

East Midlands

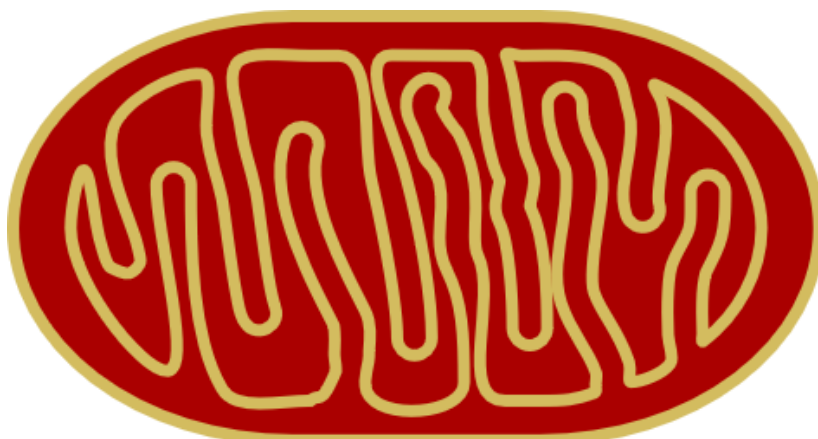
RSN NEWS

from the East Midlands Research Support Network

*** August 2015 / No 25 ***

Welcome to News 25.

This edition begins with an account from Roger and Kath Elkin of an afternoon spent learning about the use of animals in research. We also have an article from Dr Lynn Bedford of Nottingham University about her work on mitochondria.



"Mitochondria" by Nevit - Own work. Licensed via Wikimedia Commons:
<https://commons.wikimedia.org/wiki/File:Mitochondria.svg#/media/File:Mitochondria.svg>

There are several opportunities for you to get involved; there's an article about volunteering for clinical trials, a suggestion that you should join the AllTrials campaign, information about a nationwide research project which you could join and, most importantly, on the [back page](#) an advertisement for the East Midlands Research Forum on 10th of October. To assure your place at this event register now. I hope to see you there.

Caroline Maxwell, editor
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... and much more!



(Number Twenty Five with Ribbon, 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)

News & Events

Understanding animal research

By Roger and Kath Elkin

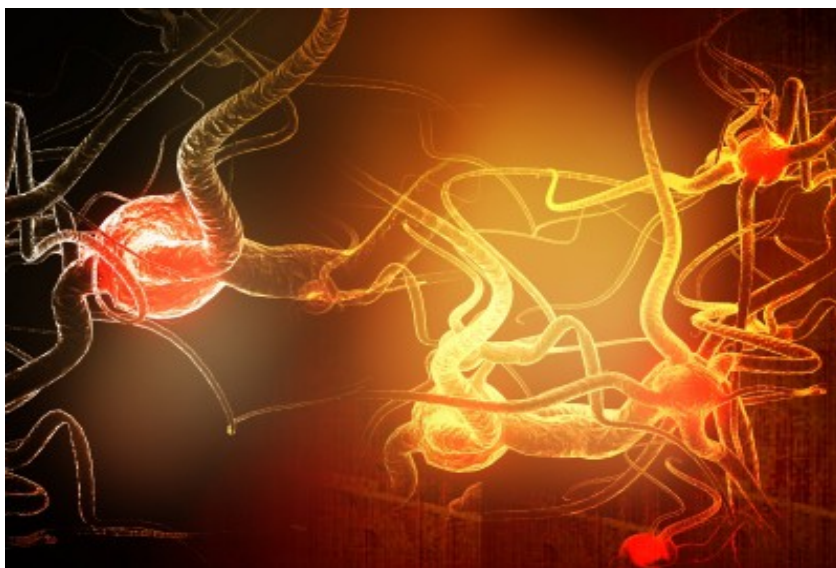
On 20th July 2015 Parkinson's UK Research supporters gathered at Oxford University for an event hosted by the Medical Research Council's Brain Network Dynamics Unit (BNDU) and arranged by Claire Bale, PUK's Head of Communications and her team.

We were welcomed by Peter Brown, Director of the Unit and colleagues Paul Bolam and Pete Magill, who also undertake research as Oxford Parkinson's Disease Centre (OPDC) Investigators. The OPDC is funded by the Monument Trust administered by Parkinson's UK, most recently with a further 5 year grant of £6m.

The event agenda was driven by questions gathered from PUK Research supporters interested in learning more about the roles of animals in Parkinson's research.

Peter Brown commenced by explaining the BNDU opened in April 2015:

- 1 to research and understand the moment-to-moment neuronal interactions, synaptic activity and brain circuitry underlying movement and memory,
- 2 to investigate how and why these systems fail,
- 3 to develop and deliver novel therapies aimed to remedy or reduce the effects of such failing systems.



www.freedigitalphotos.net

Paul Bolam went on to remind us that with some 86 billion neurons possessing an estimated 10^{15} connections and with communication within the brain changing all the time, we are dealing with an extremely complicated subject for research. With such complexity, study of the whole living brain is vital and this requires the use of animal models to complement other research activities.

