

OUR NEWS

East Midlands Research Support Network News

No 5 Jan 2013

A first meeting of the leaders of the 6 Parkinson's research projects in the East Midlands will be held in Nottingham on Monday 25 March from 10:30am - 1pm. Parkinson's UK provides funding to five of the projects.

First Meeting of Regional Researchers

The purpose of the meeting, organised by the East Midlands Research Support Network (RSN), is to enable representatives from the 6 projects to meet and to explain to each other what they are doing and to discuss matters of mutual interest. The meeting is open to a small audience to sit in and hear what they discuss. In the latter part of the meeting there will be the opportunity for the audience to put questions to the researchers from the point of view of people affected by Parkinson's who are the ultimate beneficiaries of their work.

If you are interested in attending this meeting, please email intelford@ntlworld.com or ljpaulostk@talktalk.net and more details will be sent to you later. Please write in early because numbers will be limited.

This meeting should give a fascinating insight into the research into Parkinson's that is going on in the region. It will allow RSN members to appreciate how researchers approach their work, set their objectives and achieve and assess the outcomes.

Please note that this meeting will assume that the audience has a grasp of the basics of Parkinson's disease. It will be conducted using a level of technical language that suits the researchers rather than the audience because it is essentially their meeting. They are from disciplines ranging from hospital management through to biochemistry and genetics. So those who come should be prepared for a challenge to their comprehension! Lay summaries of the projects will be sent out in advance to provide the background to what will be covered so that you can be well prepared.

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(Brain Waves, by Victor Habbick: 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)

Tracking Parkinson's

The joining interview as experienced by Lionel Paulo, Steering Group Secretary

As you may know the Tracking Parkinson's Initiative, also known as ProBaND, is the five year research study testing and following changes in our condition in an attempt to identify 'biomarkers.'

The study needs 2,000 people that were diagnosed within the last three years – this is still open and if you qualify I urge you to join this very important research project.

A very comprehensive battery of physical, verbal and written tests plus three questionnaires make up the joining interview. For details of all the above please go to [page 6](#).

The Fox Trial Finder: Is it useful here in the UK?

by Lionel Paulo, Steering Group Secretary

The question arose recently: if you can find research trials on the Parkinson's UK website, is there anything to be gained from looking at Michael J. Fox's Trial Finder website?



THE MICHAEL J. FOX FOUNDATION
FOR PARKINSON'S RESEARCH

For the details of a personal test, and some important facts and figures about trial participation please go to [page 7](#).

INVOLVE

By Maria Rice, Steering Group member

I was lucky enough to accompany Emily Hughes to an INVOLVE conference last November. It was a well-run conference with almost 500 people there. The keynote speech was delivered by Sir Ian Chalmers. My account of the Conference is on [page 9](#).



For useful research publications and other resources go to the Parkinson's UK website at www.parkinsons.org.uk, click on 'Research' and then click 'Research Resources'.

STEERING GROUP

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Maria Rice, Nottingham

Tyna Brych, Parkinson's UK
East Midlands



*(People with Network Connection, by
digitalart: freedigitalphotos.net)*

COMING UP...

LAB VISIT IN LEICESTER, 21 Mar 2013



(Laboratory Equipment,
by Photokanok:
freerangestock.com)

This is advance notice of an afternoon visit to the laboratory of Dr Flaviano Giorgini at the University of Leicester. It is planned to take place on Thursday 21 March. Please contact John at intelford@ntlworld.com if you are interested in going on this visit. Flav's work is in the Department of Genetics and it is funded by Parkinson's UK. He gave presentations of his team's work at our 1st Regional Research Forum in October and at the Parkinson's UK's biennial researchers' conference in November.

2nd REGIONAL RESEARCH FORUM IN DERBY, 14 Sept 2013

Following the successful first Regional Research Forum in October the second is being organised for 14 September 2013 in Derby. The programme will include an overview of Parkinson's research today, an outline of local research in Derby, and presentations and a panel discussion on the main theme: research on medication



(Forum definition magnifier,
by Stuart Miles:
freedigitalphotos.net)

This day-conference is intended for people with Parkinson's and will aim to be easily understandable without a scientific background. More information will be published in the next Newsletter in March.

