

OUR NEWS

East Midlands Research Support Network News

No 6 Mar 2013

Over the past year since the East Midlands RSN Steering Group was established we have developed stronger links with researchers in the region. We are pleased to be able, in this newsletter, to invite some of you to meet them for yourselves.

First meeting of regional researchers

Monday 25 March, Queen's Medical Centre, Nottingham

We know of seven Parkinson's research projects going on in the East Midlands. Representatives of all seven will be meeting to



(Neuron, by renjith krishnan:
freedigitalphotos.net)

talk with each other about their work and to discuss matters of common interest on the morning of Monday 25 March at the QMC in Nottingham. While this meeting has been convened for the researchers' benefit, we are also inviting a small audience to sit in and listen to what they have to say. You are invited to express your

interest in coming along. The nature of the meeting means, of course, that you may struggle keep up with everything the researchers discuss with each other. But if you have more than the minimum knowledge about Parkinson's you could learn a lot about the issues that arise when researchers attempt to answer certain scientific and clinical questions. This would also put you in good stead for writing up a summary of a part of the proceedings for the newsletter and the Parkinson's online Forum and I hope you can rise to this challenge.

If you are interested in taking up one of the dozen or so places available in the audience, please contact John at intelford@ntlworld.com - There will be an opportunity to put relevant questions from the point of view of the person living with Parkinson's to the researchers in a timeslot near the end of the meeting. The meeting will start at 10:30am and lunch can be purchased at a nearby cafeteria for those who wish to stay and 'network'.

Inside this issue...

- Visit to the Brain Bank
- Steering Group
- Dr Haunton needs you
- Derby Research Forum
- Diary of a drugs trial
- Speakers on Research
- Good Pharma
- World Congress
- Full articles

... and much more!



(Puzzle, by jannoon028:
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)

Join a visit to the Brain Bank

We have been given the opportunity to visit the joint Parkinson's/MS Brain Bank which is in London, near White City. The Brain Bank facilities are impressive, and the work performed by a dedicated team is fascinating – and very well worth seeing. Follow this link to an article in a recent edition of New Scientist for background information:

www.parkinsons.org.uk/about_us/news/news_items/all_news/brain_bank_in_new_scientist.aspx

The laboratories can accommodate up to 12 visitors and the visit would typically last between one and two hours. The preferred day would be a Friday, between 10.00 and 12.00 which would ensure that we would see dissection work taking place. Travel from the Midlands to the Brain Bank via public transport is neither easy nor cheap so the options could either be –

- (a) For those who prefer to make their own way we can send you either a postcode for satnav, or directions via train, underground and finally a bus / 15 minute walk, or
- (b) We could arrange a coach/minibus – either self-drive or with a driver – with participants suggesting two or three suitable pickup points (say Service areas on the M1, perhaps Nottingham/Derby, Leicester or Northampton)

To arrive by 10.00 will clearly mean an early start!

We don't believe this kind of visit should come out of hard-won charity funds, so we would have to ask participants to pay their share of the costs, which we estimate for the coach option to be a maximum of £40 per head.

There are only a limited number of places available, so would anyone interested in such a visit please contact Richard Brown at dicsue1@tiscali.co.uk and we will look at possible dates. Please say whether you would be making your own way there or if not, where you live and from where you would like to be picked up.

Doctor Victoria Haunton needs you (to volunteer)!

Lionel Paulo writes: Monday 11 February found me attending a research trial at Leicester Royal Infirmary. Put together by Dr Victoria Haunton, a Clinical Research Fellow at Leicester University, these trials are studying blood flow in to the brains of people with Parkinson's. Taking the chance that the test would expose a mere dribble feeding my brain I attended the trial then interviewed Victoria about it. For full article go to [page 6](#).

STEERING GROUP

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East Midlands



(Group of people, by Vlado:
freedigitalphotos.net)

Three Quick Questions

This is our 6th newsletter but we still don't know who, if anyone, is reading it. We send it out by email only and have no way of checking if it is read, let alone if it is serving a useful purpose. As you are likely to be reading this online, please click <http://www.surveymonkey.com/s/6ZVJ5HY> to answer 3 quick questions. It will only take a minute.

COMING UP...

