

# OUR NEWS

ISSUE 04  
September 2012

Aylesbury Branch

**Welcome to the fourth of the Aylesbury Branch newsletters, which we hope you will find useful and entertaining.**

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## **The mental impact of Parkinson's.**

Some people with Parkinson's have problems with their moods and behaviour as the disease develops which can affect their quality of daily life and that of their carers. They are currently being studied by doctors at King's College London Hospital, to help with understanding what impact Parkinson's can have on a couple. The doctors aim to develop ways of providing better information and support for both sufferers and carers. To help with this research we as a couple volunteered to be interviewed in some depth by a doctor who is a clinical psychologist. Sheila has had Parkinson's for 10 years; her husband, Robert, is her carer.

Two weeks before the interview the doctor at the Hospital first did a phone interview for about 20 minutes, which confirmed that we were a suitable couple for the research. She then sent both of us a questionnaire, which we had to complete on our own and without knowing the answers given by the other.

When we were with the doctor in the Hospital, she put us both at our ease, and laid on a nice lunch so that our energies didn't flag. We signed consent forms and understood what was going to happen to us.

The doctor then interviewed Sheila on her own for about 90 minutes, asking detailed questions covering the nature and extent of her Parkinson's, whether she experienced problems such as depression, anxiety, delusions or hallucinations. She quizzed Sheila about her current health, quality of life, general mood as a married partner and views on the relationship. Similar questions were asked by the doctor to Robert, also on his own. Sheila was also asked to do simple tasks of memory and concentration, such as reading words aloud and repeating phrases.

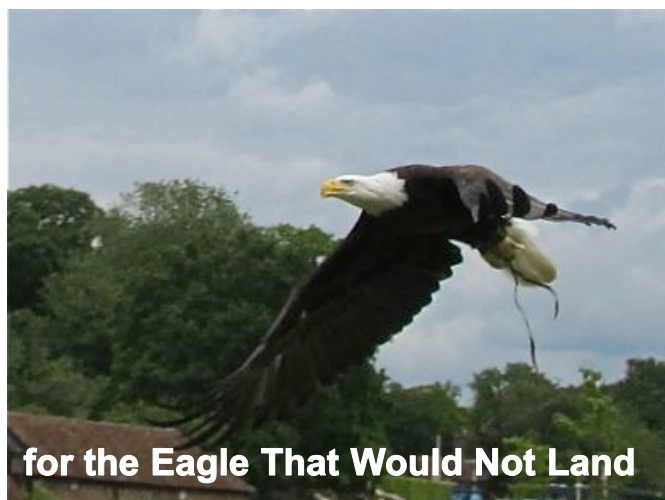
Throughout our time at King's we were treated with respect and kindness, so that we were at our ease and could answer the questions put by the doctor as honestly and fully as possible. Our answers will not be attributed to us by name, but will be combined with those of up to 30 other couples also taking part in the research. We hope the end result will be that Parkinson's sufferers and their carers will receive the best possible therapy. Then they can together stay on top of the mental aspects of the disease and live fulfilling lives.

Sheila and Robert Ridgway

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Waiting at Whipsnade Zoo.....



for the Eagle That Would Not Land

## Interested in taking part in a research study?

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.

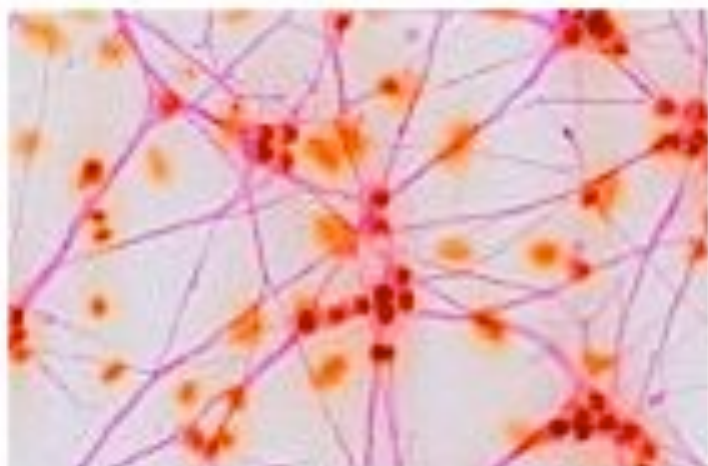
Taking part in a study is entirely voluntary. As a participant you can withdraw at any point before or during a visit without giving a reason why. This does not affect your standard care or treatment in any way. If the studies described here aren't suitable, but you would like to hear about future research 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.

