

# OUR NEWS

## East Midlands Research Support Network News

No 1 May 2012

**Welcome** to the first newsletter of the East Midlands Research Support Network of Parkinson's UK.

It all started at a meeting last summer in Market Harborough. Parkinson's UK staff and Richard Brown, a volunteer member of the national Research Support Network, encouraged East Midlands volunteers to form a group which would promote research into better care and achieving that elusive cure for Parkinson's.

Dr Lubna Arif-Schmidt, Research Liaison Manager, explained that a cure will come about in 3 stages, first by slowing the progression of the illness, second by halting it and third by reversing it. Yes, we would still take drugs, but all symptoms of the big P would be eliminated and we would live completely normal lives again.

Following discussions and sharing of ideas, that meeting agreed that Derbyshire, Nottinghamshire, Leicestershire, Lincolnshire, Northamptonshire and Rutland should be administered as one region. A steering group would be set up and people from each county would use the Internet to liaise with each other. The meeting agreed with Richard Brown that this should be a bottom up, volunteer-led group with all of us being able to contribute to ideas and strategy.

As Lionel Paulo wrote in the Leicester newsletter after the Market Harborough meeting: "I am not one of those people who like to join clubs or get involved in many things but I will be getting involved when the setup meeting of the steering group has been arranged because I want a normal life again. I want that cure, and feel if we all get behind this network and push for more research this could be our best path to our Holy Grail."

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(photo: istockphoto.com)

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)



John and Lionel



## STEERING GROUP

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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

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Those of us, including Lionel, who arrived at the first Steering Group meeting in November 2011 were mostly strangers to each other and had no model on which to base our activities. It was a blank canvas.

Since then we have identified a number of possible ways to support research and have made some very positive progress. We want to make research interesting, attractive, something to be talked about and involved in, not just something that happens in labs and is only accessible to scientists.

This newsletter, produced by the steering group, is a summary of our work so far and includes a variety of opportunities for members to get involved in research.

Caroline with input from Lionel

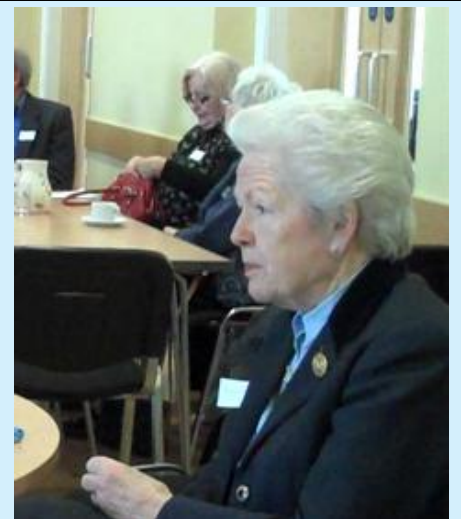
## Darien Lott

There is an old proverb that says 'As one door closes another door opens,' a message to convey optimism during hard times. But this can also work in reverse, and so it is that as the door opens on this, our first newsletter, another door closed on the life of our colleague, Darien Lott, who died suddenly on the morning of 7 May.

Although we had only seen Darien a handful of times at meetings, she left an indelible impression of a strong, no nonsense, 'call a spade a spade' person who could be

counted on to give an honest opinion on any matter up for discussion. Direct and blunt she certainly was but also, in talking with her several times on the 'phone, I found a rich sense of humour and a warm, generous heart under that tough exterior.

In earlier years Darien had been a very highly respected doctor of immunology, and later in life was manager of a farming business, and although she did not have Parkinson's was very keen to help those of us who do, as well as contributing time to other charities.



(photo: John Telford)

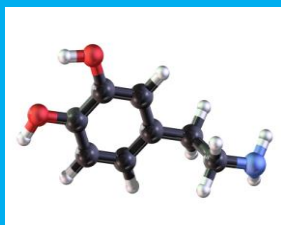
Our condolences go out to Darien's family and friends, and she will always be remembered, in the words of another Steering Group member, as 'a very sincere person.'

Lionel

# COMING UP..

## BRANCH ACTIVITIES

We know that, in 2011, 18 branches and groups in the East Midlands have together raised a total of £63,000 for research. This is an indication of the commitment of their volunteers. This commitment can be followed up by inviting scientists who are researching into some aspect of Parkinson's or a member of the Parkinson's UK research team to give a talk either at a branch meeting or at a special event. We know that several branches had such events recently and that the following events are scheduled for our region:



(photo: istockphoto.com)

- 16 August: **Spalding Branch.** Talk by Dr Katie Le Blond of Parkinson's UK Research Team. 10.30 am Pinchbeck Village Hall, Knight Street, Pinchbeck, PE11 3RB. Telephone Margaret Lomax on 01775 766217 if you want to go.
- 13 October: **Regional Research Day** – Leicester –see page 4.