2nd ANNUAL RESEARCH FORUM IN DERBY, 14 Sept 2013

Following a successful first conference in Leicester last October, our 2nd Research Forum is being held on 14 September 2013, 10.00-3.30, at The Roundhouse in Derby.



(Forum on smartphone, by Stuart Miles: freedigital-photos.net)

The programme will include:

- an overview of Parkinson's research today
- an outline of local research
- presentations and panel discussion on research into medication.

This day-conference is intended for people with Parkinson's and their partners and carers and will aim to be easily understandable without a scientific background.

This event is made possible by funding from the Derby Branch of Parkinson's UK out of the legacy of Mrs Margaret Manester and from Parkinson's UK national Research Support Network. More information and booking details will be in the May Newsletter.

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

Diary of joining a drugs trial (part 4)

By Caroline Maxwell, Editor and Steering Group member

I am now just over half way through the scheduled 32 weeks of the clinical trial which is testing the effectiveness of Rivastigmine, currently used for Alzheimers patients with memory problems, to improve gait in Parkinson's. I have been taking the full dose of 6mg each morning and 6mg in the evening, for about 2 weeks now. Unless, of course, I have been taking the placebo. But I think I am on the drug itself.

One morning I felt particularly unsteady on my feet and when I looked at the previous day's pill dispenser I could see I had forgotten to take my evening tablet. Also, my skin is still very dry which was not the case before the trial started. But it is hard to quantify any improvement. This may sound strange, but I find it so difficult to remember how I felt before I started on the drug, and the dose has been increased so slowly that improvement also has been inch by inch. But, touch wood, I haven't fallen for about 4 weeks and I feel a bit more in control of my balance. I just FEEL as though I am getting a bit of extra support which I would now be loath to give up. So, as you can imagine, I am beginning to wonder what will happen at the end of the trial. But I'll leave that for the next newsletter.

Speakers on Parkinson's Research

Parkinson's UK research staff give a number of talks across the UK on research activities, but their time (inevitably) is limited due to their day-to-day responsibilities within the research group.

One of the original aims of RSN was to meet requests from branches for speakers by providing them locally – not to replace the staff from 215 and certainly not to offer their technical expertise and content – but to explain how Parkinson's UK organises its research activity and to look at ways people could be involved in research within the regions.

With the help of Emily and Claire from 215 head office, East Midlands RSN has developed a presentation on Parkinson's research activities. It does NOT attempt to cover the technical content of the research programmes, but looks at the different kinds of grants offered, the steps in the application processes leading to potential funding, promoting the results of our research work and the way in which fundraising in the regions makes this essential activity possible.



The presentation is in simple PowerPoint form and lasts for about 20 minutes. If your branch or support group are interested in such a talk would you email Richard Brown on dicsue1@tiscali.co.uk and we can look at possible dates and times.

The Parkinson's UK web site - first stop for research information

So you are interested in Parkinson's research. But how often do you look at the Research section of the Parkinson's UK web site? It is well worth keeping an eye on.

The best place to start is <http://www.parkinsons.org.uk/research> - If you are reading this online you can click this link right now and the page will be displayed in your browser so that you can easily switch between the newsletter and the web site.

Look at the menu down the left-hand side. The second item, **Research news**, is constantly updated with fascinating stuff. But if you are interested in the research projects Parkinson's UK is supporting, click on the third item in the left-hand menu, **Current research**.

For John's guidelines on how to keep up with research news go to [page 8](#).

Campaign to promote Good Pharma

In our last newsletter (no 5) Maria Rice's report of the Involve conference mentioned the presentation by Sir Iain Chalmers on the shocking lack of information available on the conduct and results of drug trials. Why are negative results suppressed? Are commercial interests taking priority over patient care? What does Parkinson's UK say about it? Caroline Maxwell pursues these themes and gives some very welcome news from Glaxo Smith Kline. - See [page 9](#) for full article.

Look out for two fascinating articles by Lionel Paulo about less orthodox ways of tackling Parkinson's:

- Acupuncture can it help PD?
- Vitamin D3 in industrial quantities as a treatment for PD

The Steering Group, of which Lionel is a valued member, wants to emphasise that it is not promoting these treatments in any way. It is merely reporting one person's experience and would always suggest seeking medical advice before embarking on any alternative therapies. Go to [page 12](#) for Vitamin D and [page 14](#) for Acupuncture.

