

OUR NEWS

East Midlands Research Support Network News

No 3 Sept 2012

This third edition of our newsletter will reach you shortly before our first open event, the East Midlands Regional Research Forum at Leicester University on Saturday 13 October.

This promises to be a fascinating day, planned to bring us information about current research and to provide opportunities to meet other people with similar interests. You will all have received details of the event earlier and many will have already applied but places are still available. Just contact Lionel Paulo at lipaulostk@talktalk.net

Both the Forum and this newsletter are practical outcomes of work by members of the Research Support Network Steering Group. After working together for a year now the Steering Group members are learning each other's strengths and skills and developing into a productive team. We are the start of John Telford's Community of People described below. This edition of the newsletter includes personal contributions from 5 of us, all volunteers. But we should not forget the expertise and practical support given by Parkinson's UK staff and in particular Tyna Brych who has been and will, I hope, continue to be an invaluable member of our group.

Visions for the Network

Collected and edited by Chris Johnson (who is also responsible for the layout and appearance of the newsletter)

In September members of the Steering Group were invited to write a statement of their vision for the East Midlands Research Support Network. We are spending significant amounts of time and effort on the Research Support Network and believe in its importance, but what makes us want to be involved? What should we aim to achieve? What is the value of our efforts?

Inside this issue...

- **Steering Group**
- **A new Parkinson's Wiki project**
- **Skydive for Parkinson's**
- **Diary of joining a drugs trial**
- **Research Conference in York**
- **My vision**
- **More ideas on the 8 basic activities**



(Human brain, by dream designs: 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)

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The aim of publishing these statements is to show the range of individual visions and motivations which have got us to where we are now and which serve as a basis for a successful future - 'Vision is tomorrow's reality expressed as an idea today'.

Vision statements

We believe that current research is finding ways to improve the lives of people with Parkinson's and will eventually develop a cure. Our network enables people in the East Midlands from a wide range of backgrounds to share information about these developments in non-scientific language and to work together to promote further research. (Caroline Maxwell)

The East Midlands Research Support Network brings together people with Parkinson's, researchers and other interested persons to better understand and promote research into effective mutual support, improved treatment and a cure. (Chris Johnson)

At a crossroads

Put briefly, Lionel Paulo hopes the following would come to be:

- Collecting data from all areas and the web.
- Comprehending and collating this data.
- Connecting different researchers where results may be complementary.
- Communicating results to the rest of the research community.
- Collecting funds to pay for our activities.
- And still being alive the day a cure is found!

Lionel explains his vision in a longer statement (see [page 7](#)).

Community of people

John Telford's vision for the Research Support Network in the East Midlands (and anywhere else) is:

An active, inclusive and continually expanding community of people...

- ... who share a commitment to promote research into Parkinson's for the benefit of all those affected by it
- ... who are imaginative about what can be done
- ... who are keen and willing to make appropriate activities happen in cooperation with others, both volunteers and staff
- ... who communicate mainly over the internet but also by phone and by the occasional face to face meeting
- ... and who are realistic, can think through what the aim of 'promoting' or 'supporting' research really means and are focused on what would be effective.

STEERING GROUP

CHAIR:

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SECRETARY:

Lionel Paulo, Leicester
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MEMBERS:

Richard Brown, Sleaford,
Lincolnshire

Alan Daniels, Lincolnshire

Chris Johnson, Derby

Caroline Maxwell, Daventry,
Northants

Maria Rice, Nottingham

Tyna Brych, Parkinson's UK
East Midlands

William Waites, Nottingham



(Social networking, by digitalart:
freedigitalphotos.net)

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We have identified 8 types of activity as examples of what the group should promote:

- | | |
|-----------------------------------------|-----------------------------------------|
| 1. Fundraising | 5. Serving on the Lay Review Panel |
| 2. Attending meetings on research | 6. Keeping abreast of research progress |
| 3. Going on lab visits | 7. Speaking to branches about research |
| 4. Participation in trials and studies. | 8. Supporting the Brain Bank |

See [page 8](#) for more ideas on these activities.



