

East Midlands

RSN NEWS

from the East Midlands Research Support Network

*** June 2014 / No 17 ***

Welcome to our 17th edition of "RSN News". By the time you read this, a group will have visited Nottingham University to view everything involved in the MR Imaging and Tracking Parkinson's project and we look forward to a full report in a later issue.

In our last edition we had a brief report on the meeting held in Birmingham on 9th/10th May and organised by the RSN Development Team. We await the organising group's feedback with interest.



(Scanner, by renjith krishnan: freedigitalphotos.net)

However, in the meantime our Chairman, John Telford, has put together a thought-provoking article on the subject, inviting input from our readers.

There has been further progress on working out the detail of the Autumn Forum. It will start with an update on the achievements of Parkinson's research, by Dr Nin Bajaj and we have some eminent speakers lined up for the rest of the day. Registration is now open, with a registration form appearing at the end of this EMRSN News. To guarantee your seat at the Forum, please email the information requested as soon as possible. For further details see [Coming Up](#), page 11.

In our September 2013 edition, No. 9, we had an article on "The Top 10 Unanswered Research Questions". In this edition we carry an article by Caroline Maxwell updating us on the progress of this project.

There is also the second part of [Lionel's Lesson](#) on Exercise and finally we have a fascinating [Personal Perspective](#) contribution from Harry Pearman who is a member of the Bexley & Dartford Branch and the RSN

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... and much more!



(Network Definition Magnifier, by Stuart Miles: 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)

Development Team. Many thanks to our contributors.

Finally, we are sorry to announce that Tyna Brych, East Midlands Regional Manager for Parkinson's UK, who has been a member of the Steering Group since 2012, is leaving the Group as she is taking on the role of Head of Local Group Network, which will take up the majority of her time. However, we are pleased to welcome Harry Wade, Information and Support Manager, to the Group in her place.

Tyna has played a significant role in supporting and encouraging our group since it began and it is felt that without her we simply would not have achieved what we have achieved. "She has been an essential and very effective link between our group of volunteers and the staff structure". To quote our Chairman, "... [Tyna's] values and motivation have added immensely to the way the RSN has developed here. Then there is [her] practical and common sense approach, coupled with a capacity for hard work and a determination never to leave anything undone ..."

Tyna, we wish you every success in your new role.

Ian Billcliff, Editor

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East Midlands

News & Events

World Parkinson Coalition – Continuing Education



The World Parkinson Coalition, which organises the World Parkinson Congress every three years, is to organise some live webcasts in the Autumn. These will provide useful updates to the state of research into Parkinson's. You can register to watch and even participate in the events as they are broadcast online and you can also watch them as video recordings later.

You can find the 3-day programme at:

<http://www.worldpdcoalition.org/?page=2014WebcastProgram>

It sounds very interesting! Registration opens in mid-July.

A banner for the WPC Scientific Update. It features the text "Save the Date!" in a script font, "WPC SCIENTIFIC UPDATE: Parkinson Pipeline Umbrella September 30-October 2, 2014" in bold, and "Join us for an online webcast to hear about the scientific advances made since the WPC 2013. Be inspired by the progress!" in a smaller font. There is also a circular logo for "SCME CREDIT HOURS" with "APPROVED" written around it.

Save the Date!

WPC SCIENTIFIC UPDATE: Parkinson Pipeline Umbrella
September 30-October 2, 2014

Join us for an online webcast to hear about the scientific advances made since the WPC 2013.
Be inspired by the progress!

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RSN meeting in Birmingham on 9th /10th May 2014:

Developing Our Research Support Network

It was a good meeting. It was fun and there were a lot of friendly people there from around the country who were zealous about Parkinson's research. There was time to chat informally because the meeting ran from Friday afternoon to Saturday lunchtime – we were even asked to chew over a discussion topic during the Friday evening meal, such was the determination to make it a worthwhile occasion.