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

You ain't seen nothin' yet...

From Inception to December 2012: The first 15 months

A brief synopsis of the Steering Group's beginnings, by Lionel Paulo, Steering Group Secretary

When Maria asked me for a few statistics about the Steering Group's history the first question was: "When was the first meeting? Was it in 2010 or 2011?" I thought 2010 was the answer as it certainly felt like at least two years had passed since our first get-together, but no! 21 September 2011 at the Park Inn, Nottingham saw several volunteers get together with Emily Hughes and Laura Bowey to set-up a Steering Group to work with the East Midlands Research Support Network.

That first meeting saw our Chair John Telford elected unopposed, his experience and knowledge almost tailor-made for the role. Making the mistake of volunteering to record the

minutes inadvertently handed me the Secretary post, a decision that proved serendipitous as much more has happened than any of us anticipated back then.

Fast-forward to today and look at the Steering Group's résumé and you can see that much has changed! Several members have moved on and one tragically died but our numbers have stayed stable as new volunteers have joined. Also our Parkinson's UK liaison Laura was promoted to the London office, her position being taken on by the extremely able Tyna Brych.

And within these 15 months we have had eight minuted meetings, one subgroup meeting, one Research Forum held at Leicester University, four newsletters published and now you are reading this in the fifth. Also various research meetings have been attended and well over a dozen articles have been published in other newsletters.

At our most recent Steering Group meeting John put the question to us all: "Has the Steering Group successfully launched the East Midlands RSN or not?" Everyone present felt the initial goals of the group had been achieved or surpassed. So, here we are and we have lots of ideas that will come to fruition in 2013, some of which may surprise you and hopefully all of which will prove edifying, entertaining and useful to you. Thank you to all of you wonderful RSN members and followers who received and read our newsletter in 2012, and please stick with us because there is so much more to come that, to quote Al Jolson, "you ain't seen nothin' yet!"

The East Midlands Research Support Network Steering Group - some first impressions

By Wendy Morrison, new Steering Group member

Following the Research Forum in Leicester in October (reported in the last newsletter) I was invited by RSN secretary Lionel to come to the next meeting of the Steering Group - which I was pleased to do. Even more pleased to be offered a lift! However, my only qualifications for attendance at this group is being someone with Parkinson's whose original, long ago, degree was in biology and whose interest in this subject has been maintained. Below are some brief reflections on that stimulating, caffeine-fuelled morning in Newark on 7 December.

My understanding of the purpose of the Research Support Network (RSN) is to raise and maintain the profile of Parkinson's research in the East Midlands and, chaired by John Telford, there had been a virtual pre-meeting by email, gathering together members' comments/suggestions on the proposed agenda of this their 8th meeting. This was to be a focused, business-like meeting. It was attended by Tyna Brych, East Midlands Regional Manager, a full member of the group who has taken an active interest in the birth and subsequent evolution of this cooperative enterprise between volunteers and staff. Agenda items included 'Moving from a Steering Group to a Coordinating Committee' - with its attendant challenges. With this in mind Emily Hughes, Parkinson's UK RSN Manager, is to be invited to the next meeting.

Currently one way of disseminating research information in the East Midlands is via the newsletter circulated by the steering group and, in the future, possibly through the East Midlands section of the Parkinson's UK website - to be discussed further. Thought, for example, is being given to how much scientific detail it might be useful to include. Also being considered is a suggestion to the compilers that information packs given to the newly diagnosed should include a little about the RSN. Just some contact details and a brief

introduction to some current areas of research might appropriately be given at this time because it could contribute to a much needed sense of hope. Apparently local branches differ considerably in their appetite for research updates.

A meeting of East Midlands based researchers is to take place in March and speakers have now been invited (see also [front page](#)). And finding someone able to give a much needed overview of current research for another RSN Forum next autumn is also on the agenda.

I found being part of the group's vision and energy really helpful - both on a personal level and by offering a wider, purposeful research perspective on the challenging condition that is Parkinson's.