If you are not connected to a branch you may not have seen these bits of news circulated in February Network News:

The Parkinson's UK Gretschen Amphlet Memorial Lecture

This annual lecture in memory of Gretschen Amphlet, who was a member of the Cambridge Branch, takes place at the Fitzwilliam College, Cambridge on Wednesday 17 April 2013 from 6.30–9.00pm. Join us to hear Dr Patrick Lewis of University College London and Dr Flaviano Giorgini of the University of Leicester, discuss how their work on genetics is helping us find a cure for Parkinson's.

Entry is free, but availability is limited. To book, please call 020 7963 9309 or email rsvp@parkinsons.org.uk with your name, address and contact phone number.

World Parkinson Congress 2013

The World Parkinson Congress, held every three years, brings people together from across the Parkinson's community to share discoveries and initiatives. The hope is that by sharing ideas, progress towards better treatments for the condition and a cure will be quicker.



In 2010 the event was held in Glasgow. This year, the Congress will be held in Montreal, Canada, from 1-4 October 2013. Parkinson's UK will be sending a small delegation of staff and volunteers to the Congress. The delegation will promote the work of Parkinson's UK and gather information about best practice from around the world.

If anyone in your group is interested in applying for one of the volunteer roles, please contact rsn@parkinsons.org.uk or call 020 7963 9376 for a copy of the role description and application form.

The World Parkinson Congress is offering travel grants to help people with Parkinson's to attend the Congress. If anyone in your group is interested in applying, visit www.worldpdcongress.org for more information.

FULL ARTICLES

- [Victoria Haunton talks to Lionel Paulo and tests blood flow to his brain](#), by Lionel Paulo
- [The Parkinson's UK web site: your first stop for research information](#), by John Telford
- [Campaign to promote Good Pharma](#), by Caroline Maxwell
- [Vitamin D3: how important is it to people with Parkinson's?](#), by Lionel Paulo
- [Acupuncture: can manipulating qi help people with Parkinson's?](#), by Lionel Paulo

Victoria Haunton talks to Lionel Paulo and tests blood flow to his brain

Interview by Lionel Paulo, Steering Group Secretary

Lionel: Who was it that came up with the idea for this research trial?

Victoria: The idea for this research came about when a specialist in Geriatrics called Doctor Lo had some interesting discussions with a stroke specialist called Professor Robinson that studied brain blood flow in his stroke patients. These discussions centred, naturally enough, on Cerebral (i.e. to the brain) blood flow. Some researchers in America had started to look not only at stroke patients but also people with Alzheimer's, and the two specialists decided to branch out as well by looking at blood flow in patients with other neurological disorders and Parkinson's was a logical choice for the study. Then they had to find someone to help set up and run the trial – I applied and got the job. This was eighteen months ago and the time flew by as we set up everything – as usual the Ethics side of the trial took ages to be approved, but here we are now up and running! Recruitment has been slow so far so I hope that this interview appearing in the newsletter will bring us some more volunteers.



(Dr Victoria Haunton, photo by Lionel Paulo)

Lionel: What is the purpose of the study – what are you aiming to find out?

Victoria: The main thing we are looking at is the response of the Autonomic nervous system (ANS - to explain: This is a built-in primitive reflexive system for survival purposes and it regulates automatic functions including blood pressure). We hypothesized that cerebral blood flow may be very different in Parkinson's people – for example, if you suddenly jumped to your feet after sitting for a while you may feel dizzy for a moment until the ANS raises your blood pressure to keep sufficient blood flow going to your brain, but people with Parkinson's may find

the blood pressure drop more severe and it takes a lot longer for their ANS to correct the problem. The things we are testing for here are whether or not Parkinson's medicines change that blood flow to the brain, and does the blood flow change gradually over time or all at once when other symptoms become visible. In the past testing the ANS response was difficult and highly invasive, but we believe our new testing procedure is much more comfortable to experience.

Lionel: Having experienced it I can definitely say it was by far the most comfortable test procedure that I have been through. Okay, next question – how will the research outcomes from your trial fit in with other Parkinson's research?

Victoria: There has been previous research on the ANS and Parkinson's, but the tests have traditionally been very invasive. Hopefully, our non-invasive tests can help build on this previous work. Also, the use of ultrasound in imaging the Substantia Nigra is being explored in various centres, both locally and internationally. If ultrasound is useful as a diagnostic tool, our work could complement their findings.

