

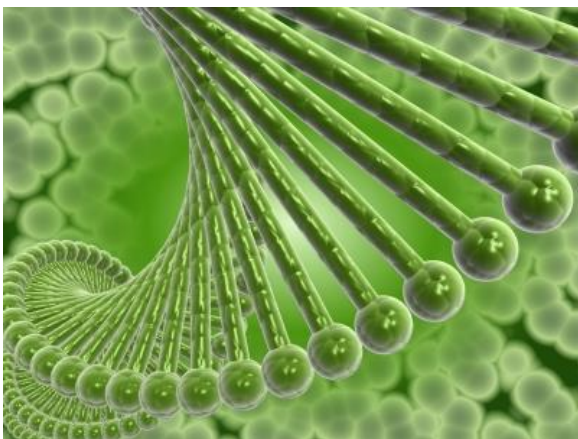
# OUR NEWS

## East Midlands Research Support Network News

No 7 May 2013

Welcome to the 7<sup>th</sup> edition of the East Midlands Research Support Network Newsletter!

This is the first edition of our second year, and its layout reflects the emerging pattern of articles. As these usually fall into 4 categories – reports of past events, news of events that are coming up, background articles in plain English on scientific research and finally personal experiences - we have decided to use this order to present the contents. We are happy to



(DNA Green, by jscreationzs: freedigitalphotos.net)

welcome Ian Billcliff, Pat Loft and John D as new contributors to this edition. My thanks go to all of them and to our regular contributors for taking the trouble to write and for accepting the amendments of the editor's red pen.

This edition includes reports by Ian Billcliff and Maria Rice on the ground breaking Researchers' Meeting, initiated by Steering Group Chairman John Telford and held in Nottingham on 25 March 2013. John then follows with his own assessment of the value gained from the day. Next is my account of an interesting Support and Information event in Kettering where the main speaker, Dr Katie Le Blond from Parkinson's UK was followed by local Steering Group Member Richard Brown.

'Coming Up' contains information about future events for your diary. Part 3, headed 'You might like to know' consists of 'plain English' articles explaining some of the science we all need to understand if we are to follow recent research developments; John Telford writes on packaging RNA while Lionel Paulo highlights why biomarkers are important.

### Inside this issue...

- News & Events
- Steering Group
- Coming up
- You might like to know
- Lionel's lessons
- Personal perspectives
  
- 4 full articles

... and much more!



(We ask, by Vlado: 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)

Our final pages contain personal accounts of involvement in research. There is the 5<sup>th</sup> instalment of my participation in the Respond (Rivastigmine) drug trial, Pat Loft's experience of volunteering for Dr Victoria Haunton's clinical trial and John D's account of encounters with low blood pressure and acupuncture.

We hope you continue to find the newsletter interesting but if you no longer wish to receive it please contact Lionel Paulo and ask to be removed from the mailing list.

Caroline Maxwell, Editor

## Researchers' Meeting in Nottingham

### Seen through the eyes of a carer

By Ian Billcliff

As a carer, and with a background in chemistry, I was interested in discovering what research is currently being done in the quest to find a cure for Parkinson's. I was therefore very pleased to have the opportunity to attend the first meeting of the leaders of six of Parkinson's research projects in the East Midlands area, which took place at the QMC, Nottingham on 25 March 2013, organised by John Telford, chair of the East Midlands Research Support Network, and chaired by Prof John Mayer.



(Dna, by ddpavumba: freedigitalphotos.net)

For Ian's overview of the event and for Maria Rice's report of Rob Skelly's presentation on improving the experience of hospital admission for people with Parkinson's see [page 10](#).

### Researchers' Meeting – what did it achieve?

By John Telford, Steering Group Chair

We - the East Midlands RSN Steering Group - invited researchers from the eight Parkinson's research projects in the East Midlands to come together for a couple of hours to meet each other and to talk with each other about their work in the

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**Caroline Maxwell**, Daventry,  
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**Maria Rice**, Nottingham

**Tyna Brych**, Parkinson's UK  
East Midlands



(Research, by jscreationzs:  
freedigitalphotos.net)

### Brain Bank

In the March edition Richard Brown offered to arrange a group visit to the **Brain Bank** in London. He asked anyone who was interested to contact him. But, surprisingly, nobody except steering group members has been in touch. So Richard is thinking about arranging for a smaller group to go. If you are interested please contact Richard on [dicansue@gmail.com](mailto:dicansue@gmail.com)

presence of a small audience of people living with Parkinson's. Why? What was the point of the meeting?