(Neuron, by renjith krishnan;

Paul then explained that there are several approaches to brain research, each of which has advantages and limitations. Alternatives to using animals for research are always used wherever possible and include:

- 1 Post mortem human tissue (the Brain Bank): useful for examining cell structure. Not very useful for studying electrical activity, as most brains are badly affected by the disease when they become available; not too applicable to early stage research.
- 2 People: MRI brain scans, samples of blood serum and cerebro-spinal fluid (CSF). Non-invasive procedures but provide limited opportunity to experiment,
- 3 Stem cells: development of neurons from induced pluripotent stem cells usually derived from skin cells provide possibilities for research but currently require further investigation and development.

- 4 Computational neuroscience models also known as 'computer models: built to replicate the activity of part of the dopamine neuron; can narrow a set of scenarios and thus accelerate research; useful in indicating where to look rather than provide solutions.
- 5 Small creatures such as fruit flies (*drosophila*): provide for basic, molecular level research but not useful for investigation of brain structures.

Animal models are seen as the final resort for research, being considered only when absolutely necessary. As virtually all human genes have 'mouse equivalents' animal research is focused on rodents, predominately mice, although rats also participate in some trials. No primates are used in any of the Unit's research.

Animals do not naturally develop Parkinson's so the condition has to be induced either by using toxic chemicals (usually MPTP) targeted to destroy dopaminergic neurons or genetic modification where every cell in the modified animal will carry the mutation. Modification of the mouse genome is relatively straightforward and the Unit, together with OPDC colleagues, develops and breeds the majority of its own research subjects. We were asked to consider what advances have resulted from research requiring animals. L-dopa is a notable historic breakthrough whose development was only made possible by using animals.

Another significant example is the development of Deep Brain Stimulation (DBS). Techniques for this operation were almost entirely established in animal subjects to predict target areas in the brain; a small number (10-15) of primates were used before the

procedure was rapidly extended for use in patients.



(Brain, by dream designs: freedigitalphotos.net)

We were then taken on a tour of three of the Unit's laboratories. The first lab demonstrated using sections of mouse brain to label individual dopamine neurons with a fluorescent marker. The resultant samples were readily identifiable by using the microscope and screen display, which also served to illustrate the extremely complex neuronal density and connectivity.

In the second lab we were shown part of an in-vivo investigation into the activity of dopamine neurons. A mouse subject with surgical implants to the substantia nigra was connected to a device where the firing of the dopamine neurons (the electrical impulse representing the action potential), could be recorded, displayed on screen and heard as a 'Morse code'. Results were taken for the animal at rest as well as when undergoing exercise, achieved by running on a treadmill.

The activity of neurons in a normal healthy mouse could then be compared with the activity of dopamine neurons in an older and/or an unhealthy mouse bearing say, a mutant strain of alpha-synuclein. As with much research, discoveries give rise to more questions. This research was already implying the unexpected existence of several types of dopamine neurons whereas only a single type had been expected.

The researchers made the point that the animals were not stressed by being wired up to

the device either whilst at rest or whilst exercising - as observed by their behaviour being normal at all times.

We were then taken to view examples of mice in their portable enclosure cages. The lab supervisor brought out cages of mice typical of those from the controlled environment laboratory where conditions are strictly maintained and which to visit we would have needed to don masks and protective clothing - for the benefit of the mice, not us!

It was explained that the controlled environment laboratory comprised 5 banks of 80 cages containing mice plus 1 bank for rats. Each cage contains up to 5 mice. A mouse's normal life-span in laboratory conditions is about 2 years and most mice used for research are 'aged animals' of around 18 months – equivalent to a human of 70 years.



(Laboratory picture by Parkinson's UK)

Mice used for research are anaesthetised and receive analgesics as required if any surgical procedures are involved. At the conclusion of the animal's participation it is humanely and painlessly terminated with its tissues then made available for examination to further inform the findings of the research project as required.

There followed a session with the BNDU's three panel members concerning animal research regulation. Animal research in the UK is conducted to the highest standards worldwide. It is regulated by an Act of Parliament and policed by the Home Office who conduct unannounced inspections – the Unit receives 3 such calls each year as well as veterinary visits.

Licenses are issued, reviewed and resubmitted for approval every five years requiring an in depth 100 page application that undergoes critical scrutiny including ethics panel review. An annual report must also be submitted. Researchers have to demonstrate why each experiment is the best approach. For example, the need must not only be justified but reflect an ongoing commitment to use less sentient animals wherever possible. Researchers are also personally licensed and undertake regular refresher courses at six month intervals. The Unit also has a Named Animal Carer and Welfare Officer (NACWO) providing further scrutiny.

