

East Midlands

RSN NEWS

from the East Midlands Research Support Network

*** **September 2014 / No 19** ***

Welcome to News 19, the September 2014 edition of the East Midlands Research Support Network Newsletter.

This edition starts with Roger Elkin poised at the top of the Northampton Lighthouse about to abseil over 400 ft to the ground in order to raise money for Parkinson's research. To maintain the suspense his article is presented in three sections.

While Roger is sliding to earth you can read John Telford's account of a possible new vaccine for Parkinson's and my report of the Tracking Parkinson's event in Loughborough.



(Medical Vaccine, by Vichaya Kiatying-Angsulee; freedigitalphotos.net)

John has also updated us on the national development of the Research Support Network and he has a suggestion about making our East Midlands RSN more of a network where members contact each other rather than all communication going through a central point.

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... and much more!



(Search Concept, by jscreationzs; 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)

There are a number of interesting web links to follow up and 'Has this been researched' finds Lionel Paulo explaining sometimes contradictory evidence on the subject of pain in Parkinson's.

I have slipped back into the editorial role to give Ian Billcliff a break. There is an appreciation of Ian's work on [page 12](#) so all I will say here is Thank You Ian and Good Luck.

I hope you find the newsletter interesting. Do remember I am always on the lookout for new writers and new ideas. If you have an idea but are not sure how to present it, do get in touch. I may be able to help.

Caroline Maxwell, editor
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or 01327 310901

PS: Our research-based forum on 11 October on "Exercise and Parkinson's – Finding out what really works" is now fully booked. If you will be unable to use your reservation please contact Lionel Paulo so he can pass your place on to someone else.

STEERING GROUP

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News & Events

Fundraising for Parkinson's UK research or How to become an Extreme Abseiler in just 15 minutes

The idea

"Are aircraft allowed to fly lower?" I ask. "About half this height" comes the reply I really don't want to hear, "and try not to look down!" From gazing at my feet, splayed against the vertical wall before me, I glance down over my right shoulder - mouth and throat go instantly bone dry. "Smile for the camera!" - I immediately look up, flash my best toothy grin, lean back on the rope and force my right foot to take the first step backwards down the building - only 418 feet to go!

How the heck did I get to be hanging from a rope far above the ground with the expectation of walking my way safely back to earth.....?

Everyone living or working near Northampton knows the National Lift Tower, affectionately referred to locally as The Lighthouse. It dwarfs the immediate suburbs west of



(Roger Elkin, photo National Abseil Centre)

the town and is visible from many miles away. Achieving national notoriety after merciless lampooning on Terry Wogan's breakfast show, the landmark structure was constructed by Express Lifts to provide test facilities, closing in 1997 after Express were taken over by Otis. Since being privately acquired and accorded Grade II listed status in 1997, it was refurbished and at 420 feet tall is now designated the highest, permanent, abseil structure in the world.



(The 'Lighthouse', photo David Harrison)

Every Christmas, as befits a national landmark, an illuminated tree is fixed atop the tower. Visible after dark as a bright, small object high in the Winter sky it inevitably starts you wondering who would brave the summit to install it. "They must surely be mad" you conclude, "They'd never get me up there !"

It's Spring and perusing the latest Progress magazine my wife Kath observes that Parkinson's UK are organising a fundraising event in our locality at the end of August. "And what would that be ?" I query, "Oh, just abseiling down the Lighthouse - and seeing you're the only person in the family who's never done an abseil this could be your chance." I'm not taken with the suggestion and think no more about it, until.....

It's early June and we're attending Parkinson UK's Self Management Programme which involves participants exploring their particular Parkinson's journeys. Developing my personal 'road map' I challenge broad brush assumptions that Parkinson's

prevents you from doing things - in fact precisely because it's a progressive condition should be reason enough for doing the things you want and are capable of doing whilst you can - in other words, don't let Parkinson's define you. Ideally I need something to demonstrate this point, something in the not too distant future. How about the end of August?!

The Commitment

So mid June finds me contacting Darren, Parkinson UK's Regional Events Organiser. "I've never abseiled in my life before" I tell him. "Is there any training to help me prepare?" He reassures me with a confident reply "Don't worry, even experienced abseilers will have done nothing like this one" adding "you'll be attached to a safety rope and get a full talk through ten minutes before you do it !!"