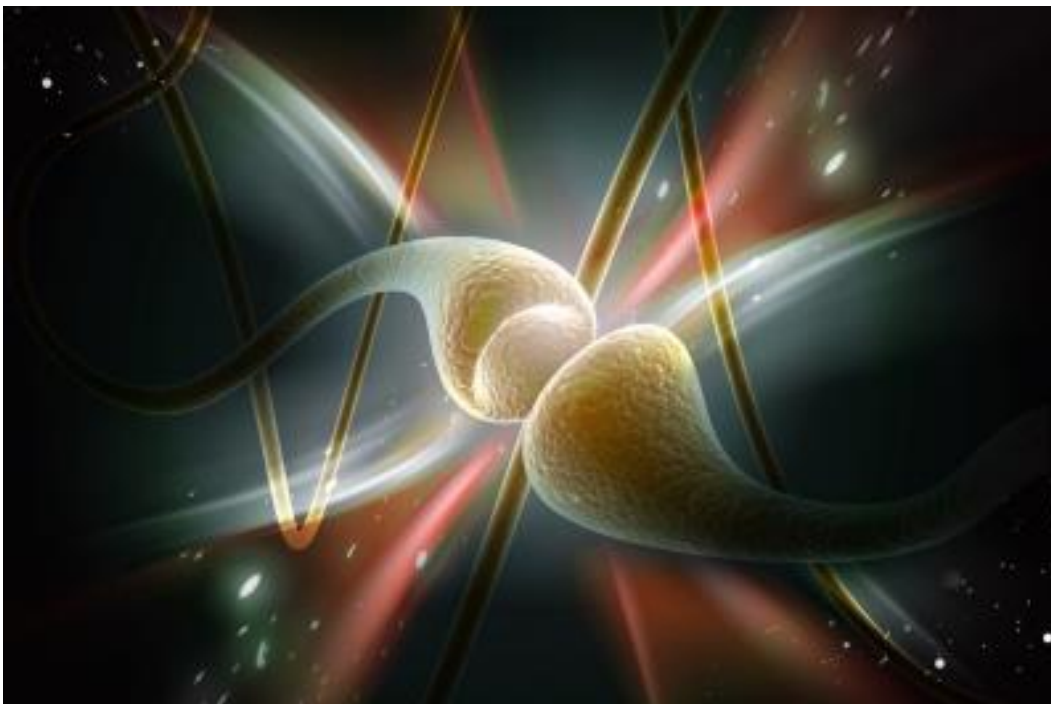
The researchers had all agreed beforehand that it was a good idea but had not been very specific as to why such a meeting would be worthwhile for them. On our part, as people interested in Parkinson's research, we were pretty sure that the Parkinson's researchers in the region would benefit from an opportunity to learn a little more about each other's work. So we felt there was virtue in setting up an opportunity for them to come together to compare notes and some of us, as representatives of the Parkinson's community, would like to listen in and to engage with them. We also wondered whether there was mileage in the idea of a team of people in this region working together for a common purpose.

The meeting did not disappoint. In an environment which allowed for friendly interaction some fascinating science was covered in a very short time and many matters of common interest were revealed (as Ian Billcliff's report below on page 10 shows) as some researchers met each other for the first time. Basic laboratory research, clinical studies and scanning techniques were discovered not to be in totally separate boxes. The common quest to improve the lot of people with Parkinson's - shoulder to shoulder with those very people as colleagues and participants - came through as a unifying principle. Some possible collaborations were raised and an enthusiasm to have a similar event in perhaps a year's time and in a different city emerged. So that is what we shall plan to do. We think a slightly bigger audience could be accommodated next time so watch this space.

## Katie in Kettering

*By Caroline Maxwell*

In April I attended the Parkinson's Information and Support Day in Kettering. I arrived just in time to hear Katie Le Blond's excellent talk on Parkinson's UK research followed, after lunch, by Richard Brown's account of his personal involvement in supporting research.



*(Synapse, by rajcreationzs: freedigitalphotos.net)*

Katie works at the Parkinson's UK London office as Research Communications Officer and really lives up to her job title. Her communication skills are enviable.