Diary of joining a drugs trial (part 3)

by Caroline Maxwell, Editor and Steering Group member

After being accepted onto the drugs trial aiming to improve gait in PWP's and spending a day at Frenchay Hospital, Bristol, being assessed, I came home with a large amount of tablets labelled 1.5mg, 3mg, 4.5mg and 6mg. They may be Rivastigmine, the drug being tested, or they may be placebos. Neither I nor the researchers know, as the randomising of participants is done independently to ensure accurate results.



(Pills, by Sattva: freerangestock.com)

My instructions are to start with the lowest strength, taking one tablet in the morning and one in the evening, then after 4 weeks move on to the next strength for another 4 weeks and so on. I started taking the medication on 31 October. There was no noticeable effect, but after a couple of weeks I found my skin became very itchy and dry. I have no idea if this is due to the drugs but it did gradually improve but then got worse again once I increased my dose. When I spoke to the researchers they said this was not a common side effect, so it is difficult to know whether or not there is a connection. I choose to think the dryness is caused by the drug because this would indicate that I am probably not on the placebo but am taking 'the real thing'.

And I think there has been some slight improvement in my gait. There have been occasions in the last couple of weeks when I have walked easily and confidently across a room and then realised, when I have reached the other side, that I have not teetered or staggered or halted. I have, admittedly, also fallen a couple of times when I was trying to do something with my hands – getting dressed, making the bed - and ignoring my feet. Because I live alone and take some pride in 'managing' I would rather not admit to these falls, especially as I have not been hurt. But this is not an option. I am part of a scientific experiment and must record what happens. So I have filled in the falls on the monthly record sheet I have to send to the researchers and hope that the next sheet will have less to record. However, I can see that if I do improve I may then take more risks and therefore find myself on the ground just as often.

My next increase in tablet strength to 4.5mg is due on Christmas Day, then, by the time the next newsletter comes out I could be on the full strength of 6mg and dreaming of taking part in the next round of Strictly Come Dancing!

FULL ARTICLES

- [The Tracking Parkinson's Initiative, also known as ProBaND](#), by *Lionel Paulo*
- [The Michael J Fox 'Fox Trial Finder': can it be of use in the UK](#), by *Lionel Paulo*
- [INVOLVE Conference](#), by *Maria Rice*

The Tracking Parkinson's Initiative, also known as ProBaND: Parkinson's Repository of Biosamples and Networked Datasets

The joining interview as experienced by Lionel Paulo, Steering Group Secretary

As you probably know the Tracking Parkinson's Initiative is the 5 year research study funded by Parkinson's UK to test and follow the changes in our condition in an attempt to identify 'biomarkers.' These biomarkers will hopefully be able to identify Parkinson's much earlier in people, possibly even before symptoms begin to appear, and will also indicate more specific and effective treatment protocols.



*(Lab, by Chance Agrella:
freerangestock.com)*

The study wants 240 people who had been diagnosed before the age of 50 (I am in this group which is now full), and 2,000 that were diagnosed within the last 3 years – this is still open and if you qualify I urge you to join this very important research project. They also want 750 close relatives without Parkinson's to use for genetic comparisons. All have the right to drop out of the study if they so wish. The end result of tests taken every 6 months for 5 years will see all results amalgamated to produce global results.

Okay, that's the serious scientific bit over with, now I want to tell you what the interview and tests are like when you join, which for me was on the morning of 12 December 2012.

The first part of the interview was handled by Parkinson's research nurse Rehanah Roopun, and consisted of signing a consent form followed by measuring my height and weight, seated and standing blood pressure and extracting 3 tubes of blood.

Next, Doctor Critchley asked questions and ticked boxes on a questionnaire about my drug use, mood, memory, behaviour etc. Physical assessing was accomplished with motor skills tests which included old familiar standbys such as finger tapping, forearm rotating, toe-tapping, heel stomping, walking back and forth and a balance test. Flexibility and rigidity were also checked with limb manipulation.

Mental agility and cognition used a mixture of oral and written questions. The written part included copying a drawing of an illusory cube, copying interlocking shapes, and the old faithful

for dementia testing drawing a clock face and putting the numbers and hands on in the right locations to tell a specific time, followed by naming 3 pictures of different animals.