Darren sends me a Parkinson's UK fundraising pack full of useful materials and information about sponsorship and websites. I confirm my fundraising will be earmarked for Parkinson's UK research; I register, as a former employee, to benefit from Barclays Bank Community Support Programme and then I announce to a wide audience of friends, family, neighbours and acquaintances what I intend to do in a few weeks' time. It works! Individual donations, often accompanied by a variety of personal comments, start to roll in.

But no effort of mine can affect the weather. The countdown sees me increasingly obsessed with meteorological forecasts. All seem to feature remnants of hurricanes blowing in from the Atlantic - turbulent weather fronts bringing heavy rain and high winds. Another source of concern.

(continued on [page 8](#))

Excitement of a different kind:

A vaccine for Parkinson's?

A small ripple of excitement recently went through the Research Discussion section of the Parkinson's UK on line Forum. (Ref 1) This followed the report that at an Austrian company had had promising results from a clinical trial for a vaccine for stopping Parkinson's.



Vaccine with Hypodermic Syringe and Needle, by Baitong333; freedigitalphotos.net)

Is this work just another case of the raising of false hopes? Or might it have legs?

To understand this, it is necessary to know a bit about what such a vaccine might be trying to do. You might do worse that to look at my article in the last edition in EMRSN News Titled "Triple Focus" (Ref 2). This explained that the misfolding and aggregating of the molecules of the protein alpha-synuclein is at the heart of Parkinson's. Moreover once a few molecules in this

damagingly mis-folded form have started to stick together, they act as a template for other, normal, useful molecules to misfold and stick together in a kind of chain reaction.

A useful vaccine, then, would be one which would intercept the misfolded forms of alpha-synuclein and remove them before they could spread their evil influence. The hope is that, in the case of someone already with Parkinson's, the progress of the aggregation process would be halted and the disease would not get any worse or, at the least, be slowed down.

This vaccine was designed to produce antibodies against just the 'bad' form of the protein so that the body's immune system would take over and eliminate it just like it does with bacteria and viruses.

The company, AFFiRiS, which has been generously supported by the Michael J Fox Foundation, has now completed a two-year Phase I trial with a group of 24 people in the early stages of Parkinson's. Phase I trials are merely aimed at assessing the safety and tolerability of a treatment but there are clear indications from the results that the vaccine, known for the moment as PD01A, actually had a disease-modifying effect. For those in whom antibodies were detected in the cerebro-spinal fluid (which was not the case for everyone given the vaccine), no worsening of symptoms and even some slight improvement in the standard Parkinson's tests were observed. In September some of the patients will have their treatment continued in a 'Boost' study to probe the effects of further doses. A Phase II study to look specifically at effectiveness will then be undertaken with a much larger number of patients.

References 3, 4 and 5 below are for a lay-language report of the trial, a web cast about it (skip to about 8 minutes for the 'meat') and the abstract of a scientific paper which describes the science. (Unfortunately the full paper is behind a 'pay wall'.)

It looks like PD01A successfully targets the 'bad' protein and does not hit the normal form. If it can really be removed as soon as it appears it will not then be exported from the cell and so will not infect a neighbouring cell and be transported through the nervous system in the way explained in the article in the July EM RSN News.

Are we allowed a modicum of excitement? Unfortunately it will, as usual, be several years before we know the answer to this. There are also a lot of potential pitfalls along the way because of the many complexities not covered in this very simple account. The encouraging news is that it has been deemed worth investing in an expensive Phase II trial!

John Telford

References:

1. "Vaccine" thread in Parkinson's UK online Research Discussion Forum:
<http://www.parkinsons.org.uk/forum/thread/62671>
2. "Triple Focus", Page 6, EM RSN News edition 18, July 2014
https://www.parkinsons.org.uk/sites/default/files/emrsn_newsletterjuly2014.pdf
3. Report in "The Conversation":
<https://theconversation.com/first-stage-trial-of-new-vaccine-offers-glimmer-of-hope-to-parkinsons-sufferers-30012>
4. Webcast:
<http://totalwebcasting.com/view/?id=affiris> - Go to 8 minutes for a description of the trial and its results.
5. Abstract of most recent paper:
Mandler et al. "Next-Generation Active Immunization Approach for Synucleinopathies: Implications for Parkinson's Disease Clinical Trials." *Acta Neuropathologica* 127, no. 6 (June 2014): 861–79.
<http://www.ncbi.nlm.nih.gov/pubmed/25009275>

