelia Hursey was appointed to the position of Participation Manager not long ago and she describes her role in this edition of RSN News on page 15. 'Participation' relates to signing up people as 'subjects' to studies and clinical trials. Amelia reported at the meeting that she is making progress in establishing a properly coordinated 'exchange'. I don't understand why a system for matching volunteers to Parkinson's research projects who need them has not been comprehensively developed up to now. But now there is a deliberate exercise aimed at identifying projects, registering people who are keen to



participate and coordinating action between various organisations. There is an existing list of Parkinson's UK funded projects looking for participants which you should look at: <http://www.parkinsons.org.uk/content/take-part-parkinsons-research-list-uk-studies>

The other side of the coin, termed 'Involvement', is the participation of people living with Parkinson's in the initiation and management of Parkinson's research projects. If people living with the condition can feed in views based on their unique experience at the earliest stages of project design, the projects are more likely to meet their objectives. There was a fear that project leaders might not want 'amateurs interfering' with their projects but it turns out that most researchers are delighted to have members of the Parkinson's community on board. There is now to be a clause in the application form for Parkinson's UK grants that asks how patients will be involved on the project board. There is a new staff person working in this area now : Izzy Abbey-Vital.

There are two RSN DT Steering Groups working on the two topics of Participation and Involvement made up of members and staff and we hope that their work will have practical results soon which will provide people like you with an easier pathway for participating and being involved in the research that is going on.

Clare Stephenson, the RSN Manager, was looking radiant and happy as she looked forward to maternity leave! Anna Louise Smith will take over her role. Anna has been doing a lot of work encouraging the formation of volunteer – researcher RSN groups around the country. We hope we can exchange information and newsletters with them as they get going and even visit each others' events. They are being formed in Yorkshire, the North East, and the South West and South Wales with potential elsewhere.

Getting good drugs to market – and more quickly – is a priority for Parkinson's UK. This is known as the 'Critical Path' project and Parkinson's UK has just appointed Jan Kulagowski as 'Drug Discovery Manager' to lead this effort to coordinate Universities, drug companies and non-profit organisations to streamline this process and ensure promising discoveries don't founder.

Overlapping with this is a project to look for treatments that are already approved that happen to have a beneficial effect on Parkinson's. This is the so-called 're-purposing' of drugs. As a supporting sub-project, the RSN Development Team has found a number of volunteers to search the whole of the Parkinson's On-line Forum for references to drugs and other substances which have affected Parkinson's symptoms even though they weren't taken for Parkinson's. Yes, they are searching thousands of 'Posts!', but many hands make light work and we should have all the results in a few weeks. There is also a form you can fill in if YOU have discovered that a drug that you were taking for something else affected your Parkinson's symptoms. Let me know if this applies to you and I'll send you the form. You never know, there might be something out there that is good for Parkinson's that we have not realised yet.

There is a lot going on. For much of it there are staff members committed to the pursuit. But there is also a lot that involves and is being initiated by volunteers around the country. This could be you!

## ‘Participation’ and ‘Involvement’

*In News 25 we reported that although many people express an interest in research only a few actually take steps to become personally involved. The 2 words, ‘participation’ and ‘involvement’ take on rather specialised meanings in this context. ‘Participation’ refers to individuals taking part in research as subjects of trials and studies. ‘Involvement’ on the other hand refers to the process in which volunteers or other lay people use their personal skills and experience to contribute to the planning, monitoring or management of a research project. See John Telford’s report on the RSN DT on page 13 of this newsletter. Parkinson’s UK has created 2 new posts, one to promote ‘Involvement’ and the other, to which Amelia Hursey has been appointed, to maximise ‘participation’ by people affected by Parkinson’s. Here, Amelia writes about her job. Caroline Maxwell*

## Increasing Participation from all Angles

By Amelia Hursey

I started at Parkinson’s UK as the Senior Research Participation Officer on 1 July this year. This was a new position, created because people told us they wanted more opportunities to take part in research – something highlighted in the last East Midlands Research Support Network newsletter, News 25

So how am I going to help with this? I suppose my overall aim is to ‘join things together’. There is already so much exciting research activity happening, I want to help share this with the right people at the right time.

I was very lucky to come into the position with some great foundations created by the research team, specifically the Research Support Network (RSN), our network of individuals who are interested in furthering research into the condition. For information and to join just email: [www.parkinsons.org.uk/RSN](http://www.parkinsons.org.uk/RSN). You do not have to be a member of Parkinson’s UK. Currently 1700 people are registered all across the UK and this number is ever increasing.