We are looking for people with Parkinson's who would like to take part in a trial investigating the benefits of rehabilitation programmes. It would involve taking part in either an exercise programme (at a local gym) or a handwriting exercise programme (at your home) twice a week for 6 months (transport costs to and from the gym and for all follow-up assessments will be paid). If are you interested and you would like further information please contact Marloes Franssen on (01865) 483272 or email [marloes.franssen-2011@brookes.ac.uk](mailto:marloes.franssen-2011@brookes.ac.uk)

### 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 groundbreaking 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 without Parkinson's of similar ages, 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.

**Don't forget.....**The Group exists for the benefit of it's members, in the long term by raising money to help fund research but more immediately to try and improve the lives of all those affected by Parkinson's, including Carers.

Entertainment, taxis and exercise therapies you know but if there are any other ways that you think we can help please talk to Dorothy or any committee member.

### 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 below) 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 (01865) 234728 or email [chrystalina.antoniadou@clneuro.ox.ac.uk](mailto:chrystalina.antoniadou@clneuro.ox.ac.uk)



## Second instalment of Research into Early Parkinson's

In April I had a call from Dr Konrad Krolikowski asking if I was still willing to have a scan and skin biopsy, this to be carried out at the J R in Oxford. I received an invitation and directions to the Oxford Centre for Functional MRI of the brain, for 3rd May. It gave directions to the relevant car park - all the car parks had queues of cars waiting to enter - fortunately I travelled by bus!

Once more form filling, mainly to make sure I had no metal bits and pieces in or on my person, and written consent. It was explained that the scan would take an hour or more to complete which sounded a little daunting until the imaging scientist Ricarda explained that it was carried out in short bursts with short breaks in between. The bursts varied from 6 minutes, 10 minutes and the longest 12 minutes, each burst had a different resonance and I found myself counting the pulses - Well you have to do something to pass the time!

The hour + went by surprisingly quickly and I didn't find the experience as claustrophobic as I had imagined. I was then collected by Dr Krolikowski and taken to the ward for the skin biopsy. A little local anaesthetic and it was over in no time. He also repeated some of the physical tests ie fingers to nose tip etc .

Apparently there is a shortage of people going on to have the MRI scan, if they are in the older age group possibly to much metal in joints or wherever.

Again it was an interesting experience and I was glad I was able to take part

Pat Kuryba '

## !! !



As you may know the Group has been given a Wii console. This has been shown to benefit those with Parkinson's (and others)  
We will be arranging soon for you to be able to try it out.

### Aylesbury Branch *A social and support group or people with Parkinson's and their Carers*

For more information visit <http://www.parkinsons.org.uk/> and search for Aylesbury in "LOCAL TO YOU"



470 g crushed pineapple (I haven't found one this size yet but got 2)  
500 g mixed fruit  
125 g butter  
1 teaspoon mixed spice  
1 teaspoon bicarbonate of soda  
1 cup sugar

Boil above together for 3 mins and allow to go cold.

2 eggs  
1 cup plain flour  
1 cup SR flour

Add above to boiled mix. Put in 20 cm round tin (I use squared) Cook in a moderate oven for 1 1/2 to 2 hrs. Turn out when cold and keep in airtight tin in 'fridge for up to a week (if you haven't eaten it before!!)

Dorothy

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## COMING SOON MEETINGS

### October 20th

Parkinson's Nurse - Liz Scott

### November 17th

Christmas Lunch

### December 15th

Bell Ringers, Mince Pies etc.

### 19th January 2013

Oxford Parkinson's Research Centre

### 16th February

AGM + Buffet Lunch

### 16th March

"On the trail of tiny mammals" Sarah Churchfield

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Meetings held at 10.30 am on the third Saturday in each month at; Quarrendon & Meadowcroft Community Centre, Bowlers Field, Meadowcroft, Aylesbury HP19 9HH

*We also meet from 11.30 on the first Tuesday of each month for an informal lunch at Waddesden Manor Garden Centre.*



## Parkinson's research: a member's perspective



Diana Symmons has been a branch member for a year and is taking part in a major research

study called "Understanding the early pathological pathways in Parkinson's".

### How has your life changed since your diagnosis of Parkinson's?

"I've tried to keep things as normal as possible. Walking isn't as easy as it used to be. I have to be a bit more sure-footed. I try to keep myself active. My outlook on life remains the same. After I was diagnosed, I decided that I wouldn't opt out of anything. My medication has been very helpful and I am very blessed with a wonderful nurse."

### Why did you decide to take part in the Parkinson's Monument Discovery study "Understanding the early pathological pathways in Parkinson's"?