Collaboration is key

A non-scientist's impressions of the *Tracking Parkinson's* event in Loughborough on 5th September

By Caroline Maxwell

Purpose of the project

The first speaker at the event was Dr Donald Grosset, from Southern General Hospital, Glasgow who is leading the *Tracking Parkinson's* project. He explained that the development of treatments to slow down or stop the progression of Parkinson's would be the first steps towards a cure. In order to know how effective such treatments may be it is essential first to define the disease itself. We need to know precisely what it is we are fighting and we must learn how to measure its progress. *Tracking Parkinson's* aims to develop biomarkers, including blood tests and scanned images specific to various types or stages of Parkinson's. These tests will then be used to supplement or confirm the subjective diagnoses of clinicians and to measure and record patients' condition. This is an essential but truly daunting task.

To illustrate the complexity of Parkinson's Dr Grosset asked the audience about symptoms they had experienced before diagnosis. The responses ranged from frozen shoulder and reduced arm swing to loss of sense of smell and depression. These problems had begun several years before Parkinson's was manifest. Dr Grosset reminded us that in addition to this wide variety of initial symptoms the rate of disease progression varies significantly and patients' responses to medication are also unpredictable. It is a complex and highly variable condition. In order to find a way through this maze of information *Tracking Parkinson's* will gather genetic, lifestyle and scanned image data from large numbers of people affected by Parkinson's. Using the technical procedures now available scientists will analyse and categorise this information looking for trends and patterns leading to the stratification of the disease into different categories indicated by specific biomarkers. Different treatments could then be appropriately prescribed and the biomarkers will enable clinicians to measure their effectiveness.

What is involved?

Tracking Parkinson's is the largest study of Parkinson's ever undertaken. It has teams working in many areas of the UK as well as medical centres worldwide. Dr Grosset says that technology has advanced so rapidly that whereas "we originally planned to analyse around 20,000 variations in DNA, we will now analyse around 200,000 variations in DNA. (These are **areas of variation** in the DNA code, where a lot of variation is known to occur between different people)".

Volunteers are recruited nationwide and with an eye to the future 6 small phials of blood are taken from each participant. Only one sample is used immediately. The rest are deep frozen and will be made available to future researchers. (No doubt Tony Hancock would have had something to say about that!) The processing of these samples and subsequent analysis of the results is carried out in different centres. The results can then be shared and made available to approved researchers for further work.

Collaboration is key

The exchange of information, all carefully data protected, is a key feature of the project. The scientists are working to increase the world's pool of knowledge about Parkinson's not to make discoveries which they then keep to themselves. Dr Grosset's words which stick in my mind are "We collaborate; we don't compete."

This ethos of working together was echoed by colleagues Dr Nin Bajaj from Nottingham



(CT Scan Machine, by dream designs; freedigitalphotos.net)

University Hospitals NHS Trust and Professor Dorothee Auer from the University of Nottingham. Dr Nin Bajaj explained how important it is to develop a scanning technique which can reliably diagnose Parkinson's. Currently, DAT scans are the top-of-the-range diagnostic tool but they are very expensive and depend on skilled interpretation to render reliable information. A cheaper, more easily interpreted scan would be enormously valuable.

Scans are significant

Prof Auer described how she and Dr Bajaj with their team at Nottingham University are working on scans of two separate areas of the brain which appear to change as Parkinson's develops. A full account of this work was included in our last newsletter News

18 (https://www.parkinsons.org.uk/sites/default/files/emrsn_newsletterjuly2014.pdf)

These scans are cheaper and more easily interpreted than DAT scans and could lead to earlier diagnosis. But they are still in the development stages. One hurdle to overcome is that there are, around the globe, many different types of scanners and associated devices that assist with analysis of data from them. These different systems can pose compatibility problems when scientists attempt to replicate results from other research teams. The will for collaboration and cooperation is there but more time and money is needed to develop systems which enable data and results to be analysed and interpreted consistently, enabling sharing of information by different centres no matter where they are.