*For an outline of Katie's talk and review of the day see [page 12](#).*



# COMING UP...

## Towards better Parkinson's medication

Preparations for the 2<sup>nd</sup> Annual Research Forum on Saturday 14 September at The Roundhouse in Derby are making good progress. Organised by the East Midlands Research Support Network this free event from 10.00 – 15.30 will focus on research into medication and is intended for people with Parkinson's and their partners and carers.



(Forum on button on mobile phone, by Stuart Miles: freedigitalphotos.net)

The aim is to discuss, in easily understandable language, key questions about the main areas of Parkinson's research, progress towards better treatment and a cure, and to explore how people with Parkinson's themselves can become actively involved in supporting research.

- What are the main current lines of investigation? what's missing in our knowledge of Parkinson's?
- Is the variety of different prescriptions a sign of a responsive approach to a complex condition or of a lack of an accepted framework?

Speakers include Professor Peter Jenner, Dr Nin Bajaj, Richard Windle and Dr Ian Stanford.

Please register your interest by emailing [researchforumderby@gmail.com](mailto:researchforumderby@gmail.com) – This will ensure that you receive booking form and other information closer to the time.

## National RSN Research Conference

Planning is now taking place for a conference for RSN members in Birmingham on 23 November. There will be a number of presentations from Parkinson's researchers and the opportunity to meet other Research Supporters. You can still apply to be part of the planning team - email [rsn@parkinsons.org.uk](mailto:rsn@parkinsons.org.uk) - or just send in ideas for the conference programme.

Put the date in your diary! We shall give you more details as they become available.

## World Parkinson Congress

This international congress takes place every three years and this year it will be in Montreal. It gathers together scientists, people with Parkinson's, their carers and medical and other professionals from all over the world. It not only has talks and workshops on Parkinson's research but also has a similar number of sessions on what it



means to live with Parkinson's. It is representative of the entire Parkinson's community and around 3,000 people attend.

Parkinson's UK will have a strong presence there including 4 volunteers, 3 from the RSN and a Parkinson's Nurse Specialist. Often the Congress is used to announce significant new research results and we'll keep you in touch with these.

**More information:** <http://www.parkinsons.org.uk/default.aspx?page=11022>

Parkinson's UK will be feeding back information during the congress using social media, will put reports in their publications and will give talks in the UK following the event.

<http://www.worldpdcongress.org/>

**Also** read the reports in SPRING Times from people who attended the WPC in Glasgow in

2010: <http://spring.parkinsons.org.uk/images/stories/SpringDigest/2010/ST57Web.pdf>

<http://spring.parkinsons.org.uk/images/stories/SpringDigest/2011/ST58Web.pdf>

**Parkinson's Together – Can you help?** On 3 April I received an email from Marina at Parkinson's UK with information about a series of 'Parkinson's Together' meetings to be held in May at various venues around the country. I expect many of you received the same message. The meetings are to help plan the direction Parkinson's UK will take over the next few years. They should be very interesting. If any readers go to one of the meetings I would love to have a brief report for the next newsletter. It does not have to be long or detailed, just an outline of what happened and what issues were emerging for our organisation to pursue in the future. Please send it to me at [caroline@paddockend.com](mailto:caroline@paddockend.com) - Thank you.

## You might like to know

### Delivering the new DNA drug

*By John Telford, Steering Group Chair*

You may recently have received a letter via Parkinson's UK from Dr Matthew Wood of the Parkinson's Centre in Oxford. In it he appeals for support for the final year of his research project which is focused on packaging up fragments of RNA into natural nanoparticles so that they can cross the blood-brain barrier and reach target cells in the brain.



*Dr Matthew Wood*

There is clearly a lot of enthusiasm about this treatment. They have worked up a so-called gene silencing technique which reduces the amount of a protein called alpha-synuclein produced in the target cells. There is good reason to believe that in some Parkinson's cases there is a genetic mutation which causes an excess of this protein to be produced. This excess goes on to form the 'clumps' in the nerve cells that you often see written about. So 'turning down the volume' by interfering with the mechanism by which this protein is produced should stop its toxic aggregation and so, should stop the further deterioration of the nerve cells in this part of the

brain that are associated with Parkinson's symptoms. Laboratory experiments have shown that this works in animal models.