So what was achieved? Do people who allow themselves to be called Research Supporters now have a better idea how they can work together to support Parkinson's research effectively in the regions and throughout the country?

The meeting was convened by the Research Support Network Development Team, which is a group of volunteers and staff whose role is to promote the development of the RSN and to monitor its development. Those of us present were determined that



(Richard Brown, Chris Johnson and John Telford (from left to right), photo Lionel Paulo)

something more than fine words should emerge from the meeting. But the organising group's output – Report? Strategy? Guidance? Manifesto? - is, unfortunately, not yet ready for this edition. There is no doubt about the seriousness of intent, but the nut we have to crack is a hard one.

For my sins, I was asked to give a presentation about our experience in the East Midlands – what we have tried, what has worked and what has not; what we have been aiming to do and why. It is a difficult question, isn't it: what should we be doing that will really support research and genuinely bring closer a cure and better treatments?

It is a difficult question because how sure are we that what we have been doing - listening to researchers explain their work and producing a well-appreciated newsletter with interesting content - is really achieving anything tangible? Do they bring a cure or better treatment one minute nearer?

On the other hand enthusing people to take part in clinical trials and other research studies certainly helps produce new knowledge that brings our quarry closer. We have been doing that too.

Being a “subject” in a research study is an example of PPI – Patient and Public Involvement, a topic that the meeting focussed on during the second day. But PPI also includes assisting in the design of research projects and even identifying what topics are worthy of research in the first place. But it is hard to find opportunities for getting involved in the last two. At least so it seems in our region. There is quite a large number of organisations and coordinating groups in the region trying to “do” PPI, but none of

them appear to provide a way in for us to get involved in specific Parkinson's research activity.

In other words it appears that what would be most efficacious for supporting research achievement is the hardest to do, while what we find easiest and most enjoyable and fulfilling – research forums and the newsletter – have a usefulness which is less obviously achieving our aims. Or do you think otherwise?

I am not actually saying that we should stop producing the newsletter or organising Forums. They are excellent at spreading information, getting people together and

building the Parkinson's research community of lay people and researchers. But if we have limited resources, we need to prioritise.



Which brings us to this matter of our limited resources. We all know what sort of illness Parkinson's is. The word is progressive. In a perverse way it is good news to have new people constantly joining the club because they can take over from those who find they can no longer do so much. But that is provided we have a way of enticing them in to help out.

(Newsletter with Pencil, by Stuart Miles: freedigitalphotos.net)

It turns out that the East Midlands RSN is the most active of the regional RSN groups, with comparatively little going on elsewhere so far. Are we the exception that proves the rule, the rule that regional research-oriented volunteer-led organisations don't work? This is a genuine question that doesn't have an answer yet.

It is to be welcomed that members take an interest in what is written in the newsletter and come along to hear researchers describe their fascinating work. It is great that members put themselves forward for research trials. But there also needs to be a minimum number of active organisers if things are to happen. In most other regions small organising groups have not arisen and the question is how such groups might be 'nucleated'. The question in our region is how we can get those who have a possibly unrecognised aptitude for oiling the organisational wheels to lend a hand to our friendly, cheerful and committed but a bit overstretched Steering Group.

You might recognise a challenge in there. Please write in and say what you think. And let's chat next time we meet at a Parkinson's UK or RSN event.

John Telford
Chair of the EM RSN Steering Group

Parkinson's UK consultation

The Top 10 Unanswered Research Questions

Parkinson's UK is determined that all the charity's activities should be guided by the Parkinson's Community – that is, by people with Parkinson's, their families and carers and their health and social care professionals. So when planning the charity's next 5 year programme for research, members of this Parkinson's Community were asked which research topics in the areas of symptoms, day-to-day life and treatment they would like the organisation to support.



(Question Mark, by artur84: freedigitalphotos.net)

Amazingly, over 1,000 people responded to the survey and produced over 4,000 questions which they wanted researched. After editing and sorting, this mountain was reduced to 94 possible questions. The questions have now been listed in a booklet headed TELL US and circulated to those who volunteered to be further involved in the decision process. The volunteers are asked to choose their personal Top Ten from the 94 questions. These

responses will then be collated at workshops in July and fed into the discussions of Trustees and staff who guide the research function of Parkinson's UK.