On the spoken tests first was the repeating of 5 words after a pause of 10 seconds, followed by repeating 3 numbers in reverse order, and listening to a sentence and repeating it. Other numerical tests included starting at 100 and subtracting a specific number repeatedly until the Doctor was satisfied. Back to letters, a string of which were read out and I had to tap the desk each time I heard the letter A.

The most amusing tests were the 60 second test to say as many words as possible beginning with the letter F (lots of F words but *the* F word not allowed, keep it clean!), and the 'name as many animals as possible in 90 seconds' test – Doctor Critchley was definitely paying attention as he mentioned the 2 extinct animals I had included in my recital. Several word association questions were asked and I confess to having a brain dead moment as I could not think of an answer to one of the questions at all (of course, as it always does, the blindingly obvious answer popped in to my head hours later!). This section was rounded off with the 5 word list that we had started with – Doctor Critchley asked me to repeat it again and I had to admit I could not remember all 5 words (My excuse? I was also trying to remember all the tests I have described for this article, as I did not have the chance to make any notes. As it is, there were a few more variations on these tests which I have not described, but they were similar enough to those described that it would be unnecessary repetition to mention them.)

After this came 2 more questionnaires of the multi-choice tick the box variety. Questions covered the whole range of typical Parkinson's experiences, asking about close family then cousins to indicate the extent of any neurological problems in relatives. General health problems also featured with sections focused on other ailments, pain, intestinal problems and in depth questions on anxiety, fear, depression, gambling, moodiness etc. (sounds like an EastEnders episode!) and other more intimate questions.

The whole interview came to just over 3 hours and the questions required very frank answers but I feel it's worth it. This is the biggest study of this type in the Parkinson's world, and may advance us a long way on that meandering path that will one day lead to a cure. The other more immediate benefit is that of having a more thorough check-up every 6 months enabling us to keep a closer eye on our own Parkinson's progression.

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The Michael J Fox 'Fox Trial Finder': can it be of use in the UK?

By Lionel Paulo, Steering Group Secretary

Let me begin by recommending Parkinson's UK website as probably one of the first websites to look at if you want to find out about research and clinical trials here in the UK. To go direct to the research section click on the link below: <http://www.parkinsons.org.uk/research.aspx>

Is there any point in looking at the Fox Trial Finder as well? After all, it is based in the USA so you could be forgiven for thinking it would not work to find clinical trials here in the UK. With that in mind I decided to test it on myself and found it worked very well at finding relevant trials over here. To try it out click this link: <https://foxtrialfinder.michaeljfox.org/>

You will see a counter on the screen showing the number of people that have joined Fox Trialfinder, when I was writing this the number stood at 12,842 and their target limit is 15,000, so it is still available to join. To join, or simply to test it, follow the very straightforward on



(photo: uk.imdb.com)

screen instructions which include an option of being able to register for a trial even if you do not have Parkinson's (acting as controls to compare with People With Parkinson's).

The site also gives the option to choose the distance you would be willing to travel to a trial, anywhere between no limit down to a minimum of 25 miles. I tried 300 miles and it came up with 37 trials, then 50 miles and it still located 10 trials. Inputting profile details further fine tunes the service, and clicking on each trial brings up full details of aim, eligibility etc. I definitely think checking on trials on both Parkinson's UK and Michael J. Fox's websites would be worthwhile.

The Fox Trial Finder website also provides some interesting statistics that, although American, are probably reasonably true here as well, and are definitely worth repeating. Apparently 30 % of trials never get going because they attract no volunteers at all. Of the trials that do take place recruitment

problems cause 85% to finish later than planned. Even worse than these statistics, up to 90% of PWP believe research is essential, yet less than 10% of us participate in trials! How many missed opportunities each year results from this? How many life-enhancing outcomes are being delayed for years or not being discovered at all in the case of cancelled trials?

If you have not done so already I strongly urge you to consider getting involved in at least 1 trial at some point – if we all did that research could advance much faster, and perhaps the day a cure is found might be brought forward by several years.

Like many things in life it's a game of numbers and the more money, research, trials etc. that we can throw at James Parkinson's shaking palsy, the sooner the day may arrive when it can be consigned to history. The gold standard drug for Parkinson's has been around approximately 50 years so is it impossible to go beyond that? Look at TB, a new drug has just come into use, the first since 1963, proof that persistence and research will find a way.