Researchers can approach us at Parkinson’s UK with their trial or study asking for help to find and recruit appropriate volunteers to participate in their project. We can pass on this request to individuals who might be interested in a number of ways, through the RSN, on our online research forum and website, on social media and through our newsletters as well as by linking the researchers with local support groups. By increasing the profile of how we can help with recruitment I hope we can provide more opportunities for people to participate in research.

The vast majority of research into Parkinson’s in UK is done by research staff supported by the government’s National Institute of Health Research (NIHR). We don’t know where exactly all of this research currently happens. So one of the tasks I have been doing is to map this out so it can be shared.

Along with members of the Excellence Network – a network of professionals created by Parkinson’s UK to improve services, increase expertise and engage effectively with people with Parkinson’s – we plan to create an interactive system where people can easily find out where research is happening and how they can get involved.

I have also been very fortunate to work with a wonderful group of people who are passionate about taking participation forward. This Participation Steering Group, which consists of both staff and volunteers is a sub-group of the RSN Development Team. It was set up a year ago and is now well established as an influential group within Parkinson's UK. We have our next big get together on the 27 Oct and will be addressing barriers to research we identified in a survey earlier this year. We are also going to be working through the information we currently have to share about Clinical Trials, aiming to confront people's research 'fears'.

With all this hard work I am sure we can increase opportunities for people to participate in research. What should the take home messages be for you? Please ask your GP, Nurse, Consultant, and any health care professional you meet about research and research opportunities. The more you ask about it, the more it will encourage them to engage with research on your behalf.

Also if you would like to hear about research opportunities please join the Research Support Network: [www.parkinsons.org.uk/RSN](http://www.parkinsons.org.uk/RSN). Being part of the list will allow us to send you details about research trials in your area.

Any research you hear about in your area please feel free to share with your Area Development Manager or email us at: [Research@parkinsons.org.uk](mailto:Research@parkinsons.org.uk)

The most effective way we are going to increase participation is by spreading the word!

## Short Pieces on a Theme of Hope

\* **Update from AllTrials: One person CAN make a difference:** Consultant Diabetologist Dr Aus Alzaid from Saudi Arabia was interested in the results of a clinical trial investigating the effect of metformin on cognitive function. The trial was completed in 2012 but results have never been published. After writing emails to the researchers and academic institution asking for the missing results, we have now heard they will be published before the end of the year! The efforts of just one person really can make all the difference.

\* Dr Patrick Lewis, Parkinson's Research Fellow, gets to the heart of the matter when he writes: "*Perhaps the biggest challenge is that we still do not really understand the changes in the brain that cause brain cells to die, dopamine levels to fall and the symptoms of Parkinson's to develop. Without an understanding of this process, we don't have clear idea of how to design new drugs that can interfere and stop it in its tracks.*" However, he continues by saying: "*But recent genetic discoveries have boosted the search for new and better treatments.*" - See more at: <http://bit.ly/1JJtmWk>

\* The University of Maryland is developing the use of non-invasive MRI guided focused ultrasound to treat severe dyskinesia in some Parkinson's patients. The principal investigator, Howard M. Eisenberg writes "*utilization of MRI-guided focused ultrasound could help limit the life-altering side effects like dyskinesia to make the disease more manageable and less debilitating.*"

Source: [University of Maryland Medicine Tests Novel Treatment for Parkinsons | University of Maryland Medical Center](http://umm.edu/news-and-events/news-releases/2015/university-of-maryland-medicine-tests-novel-treatment-for-parkinsons#ixzz3pUkQ0IWp) <http://umm.edu/news-and-events/news-releases/2015/university-of-maryland-medicine-tests-novel-treatment-for-parkinsons#ixzz3pUkQ0IWp>

University of Maryland Medical Center

Follow us: [@UMMC on Twitter](https://twitter.com/UMMC) | [MedCenter on Facebook](#)

## Beware the Armchair!

We are all aware of the importance of exercise and many of us belong to an exercise group or make an effort to exercise regularly. But researchers at the University of Michigan have suggested a different perspective. Their study has shown that everyday tasks such as doing the dishes, making the beds, walking round the neighbourhood and generally keeping moving are even more beneficial to maintaining mobility for people with Parkinson's than regular exercise sessions. People with Parkinson's often have problems with balance and freezing of gait which cause them to lead a rather sedentary life in an attempt to avoid falls.



*(Luxury Red Leather Armchair, by satit-srihin;  
FreeDigitalPhotos.net)*

The study by Nicolaas Bohnen M.D., Ph.D director of the U-M Functional Neuroimaging, Cognitive and Mobility Laboratory at the University of Michigan monitored both patients who participated in formal exercise and those who just kept moving doing everyday tasks. Researchers found that non-exercise physical activity was linked to less severe motor symptoms, and that non-exercise physical activity protected motor skills even among patients with differing levels of dopamine.