At the same time there has been consultation and discussion about how best to harness and support the enthusiasm and commitment of members of the Research Support Network. Here in the East Midlands, the Research Support Network Steering Group is awaiting the report on these national discussions with interest.

We are encouraged that 1,000 people responded to the initial survey and we hope that some of them will join us and help to develop new ways to support research. We hope, in future issues of this newsletter to be able to report on the outcome of the Top Ten workshops and to give a clear account of the research priorities and strategies of Parkinson's UK. Watch this space.



(Top Ten Prize, by Stuart Miles: freedigitalphotos.net)

Caroline Maxwell
5 June 2014

Lionel's Lessons

A series of plain English explanations of aspects of Parkinson's research

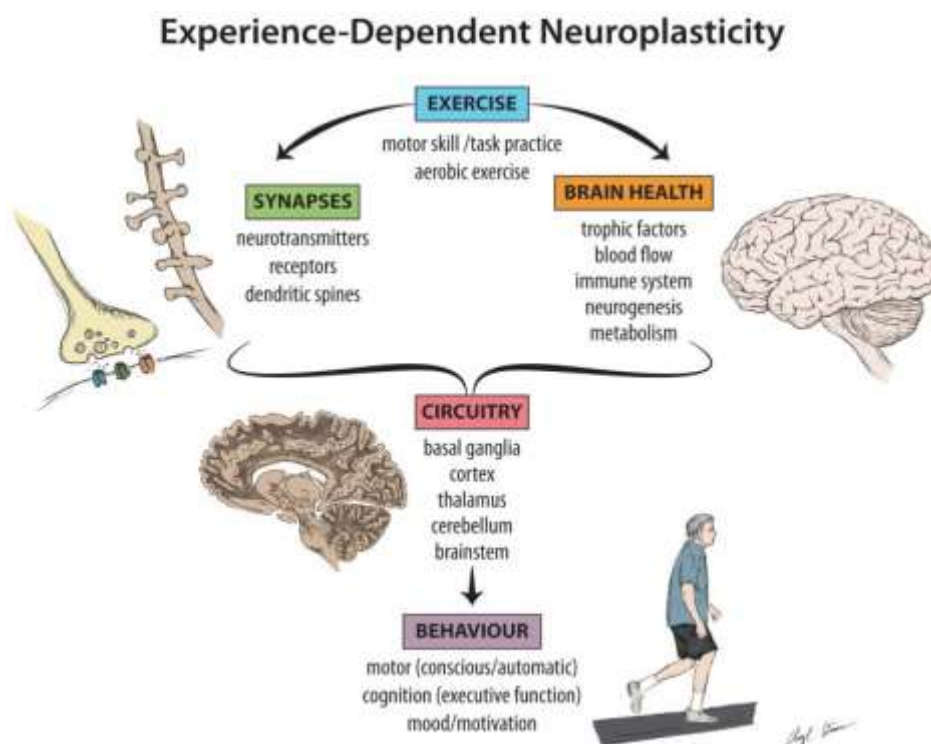
Lesson 5 – Exercise: Does it help to protect the brain cells of people with Parkinson's?

Part Two

Hello again and welcome to part two of our neurological wandering through the exercising brain of People with Parkinson's (PwP). Part one pointed out the benefits of exercising that could be perceived, but is there any real tangible benefit beyond a temporary state of feeling well?

In Part one, experiments with mice showed that exercise is definitely protective against toxins introduced from external sources, **but** this does not necessarily imply that the same protection against cell breakdown can be found to be dealing with internal problems (in other words degeneration of dopamine cells), or holding back deposits of the rogue proteins, called Lewy bodies, that ruin other parts of the brain and lead to dementia.