The use of animals for research within the UK may be summarised as being governed by legislation requiring humane practice which is rigorously policed and consequently is hugely expensive to maintain.█

The event concluded with a final Q&A session. It was evident that all the Parkinson's Research supporters present, whilst accepting that animal subjects were needed to advance understanding and develop treatments for the condition, felt much more informed and reassured that animal use for Parkinson's research was applied humanely and only where proven necessary.

You may remember that some months ago John Telford wrote a spectator's account of his visit to Lynn Bedford's lab where she is working on mitochondria. To read his article again look at our News 21 issued in December 2014. Here Lynn gives the researcher's perspective.

The fascinating life of a mitochondrion

By Dr Lynn Bedford, Senior Research Fellow, School of Life Sciences, University of Nottingham

As part of my research I have become very interested in mitochondria. There is a strong connection between mitochondria and Parkinson's disease (PD).

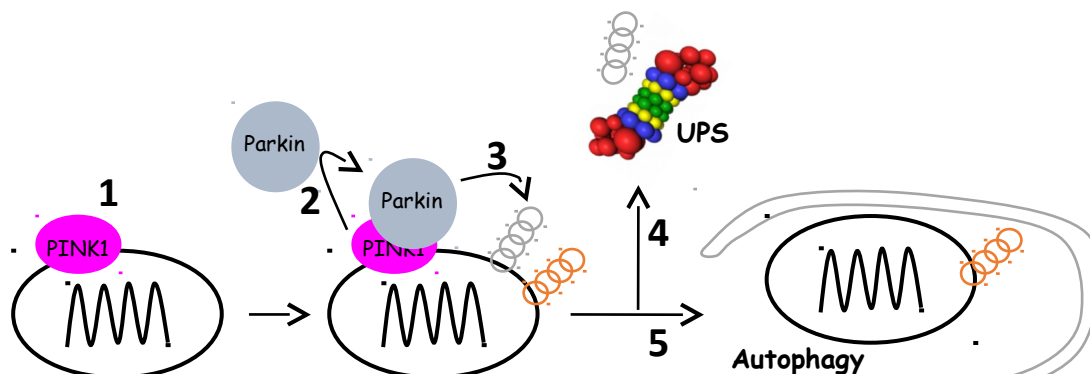


Mitochondria are the cells' batteries that produce the energy needed to power all the activities of every cell of the body. Neurons are the cells that communicate messages in the brain by the use of neurotransmitters. Dopaminergic (DA) neurons – the neurons which use dopamine as their neurotransmitter - play an important role in the co-ordination of movement. Normal mitochondria are essential for the function and survival of neurons, but when mitochondria become damaged they need to be removed from the cell to enable the cell to continue to function. Two systems are involved in removing these damaged mitochondria. They are called the Ubiquitin Proteasome System (UPS) and Autophagy.

In PD, dopaminergic (DA) neurons in the brain gradually die. Research has indicated that in PD and aged individuals the neurons that are dying display problems with their mitochondria.

Recently two genes that lead to the familial form of PD have been at the heart of extensive research; these genes are called PINK1 and Parkin. These genes operate in a single pathway that is important for the removal of damaged mitochondria. This is how we think this works in healthy individuals (Figure): When mitochondria become damaged PINK1 is stabilised on the outside of the mitochondria (step 1). PINK1 then recruits Parkin to the mitochondria (step 2). Parkin is able to modify the damaged mitochondria with signals so that it is recognised by the cells' disposal systems (step 3); UPS (UPS) (step 4) and Autophagy (step 5). Both of the disposal systems are important in the removal of damaged mitochondria.

But when PINK1 and Parkin are mutated, neurons may not be able to remove damaged mitochondria properly and this will cause problems for the neuron and may lead to cell death and eventually PD.



My research focuses on the UPS in neurons. There is evidence that this protein disposal system is important in PD. Using a model system I can disrupt the UPS and this leads to

the build-up of proteins in the model brain that is similar to the brains of patients with PD. When we do this in DA neurons, this also leads to the accumulation of damaged mitochondria. This supports the importance of properly working disposal systems to keep our mitochondria healthy. Finding out how to keep these disposal systems working properly will be a research project for the future.

Parkinson's UK Annual General Meeting

By Caroline Maxwell

As this newsletter goes to press paid-up members of Parkinson's UK have received their notices for the Annual General Meeting at **13:30 on Saturday 12 September 2015** at One Drummond Gate, Victoria, London SW1V 2QQ - You may not be planning to go to this meeting but you are still entitled to vote and in this way influence how the charity is run.. Here is a brief excerpt from the AGM papers:

Circulation of AGM papers

Since 2012 we've asked members to access the AGM papers online from our website parkinsons.org.uk/agm - Here you can see and download: the draft minutes of the 2014 AGM, the Trustees' report and financial statements for 2014 and the Nominations Panel report 2014. These papers are available right up to the date of the AGM.