"My nurse told me about it. She explained that it wouldn't do me any harm, and it might help others in future. My husband also agreed to take part in the control group."

### How has your experience of the research study been so far?

"It was great fun. The study doctor and nurse were very pleasant. What I found most difficult was standing on one leg!"

The Monument Discovery study aims to improve knowledge of the very earliest steps in Parkinson's. People with a diagnosis of Parkinson's made in the last 3 years will be eligible to take part. The study team is also recruiting people without Parkinson's of similar ages, and relatives of people with Parkinson's. If you are interested in taking part, or would like to learn more about other local Parkinson's research opportunities, please contact T 01865 234892 or E [parkinsons.research@nhs.net](mailto:parkinsons.research@nhs.net)

### South Bucks Young Parkinson's Group

This group recently celebrated its second anniversary. It meets on the second Tuesday of the month from 7.30-9.45pm at the Wesley Methodist Church, Priory Road, High Wycombe.



## The Wobbling Warblers

We have recently completed the trial series of singing therapy sessions led by Helen Bartlett in Amersham Community Centre.



These have been attended by an average of 15 members and the Wobbling Warblers have learned a number of spirituals and other songs, some sung as rounds, some in harmony and some with actions to accompany them.

Members have found their memories and concentration tested, as well as vocal cords, facial muscles and breath control, but it has been fun!

Please return the enclosed questionnaire to Dorothy Mathers regarding the future of this singing group.



### Do you like fishing?

Member Geoff Ellis, who has Parkinson's, is seeking a fishing companion to join him on fishing days out, helping with threading hooks etc. He would also welcome ideas of suitable venues with parking fairly close, in the Princes Risborough area. Please contact Geoff (T 01844 344120), or Anita Browne (contact details on back page) to discuss this in more detail.



## Parkinson's research: another member's perspective



George Burrell is taking part in the major research study, "Understanding the early pathological pathways in Parkinson's".

He was diagnosed in April 2008.

### How has your life changed since your diagnosis?

"Walking can be difficult. I find it hard to keep up sometimes. I'm not very keen on driving now, as I've lost my confidence behind the wheel. When I do the washing up at home, I often get backache. My doctor suggested I stop doing the washing up, but my wife doesn't always agree with that!"

### Why did you decide to take part in the research?

"My Parkinson's specialist nurse invited me to take part. I thought it would be a good thing to do to help out."

### How has your experience of the research study been so far?

"I've learned quite a lot more about the condition, its symptoms, and the side effects of drugs. That's been useful. The research team were very thorough. They went through many different aspects of Parkinson's. I had the choice of whether to have a lumbar puncture. I wasn't keen on the idea, so I opted not to have one. My wife is also taking part as a "control". It made sense for us to take part together."

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## Hollywood actor Bob Hoskins has Parkinson's

Bob Hoskins has retired from show business, aged 69, after being diagnosed with Parkinson's last autumn. His announcement generated considerable press coverage for Parkinson's.

Dyslexic as a child, he spent his formative years in the London gangland of the Krays, which helped form his "tough guy" image, although he also succeeded in comedy roles.

His silver screen career has spanned four decades. His films include the gangster movie "The Long Good Friday" in 1980 with Helen Mirren, "Mona Lisa" in 1986 (for which he was nominated for an Oscar as best actor), "Who framed Roger Rabbit" in 1988, and (playing Smee) both "Hook" (1991) with Dustin Hoffman and Robin Williams, and "Neverland" (2011).

## The Wobbling Warblers sing on

Thank you to everyone who completed the questionnaire enclosed with the last newsletter. As a result of your replies, we have decided to continue with our singing therapy group.

Helen Bartlett, who led the initial trial of singing therapy sessions in Amersham Community Centre, is now on maternity leave, and has recently given birth to a baby girl... BUT we have found another talented musician - Mandy Watsham - to cover her absence.

The Wobbling Warblers resumed on 3 October and now meet at 10.15am on Wednesdays in the Small Barn in the Barn Hall complex, near Amersham Community Centre. The sessions cost £2 per head.

Existing members of the group have found the sessions an enjoyable way to test their memory and concentration as well as vocal chords, facial muscles and breath control. Come and join us!

Bob Hoskins also made the BT adverts "It's good to talk" and appeared in the 1979 controversial BBC TV musical drama, "Pennies from Heaven".

He appeared in two films released earlier this year, "The Huntsman" and "Snow White". He now plans to spend time with his family. He has four children and lives with his second wife in East Sussex.