(Cell with nucleus, by jscreationzs: freedigitalphotos.net)

Maria Rice explains her vision for the group by answering three questions:

What makes you want to be involved?

1. Having a science background I realise how important it is for me to analyse what is happening in the research community.
2. I have always been interested in scientific research; all the more now that I have Parkinson's.
3. It is important that as many people as possible participate in clinical trials if we are to find a cure.

What should we aim to achieve?

1. A cure
2. Relief from the suffering brought on by Parkinson's

What is the value of our efforts?

1. Getting better medication?
2. Encouragement for researchers of all diseases.
3. Participation to help others

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**What would be your answers to those three questions?**

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A new Parkinson's Wiki Project that you can take part in

A new wiki has been started for all those interested in scientific research into Parkinson's. It is a 'Learning Project' within Wikiversity, a sister project to the highly regarded Wikipedia.

A wiki is a website which allows its users to add and modify its content via a web browser. This new wiki is called **The Science Behind Parkinson's Disease** and everyone throughout the world, particularly those affected by Parkinson's, can participate as a reader or a contributor.

Go to http://en.wikiversity.org/wiki/Parkinson's_Science to have a look at what has been produced so far.

The general idea

The project is for people who want to learn about the science behind Parkinson's.

There is a Magazine Section for articles about current research developments.

The wiki is also for people who follow Parkinson's science and current research and want to write about it and discuss emerging issues.

There is a section under development for people new to Parkinson's who want an easy introduction to what lies behind the condition – we need people like you to say what questions you had when first diagnosed and what questions arose after that.

You will find something of interest right now.

And there are ways that you can help develop the wiki in small and larger ways to make this initiative more useful to others living with Parkinson's.

http://en.wikiversity.org/wiki/Parkinson's_Science

An Active Community Contemplating and Communicating the Complexities of Parkinson's Comprehensively and Comprehensibly

This Parkinson's Science wiki has been started by a few individuals and is now being opened up globally to interested parties who would like to participate in its development. Like all Wikiversity projects it is not associated with nor controlled by any organisation but is open to all. Please contact me if you have any questions about the initiative or want more guidance about how to be involved.

John Telford

droflet@virginmedia.com (**Droflet** : Wikiversity User Name)

East Midlands Research Support Network News is published bi-monthly by the Steering Group of the East Midlands Research Support Network. The next deadline for contributions is **Wednesday 7 November**. Please send us a copy of your branch newsletter. We are particularly interested to hear of activities to do with research which we could mention next time.

Editor: Caroline Maxwell
caroline@paddockend.com

Editorial Group: Lionel Paulo, John Telford, Chris Johnson

We look forward to hearing from you!

(photo: John Baggaley)



Skydive for Parkinson's

The droning whirr of the aeroplane's propeller gradually became louder as it approached the group of people I was with, signalling that the time had come to climb on board and take to the skies. My instructor boarded first and sat down at the front, I was next and sat in front of him, somewhat uncomfortable as there were no seats, and I watched the other intrepid skydivers take their places. It was easy to spot the novices, licking their dry lips revealing nerves beginning to jangle. Strangely enough I still felt calm and cool as a cucumber.

Within minutes we were nearly two and a half miles above the Nottinghamshire countryside, and one by one my fellow passengers edged their way towards the hatch which had opened, pausing for a moment on the edge before letting go and disappearing. Finally I reached the hatch, my instructor right behind me, the two of us shackled together by huge metal clips and harnesses. The cameraman was hanging off the side of the aircraft waiting for the moment as I crossed my arms and put my head back, and suddenly WHOOSH!! The 'plane had gone and for a second my stomach went with it, the instructor quickly levelling us out and tapping my shoulder, the signal to open up. The roaring, buffeting streams of air felt like high-powered jets inside a Jacuzzi, and try as I might I could not get my hand to my mouth to blow a kiss to the camera and had to content myself with wiggling my fingers instead.