Lionel: When do you think we will see some results?

Victoria: The recruitment for the tests will close in the summer and I expect some results should be published by the autumn. There will also be a subgroup of just a few volunteers who will come back every four months to repeat the tests, and this 'natural history' group will have their results out around one year to eighteen months from now.

Lionel: What practical applications do you expect to arise from these trial studies, or is it too soon to venture a guess?

Victoria: Well, there is always the chance that something completely unexpected will arise but other than that, if it turns out that the effects gradually accrue over time, then scans could be done periodically on patients, and the results would act as bio-markers informing us of the degree of progression of the disease.



(Human Brain, by dream designs: freedigitalphotos.net)

Lionel: Where do you see your future – following on with more Parkinson's research or is this trial programme a one-off?

Victoria: I was a clinical doctor and agreed to spend two years on preparing and conducting this study, and this September time's up and I will have to return to my clinical career. My ambition is to apply for a Consultant's post next year and, although I will continue in the clinical field, I really, really would like to continue research on Parkinson's throughout my career. I suspect there will be much more we can do with this line of research once the results have been published from this trial study, so to answer the question I would say this study will not be a one-off for me.

Lionel: If somebody asked the question 'why should I volunteer for Victoria's research trial,' what would you tell them?

Victoria: For me it's a simple study to do that gives a big window into the nervous system yet

is not invasive or particularly uncomfortable, so the inconvenience to benefit ratio is definitely very much in favour of benefit to our knowledge of Parkinson's. It's an easy study to carry out and most of it is done just lying down and relaxing, and there are no nasty needles or things like that.

Lionel: When the results are published where will we find them?

Victoria: Various journals such as the Lancet, the Journal of Neurology, the Journal of Cerebral Blood Flow and Metabolism and others will be the first places to look when the results are published.

Lionel: Thanks for your time, Victoria, and good luck with your research.

Okay, friends and colleagues, that's the full story! Can any of you help out Victoria by getting in touch with her and volunteering to join the trial? Remember, helping our researchers is to ultimately help all of us. And Victoria's e-mail is: vjh12@leicester.ac.uk

(return to [page 2](#))

The Parkinson's UK web site: your first stop for research information

By John Telford, Steering Group Chair



So you are interested in Parkinson's Research. But how often do you look at the Research section of the Parkinson's UK web site? It is well worth keeping an eye on.

The best place to start is <http://www.parkinsons.org.uk/research>. If you are reading this online you can click this link right now and the page will be displayed in your browser so that you can easily switch between the newsletter and the web site.

Look at the menu down the left-hand side. The second item, Research news, is constantly updated with fascinating stuff. But if you are interested in the research projects Parkinson's UK is supporting, click on the third item in the left-hand menu, Current research. The page that appears (and the submenu that expands in the left-hand menu) contains several links. Here the web site designers have thoughtfully divided the projects into different groups: 'Latest research projects', 'What causes Parkinson's', 'Towards a cure for Parkinson's' and 'Life with Parkinson's' as well as a couple of more specific groups: 'Current stem cell research' and 'The Monument Discovery Project'. Of course a project can only appear in one list so you may have to search a bit if you are looking for something specific.

Anyway, a good piece of information that is not explicitly revealed is that if you are looking for a new project you will probably find it on the 'Latest research projects' page which lists the most recent nearest the top. Eventually projects are taken one by one from the bottom of the page and transferred to the top of one of the others.

If you browse through these pages you will find a lot of interesting work going on. If you want to locate a particular project, it is a harder job because there is no keyword index nor even a reference number index. The good news is that it is hoped to introduce this sort of facility into the radically revised web site that will take over sometime this year.

Generally speaking you can click a link on each project that takes you to its lay summary. Getting more information, if this is not sufficient for you, may be a problem but, again, it is

hoped that the redesigned web site will begin to address this.



(Info symbol on mobile phone, by Stuart Miles: freedigital-photos.net)

When the results of a project become available they are 'Tweeted'. The most interesting are also reported on in Progress magazine. What is not yet available is a direct link from the project to an account of its outcome when it becomes available. The icing on the cake would be a systematic and integrated approach so that a user can easily find information about any project from inception to the final outcome and beyond, from a variety of entry points using a range of search criteria, and no doubt the designers of the new-look web site are considering how this can be done.