There is however, a steadily-growing body of evidence which suggests that neuroprotective effects can be gained from exercise, and following are some examples of research studies – if you want the jargon see the reference links, but here I will explain in plain English what these studies tell us.



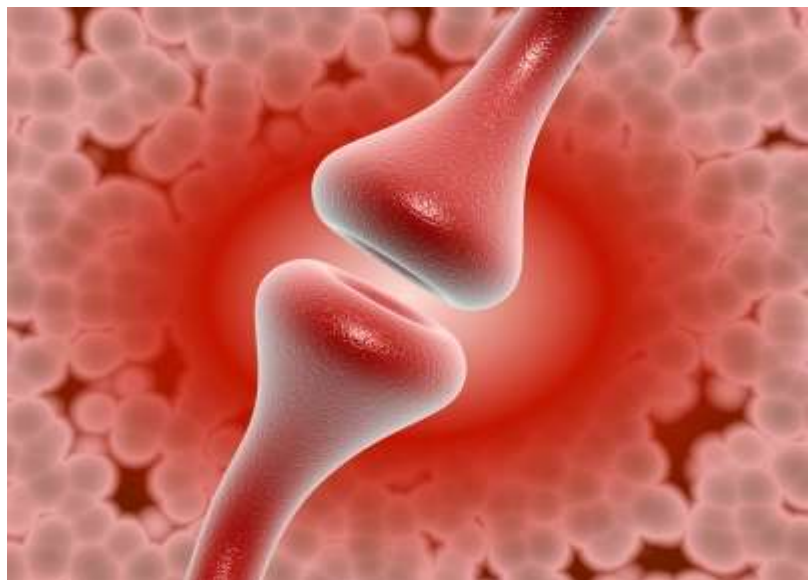
It is important to remember that the brain is constantly changing as it receives input from our 5 senses and, just like muscles, the more you use it the more it develops and adapts

(for example Mastermind winners and 'memory champions'). This ability to reshape the brain is called 'neuroplasticity' and it is hard at work in PwP before symptoms start to show. As our dopamine-producing cells gradually begin to die off, other parts of the brain pick up the slack. This goes on for years and we notice nothing until eventually the brain cannot cover any more losses, at which time we start to suffer visible symptoms. Exercise may help to improve neuroplasticity by helping to maintain old connections, form new pathways and possibly restore lost ones in our brains. Scientists working in this field identified 4 areas that help to drive neuroplasticity; intensity, specificity, complexity and difficulty.

A study was engineered to ensure all 4 areas were included, using a bodyweight-supported treadmill which prevents falls (refer to Part one in the last newsletter where this study was mentioned). Briefly, it is thought that use of the treadmill incorporates all the above 4 features that create change within the brain. First, the exercise is intense (moves fast and with high repetition). Complexity is created by running and listening to a doctor giving feedback at the same time. The task of running or walking is a specific functional task that we need in our daily lives and difficulty is increased or decreased by speeding up or slowing down the treadmill. Part one pointed out the benefits the intense training group felt, compared to the low-intensity and the non-exercising group – but now what we need to know is what effect did this have on the actual physical structure within their brains?

A parallel study was run by Dr Beth Fisher using mice, because human volunteers cannot be dissected and their brains examined, so mice performed an identical programme and were examined at the end of the study. Dr Fisher found that this type of intense exercise did not change the amount of neurons or the amount of dopamine in the brain but the brain cells were **using dopamine more efficiently**. Keeping it straightforward (see link 1 below if you want the technical jargon), brain cells communicate when dopamine fills the gap between them, known as a synapse. When this chemical signal has done its job, another type of chemical, called the dopamine transporter, 'recalls' the dopamine from the synapse. The intense exercise group had less of this transporter, meaning that dopamine **stayed in their synapses and signalled for a longer time**.