The Board of Trustees is the governing body of Parkinson's UK and is responsible for the overall governance and strategic direction of the charity. Voting for elected Trustees is only open to charity members. Details of our current and retiring Trustees can be found at parkinsons.org.uk/trustees

The meeting will be asked to approve the accounts and the annual report and **to elect trustees** for the following year. It is in this voting for trustees that your vote can really make a difference.

It is the trustees who are ultimately responsible for the direction and management of Parkinson's UK. They set the priorities and the budgets, and then employ the staff to carry out the work. It is important that between them the trustees have a variety of skills and experience which will secure the best outcomes for the charity. If you are interested in the ways that Parkinson's UK is likely to develop in the future then try to make the time to look at the details of the trustees which can be found in the AGM papers. See which individuals appear to promote activities which are important to you, try to judge if the potential trustees have a mix of skills and will make a good team balancing campaigning and publicity, fundraising, information and support and, of course, research, then cast your vote accordingly.

The instructions in the email sent to members on 10th of August explain clearly how to access these papers and how to vote. It is possible to log on, look at the papers and then log off without voting. You can then log on again at a later date and cast your vote...

News from RSN DT

By John Telford

The RSN Development Team is a dozen or so volunteers and staff who at the national level liaise with the Research Team, monitor the development of the RSN, initiate action to promote its aims and engage RSN members in research-oriented activity.

The Parkinson's UK Excellence Network - bringing together health and social care professionals to transform care for people affected by Parkinson's

It is still early days for the Excellence Network. One of its working groups that is of particular interest to the RSN is the **Research Engagement** working group which is led by Michele Hu. There are five other working groups within the network. For full information see <http://www.parkinsons.org.uk/professionals>



The first meeting of the Research Engagement working group was in May. It was mainly taken up with setting out the aims for the group and agreeing terms of reference.

The group agreed that the main aim was **to promote and encourage high quality Parkinson's research across the UK**. This would be achieved on 2 fronts:

1. Increasing the engagement of patients and their families in research.
2. Engaging and supporting health care professionals delivering Parkinson's research.

A noteworthy decision from the first meeting was to increase the involvement of people affected by Parkinson's in future meetings – and in particular to have a representative from the Research Support Network which was identified as a key partner in delivering the above aims.

From now on, the Research Team's involvement in the Research Engagement working group will be led by Amelia Hursey who joined Parkinson's UK in early July as the new Senior Research Participation Officer.

At the meeting of the RSN DT in mid-July, Amelia explained that she was still 'getting her feet under the table' but was already working on many ideas for increasing the participation of people living with Parkinson's in studies and clinical trials. Amelia's is a brand new post and she will be using her wealth of knowledge and expertise from working as a clinical trials practitioner at Norfolk and Norwich University Hospitals NHS Foundation Trust to drive forward our work to increase participation in Parkinson's research.

Drug repurposing

Parkinson's UK is involved in a multi-organisation project which is trying to identify existing drugs for different conditions which may have the effect of slowing down the disease process in Parkinson's. A whole scientific armoury is being deployed to do this. The Research Director, Arthur Roach, comes to the RSN DT meetings regularly to brief us on the latest developments and to discuss the contribution the RSN could make.



(Pills, by worradmu: freedigitalphotos.net)

But can volunteers really help in the Drug Repurposing project in any way? The RSN DT has decided that they can, but in a parallel rather than a direct way

Before the end of the year a questionnaire is going to be sent out asking people living with Parkinson's whether they have ever found that a drug that they took for another condition had an effect on their Parkinson's symptoms.

Note that this survey will be looking at effects on symptoms, not whether a drug has slowed down progression because the latter is very hard to determine objectively and needs careful measurements over a long period of time across a large number of patients. But if we can spot a particular treatment that several people said had unexpectedly improved one or more of their Parkinson's symptoms then this could point to something that others might benefit from. So the RSN DT is going to send out an initial question asking RSN members if they have ever noticed such an effect, followed by a fuller questionnaire for those who answer positively. Look out for this.

To back this up the RSN DT will be asking for volunteers to help to trawl through the Parkinson's UK On-line Forum and maybe other forums to see whether people have already mentioned such effects in their posts. Let us know if you would be interested in spending a few hours helping with this task from your own computer at home – the more people sharing this chore of searching through tens of thousands of posts the quicker it will be done!

Growing RSN Groups

There are now some budding RSN groups in Cardiff, Bristol and the South West, Yorkshire and Humberside, the North East and the Surrey area. These are in addition to the more established East Midlands and Edinburgh Groups. Before long we could be sharing interesting information and newsletters with other thriving RSN groups throughout the country!

Don't miss the East Midlands forum on
Parkinson's and Communication

See [back page](#) for details

Would you participate in a clinical trial?

By Caroline Maxwell

We all know that medical research takes a great deal of money and a great deal of time but there is another resource which is in short supply that is not so often mentioned. One of the biggest hurdles researchers have to overcome is recruiting volunteers to participate in clinical trials and studies. For research to have any validity it must involve large numbers of individuals as trial subjects. Recruiting these participants can take much time and effort and is a vital part of the researchers' task.