The research section of the Parkinson's UK web site has been constantly improving over the years and now makes available a huge amount of information about projects compared with before. We can look forward to more improvements of the sort that will make it more interesting and relevant to all of us and enable us to learn more about the consequences of the work that we have invested in through our fundraising.

Much more than what I have described is available for you profitably to explore on the web site and I would encourage you to do so and let us know what pearls you find. The more you look, the more you will be delighted at what you discover. In particular don't miss the online Research forum. This is where members can make comments and communicate with each other. You can get to it via the link on the right-hand side of every web site page. You can go direct to it from here: <http://www.parkinsons.org.uk/pdsforum/topics.aspx?forum=research>

(return to [page 4](#))

Campaign to promote Good Pharma

By Caroline Maxwell, Editor and Steering Group member

INTRODUCTION

We all know that at present there is no cure for Parkinson's. We also know that there is a great deal of research going on and we hope, indeed we believe, that one day an answer, or, more likely, a combination of answers, will be found. But research, by its very nature, is risky, and research projects by no means always have a happy ending. Nobel Prizes are hard won

and vast sums must be invested to achieve positive results because there will inevitably be so many disappointments along the way.

THE PROBLEM

What is worrying is the evidence produced by Ben Goldacre in his book *Bad Pharma* and confirmed by Sir Iain Chalmers at the Involve conference, that when drugs are the subject of various different trials, as part of the research development process, negative results have been routinely suppressed leaving only the positive reports for that drug in the public domain. This means a drug can appear to be effective and safe when in reality it is less effective than existing drugs on the market and may even be harmful. Goldacre gives examples where serious damage has been caused to people because they were prescribed drugs about which relevant adverse data had never been published. 'Commercial confidentiality' is cited as one of the justifications for selective publication of results. This is not reassuring; it indicates that commercial interests can be taking priority over patient care.

One can understand the reluctance to publicise negative results or abandoned projects but it is clearly unethical to put people's lives at risk by suppressing evidence which will affect their choice of drug. Anyone affected by Parkinson's needs to be confident that the person who prescribes their medication has full access to ALL the available information on that drug. This should include access to information at the patient level, suitably aggregated, to enable appropriate prescribing. We do not want our doctors and nurses to be told only about the positive results. They need to know about the problems too.

A BREAKTHROUGH

Sadly, this is not a new situation. These practices have, for some time, been widespread throughout the industry. However, we are delighted, and relieved to report that things are changing. The efforts of some individuals and some statutory and voluntary bodies to achieve greater transparency in the reporting of trials are bringing results. A few weeks ago Ben Goldacre and some colleagues set up the on-line campaign: www.alltrials.net - The campaign is asking for all trials to be registered, for all summary results to be reported, and for *full Clinical Study Reports* to be made publicly available. The movement has grown rapidly and is supported by a number of august regulatory and advisory bodies which is gratifying. But the major, and surprising success is that on 6 February 2013 the pharmaceutical giant, Glaxo Smith Kline signed up to alltrials.net, confirming that



they will publish the results of their trials, not only in future, but also in retrospect. They plan to share both the summaries of the results, as might be published in scientific journals, and the detailed data which led to those conclusions. For the significance of this see Goldacre's *Bad Science* blog for 6 February:

<http://www.badscience.net/2013/02/this-is-excellent-and-amazing-gsk-have-just-signed-up-to-alltrials-net/>.

WHERE ARE WE NOW?

GSK have set a great example but they will not change the situation single-handedly overnight. Others need to follow suit. A quote from the alltrials website states that: "The United Kingdom

Clinical Pharmacy Association believes that the call to publish all available trial data is a simple call to fulfil an obvious moral obligation". However, there is still much uncertainty about the extent to which existing regulations are observed and enforced, (or ignored) throughout the scientific and commercial communities. With this in mind we asked about the position of Parkinson's UK

THE QUESTIONS

John Telford, chair of the East Midlands RSN Steering Group, contacted Rachel Evans, Parkinson's UK's newly appointed Clinical Research Policy and Campaigns Advisor, to ask: "How can we learn what measures have currently been taken for ensuring all parties register and report on all clinical trials whatever their outcomes and how can we learn if these measures are working?"