Also, exercise increased the number of D2 receptors in the cells, so they could pick up a stronger signal (imagine dopamine as a key and D2 receptors as locks for that key only). Even better, another chemical that produces signals in the brain called glutamate goes on the rampage when dopamine levels drop too low but exercise helps to hold it in check. This is equally important, as uncontrolled glutamate signalling **damages cells that control movement**.



(Synapse, by sheelamohan: freedigitalphotos.net)

The above sounds promising but have other studies reached the same outcomes?

There are quite a few published papers which agree with most or all of the outcomes above, such as the study conducted by the Department of Neurological Surgery at the Okayama University Graduate School of Medicine in 2009. This study used rats split into exercise and sedentary groups, the active group running on a treadmill 5 days a week for 30 minutes each session. Trying to keep to plain English, the conclusion of this research stated that 'exercise exerts neuroprotective effects or enhances the neuronal differentiation in Parkinson's disease model of rats, with **subsequent improvement in deteriorated motor function.**'

The other most interesting statement from this study observed (bear with me, I will explain it!), 'significant preservation of tyrosine hydroxylase (TH)-positive fibres in the striatum and TH-positive neurons in the substantia nigra pars compacta (SNc) was demonstrated, compared to the non-exercising group.' To put it in a nutshell; tyrosine is one of the 22 amino acids that make up proteins and in the brain it is used to make a couple of neurotransmitters, **dopamine being one of them.**



(Elliptical gym machine, by domdeen: freedigitalphotos.net)

You can see how this ties in with the results of the treadmill training, as bad things are inhibited, like excessive glutamate signalling and shortened synapse firing, and good things are enhanced, such as preserving the ability to produce dopamine and more dopamine receptors.

Yet another more recent study at the University of Seoul, Korea, induced lesions in the brains of rats, then exercised the active group for 30 minutes twice-daily, starting after 5 days of inactivity, (see link 2). Their conclusions stated that 'In the exercise group, weight, and Type I and II fibre cross-sectional area of the contralateral soleus significantly recovered and expression of myosin heavy chain and Akt and ERK phosphorylation were significantly increased by exercise. These results suggest that exercise recovers Parkinson's disease induced dopaminergic neuron loss and contralateral soleus muscle atrophy.'

Deciphering the above, the fibres referred to are muscle fibres in the soleus (lower leg muscle) and myosin etc. refers to the physical make-up of muscle tissue. The findings state that exercise seems to reverse loss of neurons in the brain and reverses muscle atrophy (shrinkage).

Looking at the studies described above, exercise seems to deal with all aspects within the brain and should be regarded as being **absolutely essential for PwP**. Although some scientists are still non-committal about exercise, there is enough experimental evidence to say that if you have Parkinson's, then exercise is a very highly recommended addition to your lifestyle.

Link 1: <http://www.ncbi.nlm.nih.gov/pmc/articles/PMC3690528/>

Link 2: <http://www.pubfacts.com/detail/23129977/Effects-of-Treadmill-Exercise-on-the-Recovery-of-Dopaminergic-Neuron-Loss-and-Muscle-Atrophy-in-the->

Personal Perspectives

Junk

Following the Great Fire of London, the demand for brick-built houses to replace the vulnerable wooden structures rendered much of the land in north-west Kent into junk. Chalk, sand, gravel and clay were torn out to provide building materials; and the barges, which took the bricks and cement up the river to the greedy city, brought back piles of unwanted rags to be picked over to provide fibre to bind the brickearths together.

Junk is something that you do not use and you cannot bear to throw away, but put by in case it might come in useful one day. The day came when the city's demand for affordable (and unaffordable) housing exceeded the supply, and its boundaries pushed outwards into the neighbouring counties to encompass the junk land it had created previously. Now the abandoned quarries and pits became commodities: first to swallow other people's junk in the form of landfill and then to spawn new roads, shopping centres and houses.