Winding up

During the final short Q&A session a questioner raised the issue of the apparently abnormally high incidence of PD among people who had worked in the welding industry. This was not new to Dr Grosset and he explained it was the sort of anecdotal evidence which might, in due course, be strengthened or discounted by the evidence he is collecting. The audience had clearly found the afternoon informative and, speaking for myself, encouraging. Yes, there is a huge amount that we don't yet know, but this project illustrates that it is possible to plot a way through the seemingly endless variations of symptoms, genetics and environmental factors towards those elusive biomarkers which will enable scientists to monitor the effectiveness of treatments. This is a major step in the right direction.

Thank you to Parkinson's UK for organising the event.

For more information see the relevant section of the Parkinson's UK website:

<http://www.parkinsons.org.uk/content/tracking-parkinsons>

Links worth following:

World Parkinson Coalition – Continuing Education



The World Parkinson Coalition, which organises the World Parkinson Congress every three years, is organising some live webcasts over the period 30th September to 2nd October. 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>

How about holding a research event to watch and then discuss together one of the recordings?

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 a bold sans-serif font, 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 sans-serif font. There is also a circular logo for "APPROVED CME CREDIT HOURS".

Save the Date!

WPC SCIENTIFIC UPDATE: Parkinson Pipeline Umbrella
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Join us for an online webcast to hear about the scientific advances made since the WPC 2013.
Be inspired by the progress!

APPROVED CME CREDIT HOURS

The Creativity Pill

Clicking this link <http://www.theatlantic.com/health/print/2014/07/creativity-and-dopamine-pills/374599/> will take you to an interesting article in *The Atlantic* journal. It is interesting on two levels; it explores creativity and impulse control disorder as possible side effects of Parkinson's drugs, and it demonstrates the scientific rigour that is required to sift hard scientific evidence from the more appealing anecdotal reports.

Abseil Part 2 *(continued from [page 3](#))*

The Big Day

A-day, Saturday 30th August arrives. Rain has blown through leaving lighter winds with dry conditions promised for the rest of the day. Parkinson's UK have the tower from



(Roger abseiling, photo Kath Elkin)

9.00am and I'm due to launch at 11.30. I make the half hour drive with Kath, our destination being in view for the last ten or so miles.

On arrival I park and observe a couple of intrepid Parkinson's UK participants completing their vertical runs. My supporters comprise Kath and facilitator Pam of the Self Management Programme - the two whom I hold most responsible for being here today! And Darren's been on site from early morning, offering practical support to the expected twenty or so Parkinson's UK participants. Karen, a member of the Northampton & District branch of Parkinson's UK, has also arrived to take part and is scheduled at about the same time. She's accompanied by a good number of supporters including Branch Chairman Val, who comes over to wish me luck.

It's time to get going. Karen and I fall in behind a fluorescent-jacketed lady who leads us into the tower, up the functional metal stairs into a first floor room to complete the formalities and be fitted out with our abseiling gear. Every participant has to provide, under threat of disqualification, a signed declaration absolving the organisers from causing death or injury, howsoever incurred, plus a full list of health problems - I confess to PD and sciatica, adding my tight scrawl to the form which I pass to an organiser... "OK" he smiles and to my relief "we can adjust the harness for lumbar support".

Verbal instructions on how to proceed down the face of the tower are combined with being strapped into the abseiling harness, are you left or right handed, how to pay the rope through the belay ring, the route down is mainly in the lee of the building, what to do if blown off the face of the building (don't panic!). Next, with gear fully fitted and checked, Karen and I enter an available lift and are whisked to the top of the tower emerging into a small room with both seating and standing room which opens to the outside balcony from where the descent will begin. A serious looking bloke makes a final check of my harness, then offers the last chance to 'bottle it'. He phrases it much more supportively, but it comes down to the same thing.

I mentally review the amount of sponsorship and expectations riding on me - especially Judy who but two weeks ago laughed uproariously whilst pressing money on me to counter her husband's refusal..... It's her funeral on Monday... can't really give the cash back now. If only for Judy, onwards!

As a chivalrous type I agree to go first, being beckoned to stand over an 'X' marked on the floor. One last check before stepping forwards to be roped on to the safety and descent lines. Then, step up to look over the edge. I catch sight of the bright green Saints' pitch at Franklin's Gardens far below, and with difficulty tear my eyes away, turning around to face inwards. And now, following the repeated instructions, comes the most difficult part - haul yourself up to stand on the edge, lean back on the rope, move feet flat on the vertical wall and there you are, body inclined and suspended above the void stretching out below.... ..."Smile for the camera!" I lean back on the rope and force my right foot to take the first step down the building - only 418 feet to go!

