

# OUR NEWS

## East Midlands Research Support Network News

No 2 July 2012

Welcome to the 2<sup>nd</sup> edition of our newsletter.

This edition includes news of raising funds for research and of how the money raised is spent. There are details of new research projects and guidelines for possible participation in trials. Most importantly there are advance notices of 2 events, one in Leicester and one in York and suggestions of what you can do to support Parkinson's research.

The newsletter is distributed electronically to East Midlands members of the Research Support Network. This is open to members and employees of Parkinson's UK. To join the RSN contact Emily Hughes at [rsn@parkinsons.org.uk](mailto:rsn@parkinsons.org.uk) - It's free!

### FUNDRAISING

Congratulations to Parkinson's Research Supporters in the East Midlands. Our branches and groups donated over £43,000 to research in the first half of this year. This is more than any other region so far and is a great achievement.

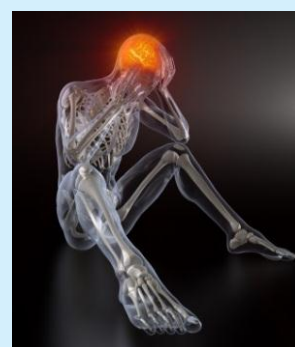
The Bourne Support Group has made a major contribution in addition to that sum and this serves as an inspiration to us all! Janet Ward wrote to tell us of their remarkable fundraising success. She says it was largely down to one person who has spearheaded their fundraising efforts. As Janet says, the Bourne Group (see photo [on p 6](#)) is "a willing and compassionate group in which many friendships have been formed" over its four years of existence. Their aim "is to make sure that no-one in our area with this ghastly condition feels isolated".

They clearly put this into practice because they persuaded a lady called Bev, with quite troublesome and disabling

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(photo: istockphoto.com)

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)

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Parkinson's symptoms, to join the group. (Since then she has had Deep Brain Stimulation surgery which has apparently improved her quality of life immeasurably.) Janet reported that Bev took on the fundraising task with relish and determination.

The highlight was a raffle held at their Diamond Jubilee Strawberries and Cream Tea in May. This was no ordinary raffle. Bev's Special Raffle included special, valuable prizes that she had inveigled out of local companies that she rang 'cold'. Her standard remark was 'they can only say No', but they clearly didn't. Amazingly the event raised nearly £4,000 with the raffle accounting for about £2,500 of that.

This means that the branch could earmark much of it for one of the Parkinson's UK stem cell research projects. Janet said in her letter: "A small group with a big heart and a lot of hard work – we are secretly rather proud!"

Janet's letter was written in such beautiful calligraphy that you would not believe that she has Parkinson's. Indeed she was chosen to draw the illustrations for Tom Isaacs' book 'Shake Well Before Use' which is the story of his walk around the British coast.

John Telford

## STEERING GROUP

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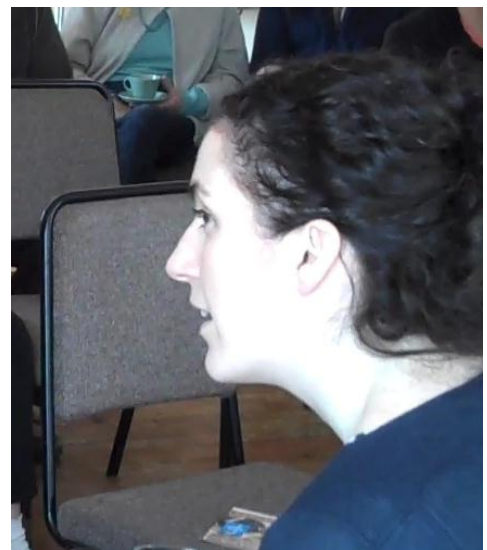
## Spending the money raised: CURRENT PARKINSON'S RESEARCH

### 1. National Office perspective

In May Michelle Gardner, Research Development Manager for Parkinson's UK spoke at the Leicester Branch meeting. She gave an overview of the organisation's research priorities and a breakdown of the 90 research projects being currently funded. She answered questions about stem cells and bio-markers and told what was involved in her typical day at the office. You can read the full report [on page 7](#).