THE REPLY

Rachel's reply, written before the GSK decision, confirms: "*As we understand **the legal framework** requires all trials to be registered. However, we are less clear of the exact requirements about the reporting of the results and we are currently working with the Association of Medical Research Charities (AMRC) to clarify this. Steps must be taken to ensure the confidentiality of those involved in the trial.*

*At Parkinson's UK we do not currently fund early clinical studies. We do fund drug re-positioning (see Caroline Maxwell's report on the Rivastigmine trial on page 3). As with most charities, **it is included in our Terms and Conditions with all researchers that we fund that they must release all data** and we publish findings from research on our website."*

So, it appears all trials should be registered at the outset but that the requirement to publicise their results is clouded by the issue of 'protecting participant confidentiality'. But GSK have said they will publish not only the summary results of their trials but also the full clinical study reports, So, clearly, the problem is not insuperable. Results should and can be shared and the benefits will be immense. Thank you GSK.

It is good to know that Parkinson's UK is involved in this issue and is working to achieve more transparency. We wish Rachel every success in her post and we look forward to supporting her efforts.

***** STOP PRESS.13 Feb 2013: Parkinson's UK has now signed up to www.alltrials.net.
Hurrah! *****

WHAT WE CAN DO

- sign up to www.alltrials.net supporting the campaign for all trial results to be made public
- volunteer to participate in clinical trials, but -
- compile a list of questions to ask the researchers about the publicising of the results.
- Monitor the ongoing situation and report back to this newsletter - (volunteer for this needed.)

(Return to [page 4](#))

Vitamin D3: how important is it to people with Parkinson's?

A personal experience with prescribed supplementation by Lionel Paulo

When I was diagnosed with PD a few years ago I spent some time looking at nutritional options and tried several things in the hope that I could avoid taking medicinal drugs. I did not have much luck with that but did have an incredible experience with vitamin D3, otherwise known as cholecalciferol. Vegans may prefer Vitamin D2 or ergocalciferol as it is found in plants and some food supplements contain this form, but note that a recent meta-analysis of 50 studies which included 90,000 people did a comparison of mortality and relative risk reduction between participants taking either D3 or D2. The outcomes were a relative risk reduction of 6% for D3, but the relative mortality risk increased by 2% for the D2 group, so best to use D3. For full details go here:

<http://articles.mercola.com/sites/articles/archive/2012/02/23/oral-vitamin-d-mistake.aspx>

A recent article in the New Scientist reporting on research that was done at the university of Oxford autumn 2011 linked vitamin D deficiency to a wide array of health problems including MS, asthma, osteoporosis, rickets, diabetes, depression, chronic pain, several cancers, loss of cognitive function, various auto-immune conditions (for example 86% of rheumatology patients were found to be D deficient), and many more. Genetic research suggests more than 2,700 gene sites are influenced by our levels of D. For more information try:

<http://www.newscientist.com/article/dn21671-immune-retune-good-day-sunshine.html>



Surprised that one vitamin has such a vast influence on our health? Well, the truth is that vitamin D is not really a vitamin! Actually, it is a hormone that is produced in the skin from 7-dehydrocholesterol when we are exposed to ultraviolet radiation (i.e. sunshine). Mad dogs and Englishmen used to go out in the midday sun and maybe the dogs still do, but today people often avoid the sun and put on sun cream, and if you do that you will produce very little vitamin D, possibly none at all. Also, people with darker skins produce less Vitamin D than people with pale skin. Ethnic diets such as the traditional Asian diet tend to be low in D but that's not a problem where there is plenty of sunshine. The problems of low D levels eventually surface for those people that live in the much-less-sunny UK and choose to eat the traditional diet without adding in foods that contain D (being fat-soluble it is found in fatty foods such as oily fish or the nasty-tasting Cod Liver oil that we had to endure as schoolchildren a long time ago!).