Laboratory results have also shown that they can get natural nanoparticles known as exosomes to pass through the blood-brain barrier. The final step is to package up the RNA fragments successfully in the exosomes, like messages inside envelopes, so that they can be addressed and delivered to the right cells in the brain.

There are a dozen reasons why this might not be successful, but the effort being put into raising the funds needed for this final year's work suggests that there is excitement that this could be a major advance towards slowing the progress of the disease for at least some Parkinson's cases. If it works, there is a further genetic target that this technique is being applied to. This is LRRK2 which is implicated in a large proportion of sporadic Parkinson's cases. See [http://www.parkinsons.org.uk/pdf/g-1109\\_wood\\_plain-english-summary.pdf](http://www.parkinsons.org.uk/pdf/g-1109_wood_plain-english-summary.pdf) for a lay summary of the project.

## ***Lionel's lessons***

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

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*Lesson 1 - Biomarkers: An essential step on the path to a cure*

### **Why they must be found**

If you become diabetic, testing your blood sugar levels or finding the presence of ketones can identify your condition beyond doubt. But what do we measure to find out if a person has got Parkinson's before symptoms such as tremor appear (by which time at least 50% of your brain's dopaminergic neurons have failed)?

*Find the answer to this question in the full article on [page 13](#).*

## ***Personal Perspectives***

### **Diary of a drugs trial participant (5)**

*By Caroline Maxwell, Editor and Steering Group member*

Well, my time on the trial drug Rivastigmine (or the placebo) is well over half way through. After 12 weeks of gradually increasing my dosage I have now been taking the full strength tablets for about 16 weeks with about another 5 weeks to go before my return visit to Bristol for reassessment. At that point I shall stop taking the tablets but will continue on the trial for another 4 months. That means I continue to keep in touch with the research team to report any falls or other relevant events or changes. Apparently there is no need to decrease the drug dosage gradually at the end of the trial period. I just stop taking it. That is when I expect to have a



*(Pharmaceuticals in a Shopping Cart, by Grant Cochrane: freedigitalphotos.net)*

better idea of whether I have been taking the real thing or the placebo.

I know that in previous editions of this diary I have said I thought I was taking the real thing but I am no longer so convinced of that. I have heard from someone else on the same trial whose enrolment procedures and initial period on the tablets (real or placebo) mirrored my own but who experienced very definite effects once he was on the maximum dose, whereas for me the effects have been less noticeable. Although there is nothing in the trial's paperwork which imposes confidentiality on participants I am reluctant to be too specific about the physical effects either of us has experienced in case this influences the reactions of other participants. The link between the mind and the body is so close that it is all too easy on the one hand to imagine or, on the other, to fail to notice physical reactions to a change in medication. But I will report that I had 3 falls in March and another 3 this month. None of these were serious but nor were they imaginary!

Since my last report I have been to New Zealand to visit my son and his family. I was a bit concerned about how to regulate my medication on the journey which crosses multiple time zones, and about whether, if I had an accident, the local medics would be able to deal with the fact that I was on medication which might or might not be a placebo. Before leaving I spoke to the researchers in Bristol and followed their advice. While on the journey I tried to take my medication including the trial drug, at roughly the same time intervals as I would have done at home then, once I arrived I picked up my normal timings. This worked satisfactorily but, not surprisingly did not exempt me from jet lag. As for my concern about an accident – it didn't happen. I took with me the card from the researchers with UK contact details in case of emergencies, but I was boringly cautious and managed to avoid ending up in A&E, so did not need to test the system out.

By the time the next newsletter comes out I shall have been for my second / final visit to the research base at Bristol and will have stopped taking the trial tablets. I wonder if I will feel any different.

## Taking part in a clinical trial proves I do have a brain

*By Pat Loft*

My name is Pat Loft and on Tuesday 9 April, my husband, Ian, and I agreed to take part in a research study for, wait for this, "Is cerebral auto-regulation impaired in idiopathic Parkinson's disease?" This, in lay man's terms, is a study of the body's ability to control blood flow to the brain in people with Parkinson's disease.

At our first meeting Dr Victoria Haunton, who is leading the trial made it quite clear in a very friendly manner that if at any point in the process I wasn't happy we could stop. Ian and I then both filled in the consent form and completed a quite detailed questionnaire. It was then a matter of setting up the instruments to collect my readings.