The ground below looked like a patchwork quilt of fields, appearing almost unreal as though it was a miniature model or a big photograph spread before me, and I felt like I was in a boiling maelstrom of air floating in the sky and not really falling at all. This surreal feeling abruptly vanished as my instructor's parachute opened and with a savage lurch I felt like we were going up again as the cameraman swiftly fell away from us, his aim being to land first and film our landing.



Serenity replaced turbulence as we slowly drifted down, conversation now being possible, so we talked about holidays and home, but the countryside below still seemed unreal. After nearly five minutes reality reasserted itself as I touched terra firma again. What an experience!

Written by Lionel Paulo, and told by Rhona Paulo, his skydiving wife. Rhona raised £1,300.00 for Parkinson's UK!

(photo: John Baggaley)

Diary of joining a drugs trial

by Caroline Maxwell

3 Aug 2012: I responded to Emily Hughes' email notifying RSN supporters of a chance to join a trial of a drug to help reduce falls.

Mid-August: Received information booklet explaining the trial will investigate whether the drug Rivastigmine, already approved for use by people with memory impairment, can help prevent people with Parkinson's falling. All participants must have Parkinson's and must have fallen in the past year. I satisfy both criteria having spent a week in hospital in January following a bad fall, and having had several minor falls since then. The side effects listed for the drug did not seem any worse than those reported for many other medications. Joining the trial involves 2 appointments, 32 weeks apart, in Bristol at which participants will be assessed and given the medication. Travel expenses will be reimbursed. In between visits they will be asked to take the tablets, keep a diary of any falls and to have a monthly phone call with a researcher. None of this put me off so, following a chat to my GP who encouraged me to join, I applied.

3 September: I received a phone call from researcher, Dr Emily Henderson, to check that I had a true diagnosis of Parkinson's, was on stable medication, had no other conditions, could travel to Bristol and understood I may get the placebo. After clarifying all this I was in principle accepted onto the trial and am now awaiting appointment in Bristol.

22 September: Read in The Guardian an extract from *Bad Pharma*, a new book by Ben Goldacre. He describes how drug trials are manipulated by pharmaceutical companies so that negative trial results get buried and new drugs may be given unjustified approval because of the lack of negative evidence (see <http://www.guardian.co.uk/business/2012/sep/21/drugs-industry-scandal-ben-goldacre> - 'The drugs don't work: a modern medical scandal'). I don't know who is funding the Rivastigmine trial, but I shall ask when I go for my first appointment. I shall also ask how the outcome of the trial will be publicised and whether the nature of the outcome will affect the manner of publicising the results.

Watch this space.

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STOP PRESS - a message from Stacey Storey at Parkinson's UK in London:

Places are still available at our **Members' Research Conference – Sunday 4 November** at the Royal York Hotel, York.

Speakers are all confirmed and we have a great agenda.

Please contact Stacey for more information at researchevents@parkinsons.org.uk

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FULL ARTICLES

- **My vision**, by *Lionel Paulo*
- **More ideas on the 8 basic activities**, by *John Telford & Caroline Maxwell*

My vision

By Lionel Paulo

Currently we are at a crossroads with Parkinson's research, the dimensions of study and experimentation having grown from being a considerably-sized body of research to being on the cusp of expanding to colossal proportions worldwide. Thanks to the internet there is more dissemination of data than ever before, but even so I feel that using groups like ours to assist researchers to study and cross-reference research studies would probably be the most significant use of our time.

My opinion of best use of the RSN

A two-pronged approach is vital. The first prong's focus is on research data. The RSN members working on this would be able to monitor web traffic and attempt to catalogue and cross-reference data – the most important qualities these members need would be the ability to comprehend and communicate, to be able to make the connections that enable different areas of Parkinson's research to come together for mutual benefit.

That's the key word: Connections! Already many research studies are being analysed but the enormity of the job, to be able to pick out the different strands of research that may enhance each other is such that assistance from groups like ours may prove helpful. It is also the case that sometimes individual researchers are so busy with their amazing work that they have very little time to study the works of other researchers, so perhaps assistance offered would be accepted.