### 2. Projects in Oxford

Caroline Maxwell attended the Open Afternoon at the Oxford Parkinson's Disease Centre where money from a Sainsbury Family Trust has enabled Parkinson's UK to fund the Monument Discovery Project with a grant of over £5million. The Oxford scientists are working on a number of very detailed fronts but all focussed on understanding and eventually finding a cure for Parkinson's. Caroline described them as 'eating the elephant in spoonfuls'. Her impressions can be read [on page 8](#).



(Dr Michelle Gardner - photo: John Telford)

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# COMING UP...

EAST MIDLANDS RESEARCH SUPPORT NETWORK

## Research Day

**SATURDAY 13 OCTOBER 2012;** 10.30am - 4pm at **LEICESTER UNIVERSITY**

- Speakers on the Parkinson's research scene in the East Midlands  
\*\* Clinical Research \*\* Laboratory Research \*\*
- Speaker on the Parkinson's UK research programme
- Panel discussion and Q&A session
- Discussion on YOUR role in the East Midlands Research Support Network

All East Midlands RSN members will be sent full information and a registration form later. Also open to anyone interested from within or outside the region. There will be no charge for attendance. A light lunch and refreshments will be provided.

**Put this date in your diary** for a fascinating day hearing about the Parkinson's research going on in the region with the opportunity to talk to and pose questions to those engaged in the research. Learn more about the Parkinson's UK research funding programme and the projects it supports. Discuss with other research supporters about how we can support Parkinson's research especially in the East Midlands.

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## Parkinson's UK Research Conference & RSN Supporters Conference

Every two years Parkinson's UK holds a large researcher conference for scientists in York. This year it will be on Saturday 3 November. This conference reviews the current state of Parkinson's research and no holds are barred when it comes to talking about technical details. This year for the first time a separate conference is being held on the next day, 4 November, for research supporters. Many of the scientists and clinicians who will have attended the main conference will be present and will speak about their work. The presentations will be geared to a largely non-specialist audience and so will be just right for those of us who are interested in Parkinson's research but are not professional scientists.

This conference has been advertised to all RSN members. If you have not applied to go to it yet, please consider doing so – it might not be too late to apply to go. This will be a good opportunity to meet researchers and learn about what they are doing for our ultimate benefit. It is always productive to meet them and ask them questions face to face and researchers always benefit from meeting and learning from people living with Parkinson's.

The conference is also an opportunity to meet others interested at various levels in Parkinson's research and maybe to build relationships that will help us to collaborate together in productive ways. Please email Stacey Storey at [researchevents@parkinsons.org.uk](mailto:researchevents@parkinsons.org.uk) if you are interested.

### 3. Another new research project

#### **The Parkinson's Voice Initiative (P.V.I.)**

*By Lionel Paulo*

In independently funded research Max Little, Ph.D. and his team have come up with a radically different method of diagnosing Parkinson's that tests out to 86% accuracy currently, yet is hopeful that it may become capable of picking up the signs of Parkinson's much earlier than present clinical assessments which utilise interview and observation methods.

Unlike most diseases Parkinson's cannot be diagnosed through blood tests, scans, x-rays etc. instead relying on doctors to correctly interpret movement patterns, loss of dexterity and several other indicators as signs of the disease. This means that diagnosing Parkinson's before symptoms become noticeable cannot be done. The P.V.I. aims to change that by using voice recordings and computer systems that will be able to identify very subtle changes in the voices of people long before other symptoms become overt.

The team need 10,000 voices to fine-tune the system! Click on the link below and anonymously add your voice (literally!) to the many others that are expanding the P.V.I. database. The website will guide you through a simple procedure to add your voice, ultimately adding up to a system that may make early diagnosis cheap, reliable and possible. Go to <http://www.parkinsonsvoice.org/index.php>

#### **4. DeNDRoN**

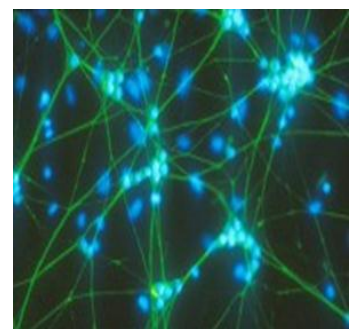
*By Olivier Bazin, Data & Communications Manager Thames Valley*

Parkinson's UK is working closely with the local NHS research network DeNDRoN to promote Parkinson's research. DeNDRoN is a research network that aims to improve the amount and quality of NHS-based research into Parkinson's and other neurological conditions.