Parkinson's UK has recently appointed a new Senior Research Participation Officer. Her name is Amelia Hursey and her remit is to increase the number of people with Parkinson's participating in clinical studies and trials. When I heard this I decided to make a few enquiries myself. I wondered why it was so hard to recruit volunteers. I did a small informal survey of the people who attend the same exercise class as I do. We are a cross-section of people living in and around Daventry who have Parkinson's disease. We meet

every week at a gym and are led through a series of exercises by our enthusiastic trainer Elaine. There are about 16 of us and we are not brought together by an interest in research but by a shared commitment to keep exercising (gently) and hopefully reduce the impact that Parkinson's has on our lives.

Although the group is friendly and supportive we don't have a lot of time to chat to each other and as far as I remember we have never had a discussion about participating in research. So we had no preformed collective view. To conduct my straw poll I produced a sheet of paper for each person with two sets of statements, one was reasons why any individual might not be involved in research and the other set was reasons which might persuade people to get involved. To assure anonymity I asked my group members just to tick the statements which were most relevant to them. The two sets of statements and the number of responses that each received are shown below. I received replies from 10 people. One person is currently participating in a trial run by Oxford University.

Suggested reasons for NOT getting involved in clinical trials:

Nobody has asked me to get involved and I wouldn't know how to go about it. 6

Researchers have been looking for a cure for ages, so I'm not sure my participation would make any difference. 3

I don't think I would understand anything of the science behind it so I would feel foolish. 2

I expect I would have to meet quite a few new people and go to an unfamiliar place possibly more than once and I don't really want to do that. 2

I don't know how I would manage the travel, especially if I had to suspend my medication. 3

How would I know that the researchers are genuine and that they will maintain my confidentiality 2

I don't want to have to collect samples or take frequent measurements of my bodily functions. 0

How would it affect my current medication? 8

Would it be a long time before we knew the results? 2

I might be on the placebo and that would just be a waste of time 0

I'm constantly tired as it is; I don't have the energy to take on anything new. 3

I did take part in a project a couple of years ago so I've done my bit. 3

Factors which might encourage participation:

My consultant, GP, or nurse has suggested I participate in this trial. 7

The research is about something which is really important to me e.g. sleep disorders, falls, hallucinations. 7

I know somebody else who is participating and we will be able to compare our experiences. 3

I might volunteer if participants were paid. 0

I heard the researcher at a Parkinson's event and found him/her very interesting and friendly 5.

I don't have Parkinson's myself but this study is looking for people without Parkinson's to form a control group. I would like to make a contribution by volunteering to participate. 0

The researchers are looking for a very specific group of people and I actually meet their criteria so I feel I should participate if possible. 3

I think it might be interesting to be part of a project.9

This was a very informal exercise with absolutely no scientific rigour but for me it provided some interesting results and I'm grateful to all those who participated. If anyone would like to conduct their own poll and share the results they are welcome to use any or all of my questions. It is encouraging that almost everyone who said they were not involved because nobody has asked them, also said they thought it might be interesting to be part of a project and that they would be more likely to consider it if their clinician recommended it. I was also interested that money was not mentioned as an issue by anyone. Finally, it appeared that encouragement from a clinician, a fellow volunteer or a familiar scientist might overcome initial misgivings about the practical issues involved.

In the next edition of this newsletter Amelia Hursey will write about her plans to increase participation. Meanwhile, for a list of trials currently looking for participants take a look at the Parkinson's UK website <http://www.parkinsons.org.uk/content/take-part-parkinsons-research-list-uk> - Several projects involve no travel so look at the 'nation-wide' list as well as your own region.

Don't hesitate, participate **NOW**

Here is an opportunity which looks painless, circulated recently by Parkinson's UK:

BioResource Initiative: King's College London

We've recently been contacted by a research team based at the King's College London who would like to invite you to join their BioResource initiative.

What is the 'BioResource Initiative'?

The NIHR BioResource is a NHS research initiative funded by **the National Institute for Health Research**. This is part of a national project aiming to build up a central library of information about people's health. This information will be used in medical research to help us better understand why different conditions such as Parkinson's happen and how we can develop better treatments for them.

Who can take part?

People with Parkinson's.

What is involved?

Taking part in this project involves providing **a saliva sample** for genetic analysis which will be done entirely by post. The team will also ask if you're happy to link the sample to your clinical records by asking your GP for a copy of your medical history.

The data you provide will be used in two ways.

- ⑤ Firstly, BioResource staff will make the genetic and clinical data available to scientists working on ethically approved projects (**on a strictly anonymous basis**).
- ⑤ Secondly, if you'd like you can provide consent to be contacted about research

studies which are looking for participants (for example a trial of a new drug). For further information about the BioResource and what is involved, please visit <http://bit.ly/1SjjUhE> - The closing date for taking part is **July 2016**.