Consider the impact hormones within us have: It's common knowledge that Insulin deficit causes

(Nature, by graur codrin: freedigitalphotos.net)

Diabetes, shortages of Thyroxin cause metabolic problems etc. so we can see why D3 deficits cause so many problems when we view it as a hormone . Yet until recently vitamin supplements contained 400 IU of D and a warning not to take more. The fear of overdosing flew in the face of research which showed no evidence of hypercalcemia (too much calcium in the blood) and hypercalciuria (too much calcium in the urine) in doses up to 11000 IU per day (ref: The European Food Safety Journal.) The EU Panel on Dietetic Products increased their upper tolerable limit to 4000IU per day based on this information, still well below the safe limit. Following are two links to articles about Parkinson's and D3 deficiency, picked at random from thousands on the internet:

<http://blogs.scientificamerican.com/observations/2010/07/13/vitamin-d-deficiency-linked-to-parkinsons-disease-cognitive-decline/>

http://www.ehow.com/how_5707133_vitamin-treat-symptoms-parkinson_s-disease.html

The link below goes to a more technical paper – note the use of vitamin K-2 as a co-factor to increase D3 absorption.

<http://www.wignet.com/2218-5836/pdf/v3/i9/137.pdf>

A couple of things to consider: Certain drugs further deplete the body of D, especially steroids (including inhaled ones), anti-epilepsy drugs etc. Also, people who suffer from chronic kidney impairment are less able to metabolise vitamin D properly, so they are more likely to be D3



deficient. Ask your GP about eGFR (estimated glomerular filtration rate). If it is below 60 ml/min, you would fall in the stage 3 (or higher) category of chronic kidney disease (called CKD 3 which is very common in older people, especially if they suffer with high blood pressure and/or diabetes, and also take medication that may affect kidney function). It's something to discuss with your GP, including your vitamin D levels, and whether supplementing would be beneficial or not for you.

(Pipette with drop of liquid, by ponsulak: freedigitalphotos.net)

The main questions are: does lack of D cause Parkinson's, or is it a side-effect of the disease, and does raising levels in the body up to the normal range benefit Parkinson's people? And the answers are: We don't know for sure, but in light of the many functions that are improved by having normal levels in normal people it is probably worthwhile to raise levels to the normal range for Parkinson's people as well – and that brings me to the truly incredible experience I mentioned earlier. Please remember this was done under strict medical guidance so **DO NOT ATTEMPT TO COPY THIS WITHOUT THE SAME MEDICAL DIRECTION AND MONITORING!**

My blood tests revealed an increase in vitamin D levels of 91nmol/l within a 4 week period, and this was accomplished by taking 100,000 IU of D3 PER DAY!! This amount would almost certainly be lethal to most people, so it would suggest that my body was absorbing only a small percentage of it. Since then I have taken a maintenance dose of 5,000 IU per day. I would not recommend such an extreme course of action as I took but that was controlled by the doctor I dealt with at the time. The lesson I learned from this is that conventional nutritional advice

such as recommended daily intakes of vitamins, minerals etc. may not necessarily be adequate for people like us.

So to the punch line: Did I notice any difference after this massive intake? No, I did not! At the time I was still able-bodied, perhaps it would make a difference to me now but I think I will leave it to someone else to try!

For much more information on vitamin D try this resource:

http://en.wikiversity.org/wiki/Deficiencies_as_PD_cause/Vitamin_D

Parkinson's UK have an information booklet 'Diet and Parkinson's'. It suggests that people with Parkinson's should have their levels of calcium and vitamin D assessed early in the condition to prevent or lower the risk of osteoporosis. We also recommend people speak to a health professional if they think they may need to take vitamin D.

See our 'Diet and Parkinson's' information booklet for more details:

http://www.parkinsons.org.uk/PDF/B065_dietandparkinsons.pdf

(return to [page 5](#))

Acupuncture: can manipulating qi help people with Parkinson's?

A brief look at Eastern ideas and a personal testimony, by Lionel Paulo

Acupuncture enjoys an elevated reputation among alternative therapies in that more people seem to accept that it can work (at least up to a point!) and quite a few heavyweight institutions endorse or at least tolerate its presence in the medical arsenals that make up modern medicine. Just for starters we can include the [National Health Service](#) of the United Kingdom, the [World Health Organization](#), the United States [National Institutes of Health](#), and the [National Center for Complementary and Alternative Medicine](#).