Taking part in a study is entirely voluntary. As a participant you can withdraw at any point before or during a visit without giving a reason why. This does not affect your standard care or treatment in any way. If the studies described here aren't suitable, but you would like to hear about future research opportunities, please register your interest by calling the DeNDRoN team on (01865) 234892, or email [Parkinsons.Research@nhs.net](mailto:Parkinsons.Research@nhs.net) - You can also ask your doctor or nurse about local research opportunities.

#### **Understanding the early pathways in Parkinson's**

A major study is currently underway to understand the very earliest steps in Parkinson's with the eventual aim of generating drugs to halt the condition before symptoms appear. This ground breaking project is funded by The Monument Trust, one of the Sainsbury Family Trusts. People with a diagnosis of Parkinson's made in the last 3 years will be eligible for study participation. Individuals will be given the opportunity to consent to a blood test for DNA analysis and a clinical assessment with a neurologist during the outpatient visits. The study team is also recruiting people of similar ages without Parkinson's, and relatives of people with Parkinson's. This study is running across 10 sites: Amersham, Banbury, Kettering, Milton Keynes, Newbury, Northampton, Oxford, Reading, Aylesbury and Ascot. Contact (01865) 234892 or email [parkinsons.research@nhs.net](mailto:parkinsons.research@nhs.net) for information.



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## Eye movements in Parkinson's

The purpose of this study is to examine eye movement abnormalities in Parkinson's patients. Using a portable saccadometer positioned on a headset (a non-invasive device that measures eye movements - see picture) we can record exactly how your eyes are responding to a red or green light, presented to you on a screen or a matt wall.

The eye tracker only looks at the eyes and does not record a video image of any part of your face. The total length of the testing is about 30 minutes and detailed instructions about the task will be given to you before the beginning of the experiment. At the end of the experiment you will be asked a few simple questions about your symptoms and asked to make some simple movements in order to assess your condition clinically.



Preliminary results indicate that there is a difference in the eye movements between individuals who have the condition and those who don't. We now hope to demonstrate that eye movements change in line with progression over time.

If you're interested in taking part, or would like to learn more, contact Dr Chrystalina Antoniadou on email [chrystalina.antoniadou@clneuro.ox.ac.uk](mailto:chrystalina.antoniadou@clneuro.ox.ac.uk)

## Participating in Research Trials

*By Maria Rice*

Before we can all benefit from the results of research funded by Parkinson's UK researchers have to run trials to ensure that the medication or treatment is safe and beneficial to use. For this they need the help of volunteers.

The trials are administered with strict controls. This means that volunteers are looked after by the doctors who are doing the research and are carefully monitored throughout the time they are receiving the treatment. Volunteers for clinical trials may trial something which will be beneficial to them or, on the other hand could suffer some discomfort. However, it is their right to withdraw from the trial any time if it is proving to be too uncomfortable to continue.

As well as volunteers for clinical trials, researchers need volunteers to respond to questionnaires and surveys, either by talking to directly to the scientists or by recording their responses on line or on paper.

For guidelines about how to find and enrol on suitable trials and what you should expect see [page 9](#).

## WHAT YOU CAN DO TO SUPPORT RESEARCH

As this is the newsletter of the East Midlands Research **SUPPORT** Network it seems appropriate to make some suggestions about what you can do to support research:

### 1. Fundraising – get others involved

You might not feel able to take on a major fundraising role yourself and you may not be involved with a local branch but if you have contacts within your community with an individual or group which raises money for charity you could suggest they make Parkinson's their Charity of the Year.

Finding a cure for Parkinson's is a cause few people will resist. Most people are willing to donate. If you identify a people who might be interested talk to your group lead/branch committee or contact the Regional Fundraiser on 0844 225 9832 or by email at [rf.eastmidlands@parkinsons.org.uk](mailto:rf.eastmidlands@parkinsons.org.uk) – Parkinson's UK are just recruiting a new Regional Fundraiser but they will be delighted to work with you as soon as they are in post, hopefully by late August.