Interested in taking part?

Please contact the research team directly:

Dr Byron Creese, Research lead

King's College London

Byron.Creese@kcl.ac.uk or 0207 848 8194

Next steps

Please circulate this opportunity to members of your Parkinson's UK local group, Parkinson's nurse, family and friends who might be interested.

This opportunity is not managed by Parkinson's UK. It is your choice to take part in the activity and Parkinson's UK cannot take responsibility for it.

Has this been researched yet?

Vibration plates as a form of exercise for people with Parkinson's

By Lionel Paulo

An interested reader of the newsletter asked this question recently – does it work? Like many people that have heard of vibration therapy/exercise, I thought the answer would be an obvious 'yes' but looking into it I found it is not as straightforward as that. As with all things Parkinson's related, it is much more complicated and contrary-wise than first meets the eye.

Looking at research on the internet there is plenty of material highlighting studies that suggest vibration therapy benefits many types of ailments and also enhances sporting ability in the healthy part of the population. The problem is most of this research has been done and written about by companies that sell these machines – look beyond these articles and there is a substantial amount of critical comments and articles that do not think vibration training is a good thing.

Okay, if you are mystified by the term 'vibration training', I will explain. Conventional exercise such as running, lifting weights, swimming etc. requires your input and effort to perform. Vibration training places you on a machine that can vibrate at many different frequencies – find the right one for you and everything in your body will vibrate along with the machine, supposedly causing muscles to contract and relax multiple times per second. This 'works out' your body without you making much conscious effort at all (you do assume exercise postures while standing on the machine, and can perform exercise movements while being shook up). No great effort, no heavy load on your body, no pounding of joints such as you get running on the streets.

This sounds like exercise heaven but hold on a minute! Is there real evidence to prove that it works and is safe? Claims made by some companies include the following benefits:

- Enhanced strength and power *even in elite athletes!*
- Prevention of age-related muscle loss.
- Increased bone density (i.e. reversing Osteoporosis).
- Removing 'toxins and cellulite.'

As an example of research, the power plate website quotes quite a few positive studies. Look closely and you can see flaws in the studies constructions which would distort results. For example:

Passive control group: In the majority of studies this group did no exercise at all, so using the machines represented a 100 percent increase in exercise, and inevitably led to improvements in fitness.

Improper control: Not normalizing intensity. Without matching starting averages there is a chance that intensities in both groups were similar and nothing to do with vibration training. To explain normalizing intensity: when testing subjects for, say, strength of their muscles in the front thigh (Vastus Medialis, Rectus Femoris etc.) the test subject performs isolated and isometric contractions to the maximum of their capability. This serves as a starting benchmark for what the subject can do without any vibration machine being involved. This is done for all in the study and a group average arrived at for each group. Now when the vibration group is tested performing the same effort but with vibrations included we can see if the vibrations yield a different result (more or less strength). If normalizing has not been done before the vibration group goes to work how do we know if it made a difference to their results?

Proper controls: Taking all the studies which employed proper controls i.e. where they did similar exercises without vibration, we see no statistically significant difference in strength or power.

Correctly performed studies showed no gains in strength, speed, reduction in cellulite or age-related muscle loss. Interestingly, improvements were noted in bone density, so vibration therapy could help people with osteoporosis.

According to OSHA (Occupational & Safety Hazard Association), vibration exposure can cause damage! Long term problems identified include nausea, hyperventilation, impaired vision, Raynaud's Syndrome (white finger disease), Carpal Tunnel Syndrome and other more minor difficulties.

Parkinson's is specifically mentioned in many studies and endorsements but I have not found convincing evidence that this type of vibration exercise really does help. On the other hand, there are plenty of critical voices, some of whom have Parkinson's, who have found vibration training to be either ineffective or upsetting to their health or both. As a Parky person myself I know we are all different and maybe some of us would find benefit from using it (PLEASE bear in mind this is not an endorsement from me!). I can only say we take responsibility for our own health problems, so if you want to try it then it is up to you. If anyone out there reading this has positive things to say (or even negative things) please share your experiences with me and I will put them in the next newsletter.

Sorry to be so ambiguous about this subject matter but all I have seen and come across on the internet adds up to a stalemate between those who praise it and those who rubbish it. As is usually the case I suspect it will come down to purely individual response to trying it out. Will I try it? Probably but don't sign up to any costly exercise programmes or buy

expensive machines without trying out a few sessions first, being sure that it helps you, not hurts you (involve your consultant/specialist nurse/GP to add to their knowledge and to be monitored by them to watch out for negative results).

Another type of vibration training, known as stochastic training, has the subject standing on two separate force plates which vibrate out of synchronisation with each other. However, that can be subject matter for another day. For the technically – minded among you, follow the link below to a German study on vibration training which is detailed and fascinating (don't worry, it is in English) - www.jssm.org/vol12/n3/11/v12n3-11text.php

AllTrials Success

Are our doctors well-informed? THE ALLTRIALS CAMPAIGN promotes sharing the ALL results of ALL medical trials to ensure decision makers know ALL the facts before reaching for their prescription pad or scalpel.