*(Human brain, by ddpavumba: freedigitalphotos.net)*



I lay on a bed which was adjusted until I was comfortable. I then had two ultrasound probes placed on each temple, with a head set to hold them in place. These were then attached to a machine to record the blood flow to my brain. Yes, it's official, I do have a brain. I also had two electrodes placed on my chest and one on my tummy to record my heartbeat. An inflatable cuff was wrapped around my arm and a sensor attached to a finger. These were attached to machines which took my blood pressure and pulse. Finally I had two small short tubes inserted into my nostrils which registered my oxygen intake, my carbon dioxide output and my breathing pattern. It may sound complicated but it was all quite painless. The main delay was setting up the ultrasound to read the blood flow correctly.

I then had to lie still for 5 minutes after which they took readings from all the machines. This was repeated once more. I then had to breathe in time to a metronome for 90 seconds which got a bit faster but caused me no problems. Then back to the relaxing again after which Victoria moved my right arm for about for 1 minute and then relaxing again.

The data collection lasted about half an hour after which the same things were done to my husband (as a non-Parkinson's sufferer). Altogether for the two of us the whole process took about 2 hours to complete. The data collection process is relaxed and not stressful at all and I would say there is a real risk of falling asleep during it but fortunately neither of us did! 3 days later, after stopping my medication the day before, I went back to have my data collected again. As this was only me this obviously did not take so long and was completed in less than an hour.

I know that Dr Haunton is still looking for people both with and without Parkinson's disease to help with her research study although people who have a history of stroke, diabetes, heart attacks, angina or deep brain stimulation are unable to participate in this study.

## One man's experience of low blood pressure

*By John D*

Lionel's article about Dr Haunton's research in Newsletter 6 reminded me of a personal experience of low blood pressure which may be of interest. But first a little bit about me. I was diagnosed with Parkinson's in September 2001 almost 12 years ago and am still relatively active. Having the idea that I must keep going is half the battle. Actually I do give in when my



*(Checking blood pressure, by markuso: freedigitalphotos.net)*

body tells me to as I have to rest at times during the day but I come back refreshed and ready to go again.

I carried on working after retiring from my main occupation and fully retired in 2007 when fatigue prevented me from driving long distances. My main symptom is extreme tiredness which, coupled with a shuffling gait, can overtake me at any time of the day. For a long time I attempted to establish the cause and timing of this but so far it has defeated all attempts to define when and why it happens. It



may or may not be triggered by forgetting to take my medication at the correct time. However the reverse can happen: I can be on time and I still get the symptoms.

Now, a little about low blood pressure. I suspect that most people with Parkinson's do suffer with low blood pressure as it is a symptom or side effect of the disease. But what is classed as low blood pressure? In my case I had a short record taken when I suffered another 'problem'; about 4 years ago for which I was taking a medication the name of which unfortunately escapes me. I experienced overwhelming tiredness coupled with extreme nausea. The attacks were happening just before I had my breakfast, and it soon became clear it was caused by taking this medication on an empty stomach. The answer was obvious: take it after food. Both my GP and specialist could not fully explain the reason but suspected low blood pressure. They recommended taking my blood pressure on a regular basis for a while to see what happened, and to keep a record. I followed their advice and discovered nothing more than the fact that my blood pressure is very low all the time, and taking that medication without food dropped it to the level just above passing out.

Today, without that medication, I am fine but take things carefully as standing up quickly makes me dizzy.

### **... and of Acupuncture**

I would also like to add my experience of acupuncture. I have always suffered from stiffness and pain in my left arm and shoulder and at a talk about acupuncture at a branch meeting I made my mind up to give it a go. I arranged for a course of treatment and apprehensively arrived at the lady's clinic. I was instructed to lie down minus most of my clothing and, as the first of many needles went in, I felt no pain; in fact it was strangely relaxing. However, as more were placed around other parts of my body, I could feel them; in fact some on my shoulders were quite painful. All in the line of duty I remained determined to go through with it.



After a couple of visits I was feeling much better and the pain seemed to be receding, but those first two visits were the best and from there on the pain reasserted itself and I was back to square one. Reluctantly I informed her that it did not help my pain and gave it up. To be fair it may have been a case of 'self-fulfilling prophecy' as I did not believe it could really work, so perhaps the Placebo effect worked in reverse for me.