*(Bourne Support Group cheque presentation  
[see p 1](#) – photo Parkinson's UK)*

2. **Participate in a trial** – follow Maria's guidelines on page 9 and see if anything appeals to you.
3. Plan to attend the **Research Day on 13 October 2012 in Leicester** and complete the application form when it arrives.
4. Consider applying for a place at the **Conference in York on 4 November**. First come, first served!
5. If you have not already done so, register to join the **Research Support Network** by contacting Emily, the RSN manager, at [rsn@parkinsons.org.uk](mailto:rsn@parkinsons.org.uk) - This is the only way to ensure you receive this newsletter.

East Midlands Research Network News is published bi-monthly by the Steering Group of the East Midlands Research Support Network. The next deadline for contributions is **7 September**. Please send us a copy of your branch newsletter. We are particularly interested to hear of any activities to do with research which we could mention next time.

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

We look forward to hearing from you!

## FULL ARTICLES

- [Dr Michelle Gardner in Leicester](#), by *Lionel Paulo*
- [Research in Oxford – eating the elephant](#), by *Caroline Maxwell*
- [Guidelines on getting involved in Research Trials](#), by *Maria Rice*

### Dr. Michelle Gardner in Leicester

*By Lionel Paulo*

Michelle Gardner, Research Development Manager for Parkinson's UK, addressed the Leicester branch meeting on 16 May 2012. Michelle said that 127,000 people in the UK have Parkinson's today and the number is set to grow as the ageing population increases. This grim statistic became the fuel to fire up Parkinson's UK's renewed drive to expand research and chase that most elusive of prizes: A cure. From this evolved the 5 year plan with 4 priority areas for research. These are: trying to find why dopamine-producing cells in the brain die; developing new animal models that react more like humans to test treatments; faster, better drug screening to try to improve lifestyle; and trying to find methods of accurately assessing Parkinson's progression via 'biomarkers' (see tracking Parkinson's link <http://www.parkinsons.org.uk/tracking> ).

Parkinson's UK began back in 1969, and since then has spent more than £50 million of which £15 million is currently funding 90 research projects. Of these 37 are trying to find out what causes Parkinson's, 23 are studying lifestyle factors such as mood and exercise, and 30 are exploring new technologies such as gene therapy and stem cells which are thought to hold great potential for new treatments. Research is also going on into slowing the progression of the disease by neuroprotective activities such as exercise and scientists are following up recent discoveries that some drugs for other ailments such as Diabetes and high blood pressure might also help with Parkinson's. The latter research has been publicised by Edinburgh University under the heading 'Repositioning of drugs.' Michelle also talked about the Brain tissue bank which is shared with the MS charity and was mentioned in our May newsletter.

Michelle then talked about the Research Support Network or RSN, and its importance in helping to select projects to be funded and how Volunteer Research Support Officers or VRSOs act as a link between researchers (many of whom have never met a Parkinson's patient!), and patients and volunteers. It was noted that drugs take years to be tested and approved before becoming available and the present government was aiming to reduce that time, although probably only shaving 1 year off a 10 year average assessment time.

At question time stem cells were inquired about and Michelle explained that it is hoped that in the future a patient could become 'their own donor' as their own skin would be the source. Bone Marrow is also being studied as another potential source of Stem Cells. Photo-sensitivity of the eyes and loss of sense of smell or taste were considered and Michelle reiterated the importance of the Tracking Parkinson's initiative, as at the moment diagnosis of PD is down to a detailed assessment by a consultant rather than recognised scientific biomarkers. The new initiative will aim to find these objective measures.

The question was asked of Michelle; what does your job entail? She explained that her first job each morning is to scan all the latest Parkinson's research and updates and pass on news to the Research Communications team who communicate it to members via Facebook, Twitter, the internet etc. Applicants for research funds are dealt with, and work in progress of Parkinson's UK funded research projects is monitored through the reports that researchers send in. In addition a report on the outcomes of our funding for the previous year is published in June each year. Also information leaflets on all aspects of Parkinson's are produced for doctors' clinics and pharmacies.