(continued on [page 15](#))

Parkinson's UK

Next Steps for the Research Support Network

I need to tell you about the Research Support Network Development Team (known as the RSN DT) and what it is trying to do. The RSN DT is made up of volunteers and members of the Parkinson's UK Research Team and its purpose is, as it says on the tin, to develop the RSN. So, if the small number of regional RSN groups in existence at the moment is anything to go by, there is a lot of work to do.

We in the East Midlands are the most active group but activity is starting up in the South West and the North East. For several years there has also been a very active [research interest group in Edinburgh](#). It started in that city before we had the idea of organising RSN groups regionally and, as you would expect within Parkinson's UK, people outside of Edinburgh can take an interest in what it is doing and can link up to it and go to its events.

Encouraging more regional RSN Groups

The idea of organising the RSN regionally arose, of course, because we wanted to avoid the sort of 'London-centric' bias which fails to encourage activity outside of London and the South East of England. The idea of organising regionally rather than at the branch or local group level was thought to be appropriate because of the difficulty of getting together a 'critical mass' of members with a strong interest in research issues in the local area alone. Regional organisation does present its own difficulties, however, and that is why the RSN DT is starting up **a Task Group** to work out how appropriately to encourage regional RSN groups to be set up, what they might usefully do and how they might be organised. (See *my article on page 11 for how we are moving things forward in the East Midlands.*)

Centrally managed activities

There is much more to the RSN than regional groups - Some activities, particularly some which individuals do on their own are best coordinated nationally. The central staff team tends to be the first to learn about opportunities for people with Parkinson's to volunteer as subjects for research studies and drug trials. It makes sense for the national team to coordinate the sending out of information to individual members of the RSN who may be

interested. Staff at the National Office are also in the best position to assess whether any of the trials should not be recommended to members.

A second RSN DT **Task Group** is being set up to look into how this aspect of getting involved in research can be improved. There are also other activities of individual research supporters that are appropriately run by the Research Team at National Office. Before the RSN was thought of there was the 'Research Network' which is now called the 'Lay Review Panel'. Ordinary members living with Parkinson's serve on this panel and there are quite a lot of them. They work individually by looking at applications for research funding and put forward their views from their own perspective. It is a good way for non-scientists to contribute to research although such is the interest that there are not always vacancies for this role.

The 'Lay Review Panel' is, of course, most appropriately organised centrally rather than regionally because awarding research grants is one of the main functions of Parkinson's UK. Applications from researchers all over the UK and beyond need to be considered and prioritised against each other in order that the available funds are used to best effect.

Deeper involvement in research projects

But in addition to reviewing grant applications there are other ways RSN members should be able to be involved in research. One is by being on the management group of a project and even by helping initiate a new research project. The acronym PPI, which stands for Patient and Public Involvement, can be used to describe this sort of engagement but it is something that is not well developed yet in the Parkinson's research field. So, as you will have guessed, another **Task Group** is being set up to see what practically can be done.

The three 'Task' or 'Steering' Groups

The term 'Steering Groups' is being used for the 'task groups' I have been talking about which, unfortunately, could lead to confusion with our own East Midlands RSN Steering Group. But they will be serious groups with tasks to do and they will be set deadlines to complete them. Recruitment of members has now begun. Everyone on the RSN mailing list, which should include you, has the opportunity to put themselves forward. Each group will meet about three times a year and travel expenses will be paid. In between times members will communicate by email so that the work does not grind to a halt.

So do consider whether you would like to be part of one of the groups which, to recap, are:

- Regional RSN development
- Facilitating participation in trials and studies
- Facilitating involvement in the initiation, design and management of research projects.

A fourth task

"Increasing awareness and understanding of research" is how a fourth task has been described. But because this is what the RSN is mainly all about, the RSN DT itself will be the 'task group' to tackle this. The RSN DT has benefited from the ideas generated at the members meeting in May and has been refreshed with some new, enthusiastic members. So it is ready to take a fresh look at what the RSN should be doing and to decide what "awareness and understanding of research" means, especially for action and activities. I shall be reporting on how this develops in future editions of EN RSN News. In the meantime, look out for communications about the Steering Groups and do consider applying to join one! For more detail of what is involved contact Anna-Louise Smith at alsmith@parkinsons.org.uk

Practical Networking

– making the East Midlands Research Support Network work.