We all like to think that the professionals who treat us have a wide experience of people with our condition, have trained for many years and studied endless amounts of data. We assume that they have access to reports of research trials that have been run in the past as well as the most recent trials. So we hope that their diagnosis of our condition and recommendations for treatment will be based on a comprehensive picture of what is available, safe and likely to be effective.

But for some years there have been voices suggesting this may not be the case. Questions have been asked about the results of trials which have not been published. It was not always mandatory to register the trial of a new drug or to publish the results of clinical trials. This meant unsatisfactory results could be quietly buried leaving only positive trial data on which doctors might base their prescriptions. Dr Ben Goldacre's book *Bad Pharma* published in 2012 revealed some frighteningly bad practices in the pharmaceutical industry and called for reform.

In various previous editions of this newsletter we have reported on the work of Ben Goldacre's AllTrials campaign which is calling for all trial results, past and present, to be made publicly available. 18 months ago success for the campaign seemed unlikely but now finally things are changing.

With gradually increasing support from members of the public, the professions, and increasingly, the pharmaceutical companies, the AllTrials campaign is succeeding in altering many practices which had been entrenched in the pharmaceutical industry. Competition is being replaced by collaboration, secrecy by transparency and, very gradually, cynicism is giving way to trust. Ben Goldacre's AllTrials campaign has become a force to be reckoned with. Below you can see excerpts from a recent email. To find out more or to register your support go to: www.alltrials.net.

Email from Ben Goldacre:

Hi all,

I've wrestled the keyboard away from the AllTrials staff to send this email because, after two years of work - from tiny beginnings - with your help, the campaign has had a ridiculously good two weeks. It's a cliché, so revoke my writing license, but this is all down to you and to your support.

Commitment from pension funds

Firstly, as you will hopefully have seen, major pension funds and investors managing a total of over €3.5 trillion in funds are now working with us to hold companies to account on their trials transparency plans. People who care about companies' behaviour, as part of their day to day work, now care about withheld trial results. This means companies' compliance with legislation and their own promises will be monitored like never before. €3.5 trillion is a big number, and one that companies will take notice of. Because of this coup, AllTrials was covered extensively in the financial press. More investors have been in touch, asking to join, and asking for help taking up the missing trials issue with the companies they invest in.

Launched in US

Then we launched the campaign in the US. The responses from American organisations have been overwhelming. Just like when we launched in the UK, people in all kinds of organisations have told us they're glad AllTrials is starting in the States, because they have been worried about this issue for a long time but didn't know what to do about it, especially as raising the issue can feel (appallingly!) controversial.

Missing data on trials has been an issue for decades

Why am I telling you all this? Because the first good evidence on missing trial results in medicine was published in 1980. The first strong prominent call for a trials register was in 1986. Since then there have been dozens of studies published on the prevalence of missing data, and endless broken promises, **but** the problem has not been fixed. Academic publications are a necessary first step to getting a global public health problem like this fixed. But they are not enough on their own.

How do we achieve change?

The real day to day business of the AllTrials campaign is a grind. It is admin. It is bottomless. This is how change happens: endlessly setting up meetings and seminars around Europe and the States, hours on conference calls and webinars, days pouring over impenetrable policy positions and dull consultation documents, constant coordination with teams in the States and UK, and collaborators around the world. I am humbled to see AllTrials staff do real work. Their work, paid for by you, is the kind of stuff that cannot be done as a hobby. It has moved the campaign onto another level, and made this issue unignorable.

Obviously I am asking you for money. That's because I can now see, more than ever before, that change happens because good people, with experience at creating change, devote their full time career and working week to making it happen. Everything that AllTrials has achieved so far has only happened because of your collective support, your targeted emails to policy makers, your endorsement, your help in getting your organisations signed up, and your money, that pays for the grinding work to be done.

We are at a tipping point

If we stopped tomorrow then you and I, and everyone involved, could probably all award ourselves a point. But we have not won, there is more to do, and we are at a tipping point. If you can give any sum of money, to keep AllTrials staff doing the kind of boring, tireless, repetitive campaign work – the stuff that would make you or I scream our tongues out with boredom but might just help everyone do the right thing by patients – then [please, please do](#).

Dr Ben Goldacre www.alltrials.net

WPC -

World Parkinson Coalition – World Parkinson Congress

You can learn more about Parkinson's, research, treatments and living with it through **free web-casts from the World Parkinson Coalition**.

They are scheduled for particular days but can be viewed afterwards because they are saved in the archives.

The next 2-day programme will be on October 6th and 7th

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 participate from your own computer or other device or view the recorded sessions later.