I must admit that some people I know have experienced different results to mine, so please don't give up on the idea of trying it because of me if you are thinking of giving it a trial.

*(Tao, by Danilo Rizzuti, freedigitalphotos.net)*

## FULL ARTICLES

- [East Midlands Researchers' Meeting](#), by *Ian Billcliff*
- [Dr Robert Skelly's Talk](#), by *Maria Rice*
- [Katie in Kettering](#), by *Caroline Maxwell*
- [Biomarkers: an essential step on the path to a cure](#), by *Lionel Paulo*

### East Midlands Researchers' Meeting on 25 March 2013 (continued)

*By Ian Billcliff*

Prof Mayer first made a brief introduction to the topic of Parkinson's research informing us that Lewy bodies were first found in the brain cells of PWP's (People with Parkinson's) 99 years ago and that subsequent research has been a sequel to that discovery. He then outlined the format of the meeting.

The first presentation was by Dr Robert Skelly of the Royal Derby Hospital on his project looking at setting up specialist care units in hospitals (see Maria Rice's article on [page 11](#)).

Dr Stefan Schwarz of Nottingham University made a presentation on the work being done on MR Imaging in the search for new biomarkers for diagnosing Parkinson's at the earliest stages of the disease. His work is linked with that of Dr Nin Bajaj on a similar project and also the Tracking Parkinson's project. This work has been mentioned previously in Newsletter 4 and is further explained by Lionel Paulo in Lesson 1 of Lionel's lessons on [page 13](#).



(Blood cells, by dream designs: freedigitalphotos.net)

Dr Victoria Haunton of Leicester University and the LRI is investigating whether blood flow to the brain may be affected in people with Parkinson's. Again this project has been covered in Newsletter 6 by Lionel Paulo. Early results indicate that auto regulation of blood flow to the brain is impaired fairly early on in the progression of the disease. Pat Loft records her personal perspective on participating in this research in [Section 4](#).

Dr Lynn Bedford of Nottingham University discussed different aspects of the clumping of proteins in brain cells leading to the death of these cells in Parkinson's.

Dr Nicoleta Moisoi's project is looking at the effects of gene mutation in Parkinson's and the possible use in the treatment of PD of existing approved drugs currently used in the treatment of other conditions which may or may not appear as secondary symptoms in Parkinson's.

Finally, Dr Russell Kitson presented on work being done by Prof Chris Moody and himself on 'chaperone' proteins and their role in the death of brain cells in Parkinson's. 'Chaperones' control the proper activity of other proteins in the body and help to remove damaged proteins from cells. It is when this activity goes wrong and there is a build-up of unwanted or damaged proteins inside the brain cells that neurodegenerative conditions such as Parkinson's develop. He went on to discuss the synthesis of new compounds from a naturally occurring substance which could be developed into new drugs for the treatment of Parkinson's.



*(Human brain, by ddpavumba: freedigitalphotos.net)*

In the concluding the discussion, Professor Mayer expressed the feeling that the key question in research is why nerve cells die in the first place causing Parkinson's to develop. Key to finding a solution is collaboration between researchers, it being essential for each team to have open access to all research projects under way. This is of course much easier today than in the past with the availability of the internet.

In summary, I found it interesting and encouraging to discover how much Parkinson's research is being carried out in the East Midlands with more information about the condition being gleaned all the time. It appears that a few projects are looking at similar aspects, particularly the role of proteins in Parkinson's, albeit each project looking at a different aspect of this. It is, however, vitally important that these research teams do collaborate in order to prevent overlap and duplication of effort and also, hopefully, to speed up the finding of a cure.

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## Dr Robert Skelly's Talk

*By Maria Rice, Steering Group member*

Although most research into Parkinson's disease is looking for the elusive cure, some research is directed towards making life for people with the disease more tolerable. This is the aim of Dr Robert Skelly, clinician at Derby hospital, who is researching ways of improving the quality of life for people with Parkinson's who are admitted to hospital.

Dr Skelly had seen many people over the years whose hospital admissions were marred by not getting their medication on time. He wondered how much better the patients would be if they had the right medication and specialised Parkinson's care. So he set up a pilot study into establishing a specialised unit within a general ward for the admission of Parkinson's disease sufferers.