Unlike local Branches and Groups, the RSN does not have local meetings where members get to know each other simply by often being in the same place at the same time. When people get to know each other around common interests and concerns they can easily build up relationships of comradeship and mutual respect that can lead to their taking initiatives to organise things. Local groups fundraise together and organise programmes of activity throughout the year. Some people may come to rue it but meeting regularly can lead to joining a committee! But equally, serving on a committee can lead to developing some profound friendships.

So how can we develop such relationships of friendship and collaboration among research supporters in the East Midlands when there are only a handful of RSN meetings and other events throughout the year? Each such event attracts a different set of people so how can we get to know others in a lasting way?

The EM RSN Steering Group actually worked the other way round: through a couple of regional meetings a handful of members were persuaded to meet together to see whether they could promote activities under the RSN banner. Through working together we got to know each other and this friendship has enabled us to do a lot of worthwhile things at the regional level.

Over time, more by luck than judgement, we have happened across a few other people through RSN events and activities who have come along to make a contribution to RSN Steering Group meetings. But as often as not, circumstances have meant that the involvement of some has not been able to endure. So we can't really rely on the chance meeting with willing members at infrequent RSN events to bring people together to be active in an organising capacity within the RSN. Without an organising group then, sadly, research-oriented activities do not happen. Things do not just organise themselves.

The Steering Group is what we call our organising group. But it needs a constant trickle of new people into it – constant renewal – to replace those who through various circumstances, usually related to the nature of Parkinson's, have to disengage. So I am partly saying that if you are a research enthusiast, even if you describe yourself as lukewarm, then why not help us out on the Steering Group?! (Email Lionel or Me for the details of the next meeting on October 21st).

There is a psychological hurdle, however, to putting yourself forward like this. Maybe another way to contribute is to discover who in your own city, town or county is also interested in research. If you knew who such people were, you could look out for them at local meetings or even arrange some informal meetings to chat about research and things you might do to support it without having to travel miles to do so. You might find out that they too belonged to the Lay Review Panel or had volunteered for a particular clinical trial and would like to compare notes. This could be a stepping stone to making a contribution at the regional level where collectively the larger number of research-motivated people can have a bigger impact.

So...

There is a 'Networking List' which holds the email addresses of people who are happy to share their contact details with other like-minded people. It is not a public list but goes only to those on it. It lists the location of each person as well as their name and email address so that people can contact each other by email or in person and maybe talk about

what they might do together to promote research. Sometimes there may be people you already know but you didn't know they had a research interest and this could lead to something. Another result of the list could be that some people who are not keen on going to branch meetings could get in touch with each other because they still want to use their energies for something positive and research involvement is something that appeals.

Would you like to be on the 'Networking List'? Just send in your name, email address and city/town/county to Lionel or me (see page 2) and we shall circulate the updated list in mid October – after we have found more people to join it at the Nottingham Forum on the 11th!

Then it is over to you!

John Telford

A great volunteer

After 13 months as Steering Group member and editor of EMRSN News Ian Billcliff has retired for health reasons.

Ian first got involved with the East Midlands RSN when he registered for the Researchers' meeting in March 2013. He kindly agreed to write a report for the EMRSN News (see May 2013 at http://www.parkinsons.org.uk/sites/default/files/emrsn_newslettermay2013.pdf) and just four months later he was a member of the Steering Group and acting editor of EMRSN News!

Ian edited 11 issues of EMRSN News with great skill, commitment and reliability. He inspired people not just to contribute but to speak to the readership of people living with Parkinson's. Ian also has a great sense of humor and I have fond memories of the laughter on our car journeys to Steering Group meetings.

We send you our best wishes, Ian, and look forward to seeing you at future events. Very many thanks for all you have done for the East Midlands RSN, and for being a great volunteer!

Chris Johnson

I owe a personal debt of gratitude to Ian for quietly stepping into my EMRSN newsletter editorial shoes last year when I found myself facing and then recovering from surgery. Without any fuss he recognised what needed to be done and set about producing regular, lively and informative newsletters which have been a major contribution to the work of our network. He deserves a break now but he will be a hard act to follow. Thank you Ian.