Let us know if your branch is planning a research event and can welcome other research supporters to it.

## LAB VISITS

When Parkinson's UK funds a research project it usually arranges a monitoring visit by members of the Lay Review Panel and the research team during the course of the project. If there are spare places on this visit they may be offered to members of the RSN. If you get a chance to go, do take it, and please write a brief report of your visit for our newsletter. Currently there are 5 research projects taking place in our region. One is run by Flaviano Giorgini in Leicester, one in Derby Hospitals Foundation Trust by Robert Skelly, two are in Nottingham by Chris Moody and Lyn Bedford, while the Tracking Parkinson's project involves Nin Bajaj for Nottingham and Derby and Peter Critchley for Leicester (see below). However, no lab visits are planned for the immediate future.

## PARTICIPATING IN RESEARCH PROJECTS

Research projects often need volunteers to participate in their work. This can range from completing questionnaires on line to being weighed, measured, giving samples, being interviewed, being regularly monitored and even taking new drugs. Steering Group member Maria Rice is preparing information for volunteers interested in participation. Currently there is a major national research project attempting to identify biomarkers for Parkinson's. The Tracking Parkinson's researchers are looking for 3,000 volunteers who were either diagnosed within the last 3 years or were under 50 when they were diagnosed. More information is at: <http://www.trackingparkinsons.org.uk/>

## MORE INFORMATION

East Midlands Research Network News is published bi-monthly by the Steering Group of the East Midlands Research Support Network.

The next deadline for contributions is **9 July**. Please send us a copy of your branch newsletter. We are particularly interested to hear of any activities to do with research which we could mention next time.

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We look forward to hearing from you!

## **PARKINSON'S RESEARCH WEBSITES**

The following 7 websites (in alphabetical order) are useful in keeping informed about Parkinson's research. A listing does not imply endorsement by us or Parkinson's UK. If you know of important omissions, please let us know:

Cure Parkinson's Trust - <http://www.cureparkinsons.org.uk/>

Michael J Fox Foundation for Parkinson's Research - <http://www.michaeljfox.org/>

National Parkinson Foundation - <http://www.parkinson.org/>

Parkinson's Disease Foundation - <http://www.pdf.org/>

Parkinson's UK – Research - <http://www.parkinsons.org.uk/research.aspx>

ScienceDaily: Parkinson's Research News -

[http://www.sciencedaily.com/news/health\\_medicine/parkinson's\\_disease](http://www.sciencedaily.com/news/health_medicine/parkinson's_disease)

SPRING (Special Parkinson's Research Interest Group) - <http://spring.parkinsons.org.uk>

## **BRAIN TISSUE BANK VISIT**

Brain tissue is a vital resource for neurological research. Last year Parkinson's UK merged its brain tissue bank with the MS tissue bank. There is still a desperate shortage of donors. Alan Daniels from the East Midlands Steering Committee has learnt that the Brain Bank welcomes visitors by appointment on Wednesdays. We are hoping to arrange a group visit for interested East Midlands RSN members. For more information contact Alan (see page 2).

## **RESEARCH SUPPORTERS' DAY**

The Steering Group is planning a Research Supporters' Day at Leicester University on Saturday 13 October 2012. The outline programme includes an overview of Parkinson's research as it relates to the East Midlands by Claire Bale from the Research and Innovation Team, talks on basic and clinical research by researchers in the region and a panel discussion. There will also be an opportunity for members to talk about the direction of the Research Support Network and the part they could play in it. We shall be looking for help to run this and will provide more details in the next newsletter.

I am very grateful for the help and support of the Regional Steering Group members, in particular John Telford, Lionel Paulo and Chris Johnson in the production of this newsletter. My thanks also go to Tyna Brych of Parkinson's UK who provided the template, information and undertook the distribution. We plan to make this a bi-monthly publication, so the next edition will be in July. This should include more information about Tracking Parkinson's, more details of the October Supporter's Day and a report on one of the current East Midlands research projects.

Writing a newsletter can be a bit like leaving a message in a hollow tree. You're never sure if anyone has picked it up. So please, if you have read this far, spare an extra 5 minutes to send me a brief message with your impressions of this edition, and ideas and news for future editions.

Caroline ([caroline@paddockend.com](mailto:caroline@paddockend.com))