So it came about that I found myself moving out of central London to own a piece of junk land of my own in an abandoned sand pit. The lorry, which moved my belongings, brought also my personal lifetime's collection of junk: obsolescent pieces of machinery and furniture; the relics of past collecting hobbies; and memorabilia from distant lands that I shall not be visiting again. One of my first tasks was to floor the loft to house this assemblage: unlike most of my neighbours, who filled their garages with their own junk piles (to the delight of the local mouse population) and consequently leave their expensive cars out in the open in all weathers.

Junk seems to permeate my life. 95% of the taxes I pay are for the provision of services I do not need, and 95% of the functionality in the Word Processing and Operating systems I am employing to write these words go unused.

Unwittingly, when I moved here, I brought in a second junk collection embedded in each of the 100 trillion cells that make up my body. When geneticists came to decipher the strands of DNA that occupy the nucleus of every human cell, they found that 95% of it served no apparent purpose at all; it is evolutionary debris.



(Scanner, by renjith krishnan: freedigitalphotos.net)

My personal odyssey from the centre of London to the outskirts is nothing compared with the evolutionary journey my cells have made from single-celled progenitors through innumerable animal forms to become the fully fledged human of today. It is like writing a novel on a PC and never being able to empty the Recycle Bin.

One of the more persuasive arguments in favour of Creationism by William Paley

is that of the Divine Watchmaker. Suppose you are walking across a field and come across a watch. Such a complex and perfectly crafted object could not have got there by any natural process and it is reasonable to suppose that it is the handiwork of a superior being. So it is with the human body and so on.

But now suppose that you find a watch and when you look inside you find that 95% of the springs and cogs serve no purpose whatsoever. What does this say about a Divine Watchmaker?



(Face old wall clock, by Stoonn: freedigitalphotos.net)

Every other creature carries a similar junk DNA load, and some have made a more tortuous journey than we have. The amoeba *polychaos dubium* carries 210 times more genetic material than we do and it still cannot speak English! Tentative experiments have been carried out on mice to breed strains with 1% of their junk DNA removed and they just carried on being – well mice.

Junk DNA was therefore removed to the attics and garages of research programmes (and the mice were no doubt pleased about that) until 1985, when an English geneticist named Alec Jeffreys found that certain regions of human junk

DNA contained molecular sequences that were repeated over and over again next to each other. He also discovered that the number of repeated sections present in a sample could differ from individual to individual, giving each person a unique genetic identity.

These DNA repeat regions became known as VNTRs, which stands for Variable Number of Tandem Repeats. The technique used by Dr. Jeffreys to examine the VNTRs was called Restriction Fragment Length Polymorphism (RFLP) because it involved the use of a restriction enzyme to cut the regions of DNA surrounding the VNTRs.

The technique has been eagerly taken up by the police as a forensic aid. On 31 March 2009 there were records of 4,859,934 individuals on the National Police DNA database comprising some 5% of the England and Wales' population. What is actually held is a profile of 20 VNTRs plus data on gender and ethnicity. However the original individual cell samples (mostly saliva) are also retained and can be referred to if necessary.

Medical researchers salivate at the thought of such a large collection of data, which could be used to determine, amongst other things, what proportion of the population is at risk from familial diseases (including PD): but access to it is unlikely within the current legislative framework.

The database has, however, focussed attention upon the possible utility of junk DNA. A surprising recent finding was the discovery of nearly 500 ultraconserved elements, which are shared at extraordinarily high fidelity among the available vertebrate genomes, in what had previously been designated as junk. The function of these sequences is currently under intense scrutiny and there are preliminary indications that some may play a regulatory role in vertebrate development from embryo

to adult, acting upon the inner workings of a cell rather like the conductor of an orchestra. What we really need is to study the workings of a human that has had all of its junk DNA removed. In the meantime some geneticists are suggesting that junk DNA be renamed regulatory DNA.

It is a paradox of Parkinsonism that it has at the same time too many associated points of origin and too few. Diseases can be distinguished by classes of causes and Parkinsonism ticks all of the boxes: - genetic, toxins, drugs, pathogens, metabolism, and we have not even mentioned vascular conditions and trauma. Yet this surfeit of causes has so far explained only some 15% of the diagnosed cases, so what are we missing?