PS: Don't forget you've promised to write for us from time to time!

Caroline Maxwell

“Has this been researched?”

A question and answer forum on Parkinson's research

Pain: Is it an underreported non-motor symptom of PwP?

Medical classification of pain

Pain: Perhaps Carl Jung, formerly the colleague of Freud and later his rival put it best when he stated: “There is no coming to consciousness without pain.” As Jung admitted that pain is a near-universal experience that most of us would gladly forgo we must also remember that generally pain afflicts us in many different forms and degrees of severity, acting as a warning system that lets us know something is wrong.

A general definition of pain used by the medical profession is “An unpleasant sensory and emotional experience associated with actual or potential physical damage.” People with Parkinson's (PwP) are no strangers to pain and as is typical of Parkinson's disease there are a great deal of variations in the way pain afflicts us, and a considerable difference in opinions among scientists as to how common it is. Based on the research studies I have seen myself the incidence of pain in PwP has been estimated at anywhere from 40 percent to 85 percent, yet pain seems to be one of the non-motor symptoms that is rarely mentioned by most PwP! Perhaps PwP are stoics who only admit the full extent of their suffering in research trials? Regardless of the true incidence of pain medical science analyses and catalogues this subject into several layers of complexity, beginning with the three main headings below:

Pain can be **nociceptive** which comes from actual physical damage (cuts, bruises, broken bones etc.). Pain can be **neuropathic**, originating within nerves, or pain can be a **mixed pain syndrome (panociceptive)** involving both of the pain types above. As PD is a neurological problem It would appear obvious that PwP would mainly suffer with neuropathic pain, but perhaps surprisingly this is not the case according to research which indicates the majority of PD pains actually come from physical injury. Causes can include persistent tremor, muscle rigidity, musculoskeletal injuries such as bruises and fractures from falls, inflammation and dystonia (dystonic cramps in my calf muscles were the most excruciatingly painful sensation I have ever felt!).

Although neuropathic pains are less common in PwP than nociceptive pain there are some conditions that are not directly related to Parkinson's which are diagnosed with greater frequency than among the general population such as carpal tunnel syndrome, shingles, cancer pain, diabetic neuropathy and peripheral neuropathy. These kinds of pain can be felt as burning or numbness or tingling or even resembling electric shocks, and generally the most common areas that PD people feel these pains are in the neck, upper back and extremities (hands and feet).

This is supposed to be an article written in plain English but already we have gone through quite a few bits of medical jargon and we are not done yet! Aside from the three types of pain categories above specialists in pain view PD as originating from the five different categories below:

Musculoskeletal (from muscles and skeleton), **dystonia** (from twisting and contortions caused by cramps), **akathisia** (inner restlessness such as 'St. vitus dance'), **neuritic** or

radicular pain (from nerves and/or spinal roots), and **central pain syndrome** specific to Parkinson's caused by changes in the levels of chemicals in the brain.

Living and coping with pain

Chronic pain can certainly make life much less bearable as it causes or worsens sleep disturbances, anxiety, impaired cognition, social withdrawal and depression to name just a few problems. It can create a vicious circle of discomfort as depression causes the sufferer to focus on their pain and in turn more pain can deepen depressive states.

A further complication for some PwP is the fact that the medicines that move us from 'off' states to 'on' states gradually (or suddenly for those experiencing difficulties with controlling their PD) wear off and we start again with our next dose. This constant fluctuation of neurotransmitter levels influences physical and emotional states in PwP making it potentially more difficult to 'steady the ship' as it were.

Looking at the positive side of things it is possible to increase one's ability to cope with pain purely through mental attitude. A phrase often used inaccurately is 'pain threshold,' when what is really meant is 'pain tolerance.' Pain threshold is the point at which one begins to feel pain, and it is quite possible to have a high pain threshold but a low pain tolerance, reacting negatively to even mild discomfort. In contrast a low threshold would have you feeling pain at a lower level but coupled with a strong mental attitude your pain tolerance would be higher and may enable you to cope better with higher levels of pain – this is the way psychotherapy can help with pain management.

Also, there is no doubt that in an 'on' state the greater dopamine levels in the brain improve mood and reduce perceived pain. Dystonia (cramping) pains are often a result of undertreatment and may respond to revised medicine intake, but this is something to work out with your consultant or specialist nurse. Due to the individual nature of PD very specific use of medicines is required making general recommendations impossible.