Finally Michelle told us about research conferences and the Cure Parkinson's Action Group (CPAG) which meets regularly to decide on higher level strategy for Parkinson's research which is a collaboration between Parkinson's UK staff, the RSN, external organisations such as the Cure Parkinson's Trust and the Medical Research Council and representatives from pharmaceutical industry and European Union. ([Back to p 2](#))

## Research in Oxford - eating the elephant

*By Caroline Maxwell*

In May 2012 I attended the Open Afternoon at the Oxford Parkinson's Disease Centre where the Monument Discovery Award Team is working on 3 themes – exploring what changes occur inside the nerve cells affected by Parkinson's; developing better animal models that truly reflect Parkinson's and finding ways to diagnose Parkinson's earlier, ideally before symptoms develop. (See Parkinson's UK website for details.)

Presentations by the 4 researchers were necessarily condensed and, for a non-scientist, challenging. I could not report accurately on their content but some general impressions have stayed with me. First of all what a clever and committed bunch of people those researchers are. We are lucky to have them working on our behalf. Next, I was struck by the contrast between the huge numbers of cells that are involved in an individual's brain and the minute size and complexity of each molecule under investigation.

The researchers are determined and confident that they will find out exactly what happens within the affected cells and how messages are passed, or not passed, from one part of the brain to another as the disease progresses. Then they will develop intervention strategies. But it is a complex matter. Each item of new knowledge gives rise to a further question. I doubt if we are going to hear about a cure just yet.

But new developments are emerging all the time. Research has identified genes which are defective in people with Parkinson's. Nerve cells for research can now be grown from skin cells in the lab. Scientists now have available new animal models to monitor the effects of genetic interventions. Hundreds of volunteers with Parkinson's have been recruited to the Tracking Parkinson's Project aiming to identify bio-markers essential for early diagnosis

And so the list goes on illustrating the complex nature of this condition and showing that the way to deal with it is to 'eat the elephant in spoonfuls' remaining confident that gradually the disease as a whole will be mastered. ([Back to p 2](#))



# Guidelines on getting involved in Research Trials

*By Maria Rice*

If you are still keen to help, then the Parkinson's UK website is probably the best place to start looking. This is what you do:

1. Find the home page for Parkinson's UK on your computer.
2. At the top you will see a black bar; click on "research".
3. The next page - go down till you find the blue box with "Get involved in our research" - click on this and you should be on another page.
4. Now find "Take part in a research study" and click on the "list of UK studies"
5. You will see a list which includes UK wide studies as well as those based in East Midlands and Eastern England. There is also a heading for web based studies and some advice from Parkinson's UK.

You can look both for clinical trials and for non-participatory research such as surveys or questionnaires for which you do not have to attend a clinic, undergo a procedure or take special medication. You may not even need a computer as some surveys are sent out printed for you (or your carer) to fill in.

Another website to consider is the Fox Trial Finder (<http://www.foxtrialfinder.org>) recently launched in the UK and Canada by the Michael J. Fox Foundation for Parkinson's Research (MJFF). This first-of-its-kind online platform anonymously connects volunteers with and without Parkinson's disease to clinical trials in critical need of participants. Fox Trial Finder matches volunteers with the trials most likely to need them, increasing the efficiency of the enrolment process and empowering patients to get more involved in the discovery of new treatments.

Information boards at your local hospital or surgery or even your local paper may also have notices asking for volunteers.

When considering whether a trial is suitable for you look first at the criteria set by the researchers. If they say they need people who were diagnosed before they were 50 and you were diagnosed at 60, then you do not fit the criteria and there is no point in applying. Also look at the geographical area covered to make sure you can get to the research site.

If there is some intervention to yourself, e.g. you are asked to take tablets or have injections, then you really need to get your own doctor's (GP) opinion. In fact it is a good idea to talk to other professionals and to your family to let them know what you intend to do. If you have Parkinson's and you're considering taking part in a research study, you should consult your neurologist and speak to the healthcare professionals managing the study about whether it is suitable for you.

These guidelines are provided for information only and should not be treated as advice or a recommendation to participate in any of the studies. ([Back to p 5](#))