Before the study started about 60 nursing staff were trained in the care of Parkinson's disease patients. In particular this meant looking at 'on time' medication and about communications.

Data was also collected from the unit about the patients. The aim of the pilot study was to identify problems which might arise during larger scale research.

The hospital had recently introduced a computer system dealing with the distribution of medication. This came in useful when the data was being collected because the nurse administering the medication could record the time it was given by just click on the computer. This showed whether the medication was on time or late. It was decided that if it was given within half an hour of the time stated it would be counted as on time. A focus group of patients and staff recommended that patients should self-medicate but in fact no one could do this as the patients were too frail or confused. Staff had to get the schedule of medication from the relatives or the patients' doctor.

The plan was for the special unit to be located in a general ward and to accommodate two sets of 25 patients in succession. In fact they got 20 patients at first admission and 24 patients the second time. The results will look at the medication and the amount of time each patient spent in hospital.

Dr Skelly explained that there are some drugs used on general hospital wards which must not be given to people with Parkinson's disease. When people with Parkinson's are admitted to hospital they generally go either to the specialist area for which they were admitted (e.g. heart attack, stroke, or broken hip) or to the general ward. The drugs used on a general ward may not be compatible with the Parkinson's patient's own drugs or the state of their disease.



*(Medication, by renjit krishnan: freedigitalphotos.net)*

There may also be a lack of Parkinson's medicine on the ward. This was remedied and now there is a full complement of Parkinson's medicine at the special unit. This is very important for Parkinson patients who may be taken to hospital as an emergency and therefore without their medication. We were told how bad it is not to have one's medication on time but also that it can be fatal to stop taking medication altogether. I made up my mind there and then to carry spare tablets wherever I go.

This pilot study identified problems which will be solved before setting up the next stage of research into a multiunit study. Dr Skelly was confident that analysis of the results would show that the special unit had reduced the length and improved the quality of the hospital stay for Parkinson's patients.

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## **Katie in Kettering (continued)**

*By Caroline Maxwell, Editor and Steering Group member*

Katie gave a very clear account of the overall Parkinson's UK research activities. She explained the strategy, the priorities, the different types of funding, the numbers of projects (about 90 are being funded currently), and the location of projects which now includes some



outside the UK. Katie also mentioned the role of lay grant reviewers and of the Research Support Network.

The audience of about 60 listened intently as Katie managed to explain some quite complicated issues without resorting to jargon or talking down to us. Not surprisingly, many of the questions put to Katie were about current research into symptom management and care of people who have already developed Parkinson's. There was interest in finding the causes and, ultimately, a cure, but for many people this seemed too distant to be relevant to their situation. I don't remember anyone asking what we, as individuals, could do to support research apart, that is, from the vital task of raising money.

After lunch Richard Brown had a chance to try out the Powerpoint presentation he and Emily Hughes have created to give a short overview of current research into Parkinson's. Richard's talk was well prepared and interesting but, not surprisingly, repeated much of what Katy had said. However, this was good reinforcement for those who stayed to listen and provided another opportunity to ask questions. Richard explained his role as a lay grant reviewer and as being involved in establishing the national Research Support Network. He emphasised that he gained great satisfaction from his involvement. It was a clear example of 'the more you put in, the more you get out'. Richard described himself, not as a scientist but as a 'wrinkly engineer'. His presentation demonstrated that research is not exclusively the domain of 'scientists' but also benefits from the involvement of people from other backgrounds, be it a wrinkly engineer or anyone else with the commitment to see Parkinson's banished.



*(Medical symbol, by dream designs: freedigitalphotos.net)*

The overall feeling I had was that most of the people who attended that event in Kettering came to listen in the hope of finding out some new information rather than to find out how they might take some action to support research. Many non-scientists assume they have nothing (except money) to contribute to the rarefied world of scientific research. If Parkinson's Research Support Network, and even, in a small way, this newsletter can help persuade them otherwise, without trespassing on the scientists' territory, it will be doing some good.

*Richard's Powerpoint presentation is designed to be delivered to local groups. If you would like a speaker to come with the presentation to your group please contact Steering Group Secretary, Lionel Paulo.*

*(return to [page 3](#))*

## **Biomarkers: an essential step on the road to a cure**

*By Lionel Paulo, Steering Group member*

This is the first in a series talking about all things PD in an easily understood format; hopefully every reader will then be as informed as the technical whiz kids among us as to the meaning of important parts of research.