Okay, having preached to you, I would be letting the side down if I was not involved in at least one research trial, and elsewhere in this newsletter you can read about my signing up to the ProBaND Tracking Parkinson's Initiative (see [page 7](#)) – a very important study that I recommend if you meet the selection criteria. Also don't miss Caroline's excellent diary on the clinical trial she is participating in (see [page 5](#)).

Here's hoping the next major breakthrough involves a treatment for Parkinson's!

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INVOLVE Conference

By Maria Rice, Steering Group member

“INVOLVE is a national advisory group that is funded by and part of the National Institute for Health Research (NIHR). Involve supports public involvement in NHS public health and social care research. “ (From INVOLVE booklet May 2012)

Last year I saw an advert for a NHS backed conference about participating in research so I told Parkinson’s UK about it. This resulted in me being asked to accompany Emily Hughes to this conference. It was called INVOLVE because that is what the organisers were hoping people would do i.e. get involved in research.

When I first saw the advert for the conference it made me think that this was just what we were doing in the East Midlands Research Support Network Steering Group. We are supporting the Parkinson’s UK Research Support Network (RSN) as volunteers, so we are members of the public getting involved in the research gathering.



However the role that the organisation INVOLVE envisages for their public members is much broader. It encourages people to try to take an active role in the actual research. This may involve them in the planning of the research or helping researchers make the results understandable for the lay person as well as training to aid in running the research. So it may involve

a member of the public or a patient or a carer.

Some of the ways that members of the public can make a difference to health and social care research is by:

- “Making sure that researchers ask the right questions in a way the public understands.
- Keeping the research on track so that it stays relevant.
- Making sure the people who are being researched are approached in the right way.
- Improving the quality of the research by adding another point of view to the design and conduct.”

(From the INVOLVE website at www.involve.org.uk)

The idea is that this participation will make the research more ethical by:

- “Making research more relevant
- Helping to define what is ethically acceptable
- Improving the process of informed consent
- Improving the experience of participating in research
- Dissemination of research to both the participants and the wider public”

(From INVOLVE booklet May 2012)

The keynote speech was given by Sir Ian Chalmers and he included a review of Ben Goldacre’s book “Bad Pharma”. This book has stirred up a controversy about how much information we get about the research that is being carried out. Not only at the end when the results are published but also while the research is ongoing. In fact some of the pharmaceutical organisations do not publish negative results. This practice has culminated in

harming individuals. Sir Ian showed us some young men who had had to have some of their digits amputated due to being in a trial which was run in spite of the fact that a very similar drug had been shown to have these ill effects. The problem was that the initial research had not published the findings perhaps because it did not support their theories? So, it is important to ask for the results of any research we are involved in; and to ask where the results would be published. It does not matter whether the research outcomes are positive or negative the research should be published. Otherwise we are looking at waste ie of time and resources, For instance 50% of research is never completed or published.

Sir Ian is also involved in an analysis of uncertainties about the effectiveness of treatments. He maintains that the new research does not give enough time and effort to finding out about research done in the past. This is again a dreadful waste.

After the speech we participated in a variety of workshops and listened to talks and viewed poster presentations. Towards the end of the first day it was our turn to do our presentation.

Emily started us off, giving the audience (by this time standing room only) some information about Parkinson's UK and about the Research Support Network (RSN) and how we work together- staff with volunteers. She had some slides to illustrate the points she was making. Then it was my turn to talk about the East Midlands RSN Steering Group. So I said how much we had achieved in the 14 months we had been active as a group: we had 7 meetings and 3 newsletters and one major event which was a Research Forum. This was due to the hard work of our Chair and Secretary supported by the group. People asked questions and were impressed by the newsletter. Altogether, it was a successful presentation thanks to Emily.

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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 **Monday 4 March**. 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 (Guest editor for this edition)

We look forward to hearing from you!

STOP PRESS: Dr George Gveric, Manager of the Multiple Sclerosis and Parkinson's Tissue Bank at Imperial College in London, will give a presentation to the Leicester Branch on Wednesday **16 October 2013**. Dr Gveric will give an overview of Parkinson's research and brief details about the work of the Parkinson's Brain Bank and its vital role in this research.

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