Other therapies that may also be helpful in pain management include physiotherapy, massage, acupuncture and acupressure, exercise, stretching, botox and better diet. Most of these subjects have been discussed in previous editions of this newsletter.

Currently Dr Monty Silverdale of the Salford Royal Foundation Trust is conducting a 4 year study on pain and Parkinson's using information derived from the massive Parkinson's UK funded 'Tracking Parkinson's' study. Among blood tests, memory and cognition and smell tests was a pain questionnaire and combining this with genetic information from the participants Dr Silverdale hopes to identify some of the causes of PD pain which hopefully will lead to improved treatments for pain in the not-too-distant future.

So, the answer is yes to the question 'Has this been researched yet?'

Reference 1: <http://europepmc.org/abstract/MED/10785830>

Reference 2: http://www.pdf.org/winter12_understanding_pain_pd

Reference 3: http://www.parkinsons.org.uk/sites/default/files/k-1301_silverdale_plain-english-summary.pdf

Lionel Paulo

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>

Coming Up ...

Sat 11 October 2014, 10.00 – 15.30h:

East Midlands RSN 3rd Annual Research Forum

The Regent Suite, Park Inn, 296 Mansfield Road, Nottingham NG5 2BT - The theme is “**Research into Exercise for Parkinson’s: Finding out what really works**”. The official registration deadline for this exciting event has now passed. The places have all been taken and an 'overflow' list established. No more new bookings can be taken. However, if you have booked but now find yourself unable to attend please contact Lionel Paulo: by email office@em-rsn.info or on 0116 282 7340 to cancel and give someone on the overflow list a chance to attend instead. We hope to see you there.

Sun 2 November 2014:

3rd National Research Supporters Day

Royal York Hotel, Station Parade, York

Bookings may be made from August 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>

Abseil Part 3 *(continued from [page 8](#))*

Concentrate!!

I start paying the rope through the belay ring, a movement which inevitably eases me downward. Strenuous, it's heavier than expected, 420 feet's worth of its weight hanging down below. Focus on walking downwards, backwards, maintain posture. Concentrate !

I start to find a rhythm, pull the rope up through the ring, move each foot down, pull up the rope, move each foot down, quickly glance down, look back even faster..... progress! The rope gradually becomes lighter to work as the descent proceeds. I estimate 10 minutes gone and two thirds down the tower when the wind picks up and suddenly my



(Roger with certificate, photo Darren Worthy)

feet lose contact with the building....keep calm !!

Strain to regain contact. Think ! Wait 'til you drift back to the wall. I drift back to the wall, re-establish contact briefly, only to be blown away again. Decide to resume descent to discover that being blown sideways can be countered by fast feeding rope and dropping more quickly.

New confidence found - down I go again.

Landed

Suddenly the rooftops of the surrounding houses seem much closer, nearly there, nearly there...touch down to a smattering of applause from the onlookers and supporters. I feel like cheering too but there's a burly instructor releasing me from the ropes. More applause as Karen makes her landing. Time to wander across to the supporters and down a bottle of water, make that two bottles, to fix the parched throat.

I've done it - in one literal fell swoop, progressing from complete amateur to 'Extreme Abseiler' (that's what it says on the T-shirt) and more importantly raised at least £1,500 for Parkinson's UK's research programme in the process. Not bad for 15 or so minutes work!

Time to update the web page and send out emails to all and sundry, thanking the advance sponsors and encourage those waiting for me to prove my credentials to now cough up. But first to really address that dry throat - a pint or two at the pub beckons...

Roger Elkin

Latest estimate indicates some £2,000 including Barclays £750 matched funding and £205 Gift Aid to be claimed. At Parkinson's UK's published rates that should pay for eight days of a research project. After reading this article, anyone who wishes to sponsor my efforts please see my JustGiving page at <http://www.justgiving.com/Roger-Elkin>

Our congratulations and thanks go to Roger for his support. – ed.

In future issues...

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

- Reports of the presentations at the Nottingham Research Forum
- Article by Bob Raeburn on his boxing training experience
- More about the RSN DT ("What's that? " I hear you say. Just wait and see)
- How to network within the network

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.

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We look forward to hearing from you!