The other key word is Comprehension. Without it none of the above is possible, and it is the case that for most of us deciphering research may be too complicated, which would mean the majority of us applying ourselves to the second prong which includes the rest of the 8 disciplines, and leaving the data search to a few specialists. And most fundamental of these disciplines is fund-raising, as money is needed to perform all of these functions.

Nothing can be done without funding, so I feel that at some point all those of us who are able should attempt to raise some funds, and those with an aptitude for fund-raising can help others to raise money.

To sum up, our core purpose should be to attempt to assist researchers with identifying and connecting with other researchers whose work would enhance their own, and surrounding this core would be the other disciplines, with perhaps a little extra focus on fund-raising. To be realistic, I also realise that helping to identify the right research projects will be very difficult, but that's life – life with Parkinson's is difficult and it won't be beaten easily, so we must not stop trying.

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More ideas on the 8 basic activities

By John Telford and Caroline Maxwell

1. Fundraising

The Steering Group could have an ongoing role in finding out and publicising what research fundraising is going on and using the best ideas to initiate occasional campaigns.

2. Speaker meetings/presentations on research topics

Branches and groups often invite researchers to speak to them and occasionally other organisations put on events relevant to Parkinson's research. Branches also invite the Research & Innovation Directorate to send someone to talk about the Parkinson's UK's research programme.

The Steering Group could have an ongoing role in: encouraging, monitoring, publicising and reporting such events.

3. Laboratory visits

There are a number of academic institutions within the Midlands where research funded by Parkinson's UK is being carried out. Parkinson's UK has a programme of visits to each project over its lifetime and research supporters are invited to attend them. There are sometimes some Parkinson's research projects which are not funded by Parkinson's UK.

The Steering Group could have an ongoing role in acting as a link with National Office to ensure local research supporters have a chance to join these visits and to report on their experiences.

4. Studies and Clinical Trials

Parkinson's UK can provide details of current studies and clinical trials. Generally these are all on the Parkinson's UK web site.

The Steering Group could have an ongoing role in monitoring and publicising trials and studies likely to be relevant to East Midlands RSN members and in facilitating the sharing of experiences and outcomes of any participants.

5. Lay Reviewers

The Lay Review Panel members help the Research Advisory Panel assess applications for research project funding from the perspective of people living with Parkinson's.

The Steering Group could have an ongoing role in:

- ✧ Asking lay reviewers in the region to provide non-confidential information about the projects they have been asked to assess
- ✧ Asking lay reviewers to write about the process of project review from their experience and on the outcomes of their reviews
- ✧ Encouraging others to apply to become lay reviewers.

6. Research progress and new developments

This is the key issue but is also very complex and requires input from people who can both understand the science and explain it to non-scientists. There are likely to be such individual research supporters in the region. There is also an initiative to start a scientific interest group at the national level and there will no doubt be participants in that living in the East Midlands.

The Steering Group could identify and work with these individuals to collate and disseminate research information.

7. Speaking to Branches and other groups

We expect that through the RSN, members of the Steering Group and active research supporters in the region will grow in knowledge and understanding of current research and will want to share this information. They will also get to know about the most effective ways of fundraising and be keen to pass on these ideas not only to UK branches and groups but also to other groups such as Rotary clubs and companies which may be interested in sponsoring Parkinson's research.

The Steering Group could have a role in identifying suitable groups and offering them a speaker, and in providing training and materials to support volunteer speakers.

8. Promoting the Brain Bank

The Parkinson's UK Tissue Bank needs more patients to sign up to donate their brains and spinal cord. They also require tissue from individuals who in life did not have a neurological condition.

The Steering Group could have a role in disseminating information about the tissue bank and the donation process to members and other interested members of the public.

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AND FINALLY... please encourage your branch to organise a research event and let the Steering Group know about it so we can advertise these events and report on them. In particular, let us know whether other Research Support Network members may attend.

You could invite researchers or neurologists to give talks and answer questions. And you could also ask Steering Group members along to talk about promoting research.

Please help us raise the profile of Parkinson's research and of the East Midlands RSN!

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