It is not too great a leap of imagination to suppose that if there is junk DNA functionality there could be junk-related diseases. These could take two forms. In one instance a piece of junk DNA is quietly carrying out its unseen catalytic role and suddenly loses the plot, precipitating an aetiological car crash; in the other, a piece of non-coding DNA suddenly starts producing a rogue protein and generating molecular mayhem in its host cell.

In either case it could perhaps mean that the Divine Watchmaker is having the last laugh.

Harry Pearman

Coming Up ...

Sat 11 October 2014, 10.00 – 15.30h:

East Midlands RSN 3rd Annual Research Forum

The Regent Suite, Park Inn, Mansfield Road, Nottingham NG5 2BT

The theme has been finalised as “**Research into Exercise for Parkinson’s: Finding out what really works**”, with an update on the achievements of Parkinson’s research by Dr Nin Bajaj. Further details will appear as they are confirmed. A Registration Form is at the end of this newsletter.

Tues 30 September - Thu 2 October 2014:

World Parkinson Coalition Scientific Update

an online webcast – see page 2 for more details.

Sun 2 November 2014:

3rd National Research Supporters Day

Royal York Hotel, Station Parade, York

Bookings may be made from August, but you can register your interest by e-mailing researchevents@parkinsons.org.uk or phoning 0207 963 9356

Full information on events throughout the country can be found on the Parkinson’s UK website, by visiting <http://www.parkinsons.org.uk/researchevents>

Next Issues...

Just a few of the topics to be covered in the next few issues of RSN News:

News and Events

Detailed report from Parkinson's UK on the Birmingham RSN Meeting
Report on a group visit to the MRI Imaging and Tracking Parkinson's Project in Nottingham

Has this been Researched?

Relationship between jobs and risk of developing PD
Pain and PD
Dyskinesia

And much more

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EMRSN News is published monthly by the Steering Group of the East Midlands Research Support Network (RSN). The RSN brings together people driven to help find a cure and better treatments for Parkinson's. Through our 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 your questions, contributions and a copy of your newsletter and event notices.

Editor: Ian Billcliff (imb248@outlook.com)

Editorial Group: Caroline Maxwell, Lionel Paulo, John Telford, Chris Johnson

We look forward to hearing from you!

Visit our page on the Parkinson's UK website:

<http://www.parkinsons.org.uk/content/east-midlands-research-support-network>

There is also a new section on the Parkinson's UK forum dedicated to the RSN:

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

**East Midlands Research Support Network (RSN)
3rd Annual Research Forum:**

**Research into Exercise for Parkinson's:
Finding out what really works**

**Saturday 11 October 2014, 10.30 – 15.30h
at Park Inn, 296 Mansfield Road, Nottingham NG5 2BT**

A one-day conference to explore the research evidence about exercise and Parkinson's, covering physical exercise of various types and intensities, and related therapies such as rhythm, music and dance, as well as 'exergaming' exercise video games such as Kinect and Wii. Presentations will include:

- Parkinson's research today – an overview
- Exercise to control symptoms
- Neuroprotection and disease modification through exercise
- Panel discussion on effective techniques and the merits of different forms of exercise
- Practical exercises helpful for Parkinson's

The 3rd EMRSN Research Forum has been made possible by generous funding from the Nottingham Branch of Parkinson's UK, the Derby Branch out of the legacy of Mrs Margaret Manester and the national Research Support Network.

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REPLY SLIP

To register please send an email to office@em-rsn.info **by Monday 15 September** with the following information for each participant:

Title: First Name(s): Surname:

Telephone Number: E-mail:

If any participant has a special dietary or other requirement please state it.

Alternatively you may phone in the information to Lionel Paulo, 0116 282 7340, or send it by post to: Lionel Paulo, RSN 2014 Forum, 2 Vyner Close, Leics, LE3 3EJ

Further information about the Forum and confirmation of your registration will then be sent to you.