Despite this list some scientists are unhappy that credibility seems to have been easily earned and criticism kept in the background. I will leave that debate to the politicians among us and look at the question of interest to us: Is it beneficial for people with Parkinson's? This is not a technical article but a little understanding of how it is alleged to work could be useful. So, how does it exert an effect upon the human body?

Acupuncture is an alternative medicine treatment that, in common with other items of great antiquity such as fireworks and tea originated in China. As is generally known about it these days it treats patients by manipulating thin solid needles that have been inserted into specific points in the skin. According to traditional Chinese medicine, stimulating these points can correct imbalances in the flow of qi (pronounced CHI) through pathways called meridians. Scientific research has not found any physiological or histological equivalents for qi, meridians and acupuncture points; indeed some modern day practitioners needle patients without using the traditional 'map' of points on the body.

Eastern religions and philosophies all have the theme of energy streams in the body; whether the Chinese call it qi or the Hindus call it prana, meridians or chakras or spinning vortices, their

beliefs are unhampered by western evidence-based science which refuses to accept anything it cannot quantify – in the east the view is ‘if it works, it’s real’ and the how behind it does not matter. And that brings us to ‘does it work for Parkinson’s people?’

Please remember a true scientific study would involve strict test conditions and quite a few participants, so when I tell you I have heard some Parkinson’s people say it helped them and have known heavy smokers who quit with the help of acupuncture, and recall President Nixon of the USA visiting China in the early 1970s and being taken to watch open-heart surgery on a man who was fully conscious during the surgery (his pain being completely controlled by acupuncture alone!), well, take it merely as a series of positive anecdotes. I don’t know if the surgery was real or they wanted to fool Nixon for some obscure reason, as it seems so incredible that I find it hard to believe.



(Silver needle acupuncture in medicine cup, by Praiseng: freedigitalphotos.net)

What is my own opinion on this? Try it and see for yourself, what have you got to lose by trying it? Unlike drug trials, testing acupuncture will not expose you to possible unpleasant side-effects; at worst it won’t work and at best you may get a result like the lady in the following summarised version of an interview she gave:

“I was diagnosed with Parkinson’s disease seven years ago and went and stayed with my son in Canada for a while. At this time I was not taking any medication for it as I was already on medication for Bowel Cancer and having occasional bouts of chemotherapy as well. I was experiencing quite a bit of pain and a lot of tremors.

My son suggested a course of acupuncture and set me up with a therapist who saw me every third day until ten sessions had been completed. This therapist used a lot of needles all over my body, and a couple of times made me jump when a needle went in wrong, but most of the time there was no pain from it. I did feel a bit better after each session but did not realise anything else had changed until my son said “your shaking has stopped.” I was surprised that I had not noticed but it was true my tremors had gone.”

Much more recently (back in the UK) my back was giving me a lot of pain so I took another ten session course of acupuncture which helped a lot. Then there was a gap of nearly a year after which I had a one-off treatment which did not seem to help at all. My sister-in-law also found one-off treatments ineffective but acupuncture worked for her when she took a course of twice-weekly treatments.

My experience with acupuncture has convinced me it works – I felt better, slept better and generally felt in a happier mood most of the time. I have tried massage, spas, a TENS machine and exercise at various times, but none of these worked as well as acupuncture did for me. I would definitely recommend anyone thinking of trying it to go for it.”

I would echo this lady’s sentiments and suggest that if you are considering trying it out then yes, ‘go for it!’ I would ask a favour if you do – let me know if it worked or failed for you. This won’t be a proper scientific study, but if quite a few people inform me about their own experiences we might end up with being a bit more certain as to whether or not it helps the majority of people with Parkinson’s.

(return to [page 5](#))

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NOTE FOR YOUR DIARY: Amber Valley Support Group have invited **Dr Skelly** to their meeting on 13 April at 2.30pm at Ripley Leisure Centre to hear about his research - to see if a Specialised Parkinson's Unit can reduce medication errors, improve patient satisfaction and reduce lengths of stay in hospital. His other project about PROBAND (Tracking Parkinson's) will also be highlighted. To secure a place contact: Mike Smith - email: mikeandkarensmith@talktalk.net

STOP PRESS: The **Leicester lab visit** on 21 March (see newsletter no 5) is taking place and full. You can email John Telford at jntelford@ntlworld.com if you would want to join the visit in the event of someone dropping out at the last minute.

[\(Back to top\)](#)