"I tell my patients to stand up, sit less, and move more," said Nicolaas Bohnen.

For more details of the report see <http://www.uofmhealth.org/news/archive/201509/everyday-activity-more-beneficial-occasional-strenuous>.

*Thanks to John Telford for spotting this piece of news. Ed.*

---

### **Free online course run by the University of Birmingham**

<https://www.futurelearn.com/courses/good-brain-bad-brain-parkinsons>

## Good Brain, Bad Brain: Parkinson's Disease

**Learn the fundamentals of Parkinson's disease with this free online course. What causes it and what we can do to treat it?**

This free online course is aimed at anyone who wants to find out the fundamentals of Parkinson's disease. We will look at how Parkinson's disease affects people, what causes it, what we can do to try to ameliorate the symptoms of Parkinson's and what we don't yet know about it.

Follow this link to go to the Future Learn website which has a video about this course:  
<https://www.futurelearn.com/courses/good-brain-bad-brain-parkinsons>

## WPC -

# World Parkinson Coalition – World Parkinson Congress

Listen to some excellent, short  
**Conversations about Parkinson's**  
in the **Portland Countdown** series of podcasts.

Recent Topics:

**Parkinson's: the basics; Stopping disease progression; Exercise**

Go to: <http://www.worldpdcoalition.org/?page=PortlandCountdown>

*They are very interesting and up to date!*



If you want to continue exploring the scientific advances in understanding Parkinson's, you can learn more by viewing the free archived

**Web-casts from the World Parkinson Coalition.**

**The last 3-day programme took place on October 6<sup>th</sup> - 8<sup>th</sup> and are now available on-line.**

These web casts are a bit like having the World Parkinson Congress every year – and you do not have to go thousands of miles to attend. You can view the recorded sessions right now.

For more information and to register go to:

<http://tinyurl.com/WPCUpdate>

When you register you will be emailed the link for accessing the sessions directly.

These sessions include:

**Therapeutic Strategies; Alpha-synuclein; Emerging Targets;**  
**Exercise; Cognitive Challenges; Stem Cell Therapy.**



***The next full World Parkinson Congress is in  
Portland, Oregon, USA in October 2016***

## [Parkinson's UK joins the Charity Open Access Fund](#)

Parkinson's UK is now a member of the Charity Open Access Fund. This will mean that all the research funded by the charity can be published in high-quality, peer-reviewed journals and shared as widely as possible through free, unrestricted online access. That means that you can access it online too and read the scientific papers for yourself rather than having to rely on short abstracts.

Find out more: <http://www.parkinsons.org.uk/content/open-access-publishing-researchers>



## Coming up in the next issue...

- Future plans for the East Midlands RSN Steering Group
- What is involved in donating to the brain bank?
- Clinicians' 'tools' for diagnosis and monitoring
- What is the point of Lay Grant Reviewers?

Any other suggestions are welcome. Please contact the editor.

EMRSN News is published by the East Midlands Research Support Network (RSN). Through the RSN network, anyone can get involved in research and raise funds and awareness for Parkinson's research.

The views expressed EMRSN News are not necessarily those of the Editor, the Editorial Group, the EMRSN Steering Group or Parkinson's UK. Please send us questions, contributions, event notices and newsletters.

Editor: Caroline Maxwell  
([caroline@paddockend.com](mailto:caroline@paddockend.com) or  
01327 310901)

Editorial Team: Lionel Paulo, John Telford, Roger Elkin, Daniel Paulo, Chris Johnson

Visit our page on the Parkinson's UK site:  
<http://www.parkinsons.org.uk/content/east-midlands-research-support-network>

There is also an RSN section on the Parkinson's UK Forum:

<http://www.parkinsons.org.uk/forum>

### STEERING GROUP

CHAIR:

**John Telford**, Leicester  
[jntelford@ntlworld.com](mailto:jntelford@ntlworld.com)

SECRETARY:

**Lionel Paulo**, Leicester  
[ljpaulostk@talktalk.net](mailto:ljpaulostk@talktalk.net)

MEMBERS:

**Richard Brown**, Sleaford, Lincolnshire

**Roger and Kath Elkin**, Preston Capes, Northants

**Chris Johnson**, Derby

**Caroline Maxwell**, Daventry, Northants

**Maria Rice**, Nottingham

**Graham Thorp**, Shepshed, Leics

**Dr Lynn Bedford**, University of Nottingham

**Claire Stephenson**, Parkinson's UK

[Return to top](#)