## Why testing is essential

Arthur Jones, the famous inventor of Nautilus and MedX exercise machines was known for his obsession with facts and figures. When it came to the importance of measuring the results of any endeavour he stated that “it is impossible to evaluate, or even understand, anything that you cannot measure.”

That statement is unfortunately completely true when it comes to Parkinson’s disease. By comparison, it is generally known that if you become diabetic, testing your blood sugar levels or insulin levels or the presence of ketones can identify it beyond doubt. Likewise, it is possible to measure countless other things in our bodies and compare the results against ‘normal’ levels in order to diagnose illness. In a real sense, the medical profession is all about measurements – if your levels are abnormal, because they can be measured, whatever your problem may be it can be identified and appropriate action taken.

So what do we measure to find out if a person has got Parkinson’s before symptoms such as tremor appear (by which time at least 50% of your brain’s dopaminergic neurons have failed)? There is a blood test or scanner that would tell us, right? NO!! Before symptoms show up we do not have any way of testing a person and finding Parkinson’s is established in them.

Remember when you were diagnosed? Your specialist watched you walk, asked you to perform simple toe and finger-tapping exercises, and on the strength of these types of tests told you that Parkinson’s had afflicted you. The problem with diagnosing an illness by its symptoms is that some neurological problems are so similar that mistakes can be made; for example Parkinson’s and MSA can easily be mixed up in the early stages.



*(Neuron, by dream designs; freedigitalphotos.net)*

## A cure cannot be found if we cannot test whether medicines work

But the really serious problem behind being unable to do a test which diagnoses Parkinson’s accurately comes when we try to develop drugs to stop it. How can you evaluate the success of a drug designed to stop Parkinson’s if you cannot measure whether or not it works? As our state of health and symptoms can fluctuate for no apparent reason, personal perceptions while on a drugs trial do not prove anything other than that we are having a good day or a bad day.

## Prevention could be the best form of cure for future patients

Now picture this utopian vision in the future: biomarkers have been found and are easily tested for and people can choose to be tested for Parkinson’s when having a health check-up. A young healthy person has a check-up and a biomarker is found! The doctor calls this individual and prescribes a low dose of a proven Parkinson’s blocking drug, and that’s it: job done! The Parkinson’s in this person is now blocked from getting worse BEFORE any symptoms have begun to show, in effect ‘curing’ him or her before they show any ill-effects from Parkinson’s. The patient can live a full, normal life without suffering the bad effects of Parkinson’s, and the pharmaceutical company is happy because they will supply this individual

the drug to prevent Parkinson's getting worse for the rest of their life. Potentially expensive you say? Not as expensive as the carnage that Parkinson's currently wreaks on our lives.

### How can we help to find biomarkers?

Is there a way that we can help to find these biomarkers? Quite a few studies are now being conducted around the world but there are two studies that stand out. The largest one you could join is the **Tracking Parkinson's** 5 year study (otherwise known as **Proband**) being funded and administered by Parkinson's UK. They are still looking for hundreds more participants and lots of non-Parkinson's people as controls to compare against.

In our newsletter number 5 there is an article about joining the study, and here I am again beating the drum! **But it really is that important;** I urge you to read that article and then you will know what to expect if you join the trial (if you have not done so already). It could be our children that benefit directly from this! For information on joining follow this link:

<http://www.parkinsons.org.uk/default.aspx?page=12365>

And to read newsletter number 5 article click link below:

<http://em-rsn.info/newsletter/EMRSNN%205w.pdf>

The second study is **The Parkinson's Progression Markers Initiative (PPMI)** sponsored by The Michael J. Fox Foundation. Our American cousins are also looking for biomarkers and to quote the latest from them 'PPMI leadership has decided to add a new arm to investigate potential risk factors of PD: reduced sense of smell (hyposmia), rapid eye movement sleep behaviour disorder (RBD) and a mutation in the LRRK2 gene (the single greatest genetic contributor to PD known to date).'

This is in the USA, of course, and they have already closed the doors on recruiting participants but we can still contribute to their online survey about sense of smell as they need at least 10,000 people to take part - For more information, visit [www.michaeljfox.org/PPMI/smell](http://www.michaeljfox.org/PPMI/smell)

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