For more information and to register go to:

<http://www.worldpdcoalition.org/?page=2015Webcast>

The Programme for the October sessions includes:

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

Also: *(or instead, if you don't have much time)*

You could listen to some excellent but much shorter
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!

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



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Parkinson's websites in Europe: little-known gems

By Lionel Paulo

It's fair to say that everyone reading this has heard of Parkinson's UK (the biggest PD charity in the UK). We would all be much worse off if they did not exist, so personally at least a vote of thanks goes to them.

Again, making an assumption, most of us have heard of the Michael J. Fox Foundation in the good old USA. Mr. Fox has turned his celebrity into a charity magnet, to date taking well over 300 million dollars in donations! There are many other groups in America (probably the most well-known being Muhammad Ali's).

When I started looking at European websites I was surprised by how many there are and how unknown they are to most of us. Starting in this edition of our newsletter it is my intention to let you know about some of the Parkinson's websites based in Europe that have items of interest on research.

European Parkinson's Disease Association (EPDA)

Ironically, for the first European site I picked, its registered address is Trafalgar Square, London. The EPDA describe themselves as the only European PD umbrella organisation, representing 45 organisations from 36 countries totalling 1.2 million People with Parkinson's (PwP) members. Their declared aims are to influence European policies

towards PD, encourage national organisations, healthcare professionals, pharmaceutical companies and the media. The ultimate goal is to secure fair and effective treatment and care for all PwP in Europe, and to better educate the public about the realities of living with PD.



The website consists of several modules containing different themes, and I was particularly interested by 2 ongoing trials that are being followed by EPDA. The first study is the Neurological Regeneration Trial (NRT), an EU-funded project currently in phase II (see Critical Path article in newsletter 24 to see what phase II means), studying rhPDGF-BB (to over-simplify it is essentially a human growth factor found in blood). If this

works out it may be able to act as a restorative therapy for PwP.

The second major study (also EU-funded) is Remote Management of Parkinson's disease (REMPARK), based around a portable monitoring system that picks up our tremors, freezes, clumsy walking and other manifestations of PD. All this information is stored and run through a program that builds up a profile of the physical difficulties that the PwP is experiencing. The long-term aim here is to create a system that can feed back to PwP information that would help him or her to correct these movement and postural problems. Above is the menu page for EPDA, note the modular layout around a central hub.

As I mentioned previously the EPDA website is user-friendly, being easy to navigate and I would recommend having a look at it, but if you choose not to, I feel there is a strong optimistic element to this. There has never been a busier time world-wide for Parkinson's researchers, and this site is one of many that is helping with spreading the word to researchers, clinicians and those of us afflicted with the disease. The more communications can link people, the greater the chance that research that is complementary will be matched up and possibly achieve something. The link for the EPDA website is - <http://www.epda.eu.com/en/#>

Parkinson's UK Research Supporters' Conference on 14th November 2015 in Birmingham is now fully booked. But if you find yourself able to attend at very short notice because you live locally, it may be worth contacting Claire Stephenson or Anna-Louise Smith at Parkinson's UK on 0207 963 9313 to ask if there are any last minute cancellations.

Would you like to help with the newsletter?

1. Could you spare the time to keep an eye on the Michael J Fox website and pick out any items you think might be of interest to our readers?
2. Have you any experience of using an app on your mobile phone to monitor your PD? The U-motif Big-PD project to develop a PD specific app is slowly coming together and it would be good to hear from someone who has previously used such a gadget.
3. Have you any suggestions for topics to cover or have you written any articles with a research slant which might interest our readers?

If you could help with any of these please contact me at caroline@paddockend.com. Thank you.

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.

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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>

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Parkinson's Communications Research

We have fixed the date: **Saturday 10th October 2015, 10.30 am to 3.30 pm** – *put it in your diary!*

We have booked the place: **The Link Hotel, Loughborough**

We have booked the Speakers:

Progress towards a cure and better treatments for Parkinson's

Dr Simon Paine - Nottingham University

Perception and Non-verbal Communication in Parkinson's

Dr Ellen Poliakoff, School of Psychological Sciences, Manchester University

Parkinson's Voice Initiative and other smartphone apps

Dr Max Little, Aston University

LOUD Therapy and the effects of DBS on the Voice

Dr Elina Tripoliti, University College London

The Forum is mainly about communication issues and Parkinson's.

There will also be a panel discussion and a session with audience participation when you least expect it!

*There will also be a stall with various types of **Communications Devices** relevant to Parkinson's.*

Remember how good last year's Forum was!!

To register for this **free** event please send an email to **office@em-rsn.info** **by Monday 14 September 2015** with the following information for each participant:

Title: First Name(s): Surname:

Telephone Number: E-mail:

Also:

- 1 Lunch is free but donations to cover cost are welcome. Please state any special dietary or other requirements.
- 2 Let us have any questions that you would like to address to the Panel, and
- 3 Say if you can help out with the smooth running of the Forum on the day!

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