

## Early diagnosis of Alzheimer's – a brave new world

It is in the early phase of dementia that treatments are most likely to be effective. This is one of the important drivers for research into 'biomarkers' of Alzheimer's disease. A biomarker is a biological signal that can be detected for diagnosis, ideally very early and before too much harm has occurred. A biomarker can also tell us how far a disease has progressed.

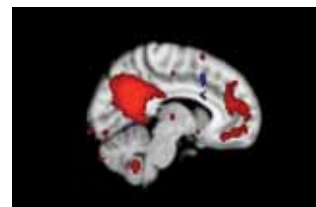
Our 'Feature Study' (p.2) describes one of our current studies, looking at functional MRI (a brain scanning

technique). This form of imaging might eventually help to speed up assessment of new treatments. This study is part of an exciting new wave of biomarker research happening around the world.

The Alzheimer's Association in the US has proposed that biomarkers become an integral part of diagnosis, but there is no 'blood test for Alzheimer's'. Still, colleagues at the Institute of Psychiatry have used information and brain tissue from another one of our studies, Brains for Dementia Research, to

make definitive links between levels of specific proteins in the blood in life and levels of amyloid plaques in the brain after death.

By establishing cohorts of people assessed in research in life and then donating their brains to research after death,



Possible biomarkers include brain imaging techniques

Brains for Dementia Research will help in the search for biomarkers for better and earlier diagnosis. However, unless we have good preventative treatments to offer, this could be a double-edged sword.

The good news is that BDR brain donations will also contribute to understandings which bring forward the possibility of new treatments for Alzheimer's disease.

**Dr Rupert McShane**  
Clinical Director  
Thames Valley DeNDRoN

## Research: a participant's perspective

*Interview with a participant & caregiver, who took part in a study on the long-term effect of rigastigmine (Exelon) capsules and skin patches in Parkinson's disease dementia.*

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

"It's like a day out really. We enjoy the journey & like coming to see {the research team}. We're not worried about asking any questions. We really feel involved in the process. It's not like 'us and them'."

### Why did you decide to take part?

"We just hope that something might help because Parkinson's Disease (PD) is such a nasty condition. Anything that could make a difference is worth trying."

### What do you most enjoy about your visits?

"We get a lot out of coming here. When we have questions, they are answered there and then, or at least, on our next visit. The research team look at the patient as a whole, they don't just think about the drug intervention or the study.

We also feel grateful that somebody is taking an interest in us and trying to help us. By 'us', I really mean everybody with PD, because PD really knows how to hit you."

### What do you least enjoy about your visits?

"Injections for blood samples! I've never liked needles..."

Also, we start with high hopes, but we have to accept that we won't necessarily get our dream wonder drug. Still, every little helps. And I guess we're used to that uncertainty anyway."

### What do you hope to get out of your participation in the study?

"Slightly better quality of life, and helping to provide information the medical community can use to advance treatments. Anything that gives any hope is worth a shot. Helping other people also plays a part."

### What would you say to someone in a similar position who's unsure about taking part in research?

"Well, I'm biased of course, but I'd say 'go for it'. We were advised very clearly at the start that we could always decide to withdraw from the study if we wanted. I would personally prefer to have slightly better quality of life for 5-10 years, rather than 10-20 years of mediocre life. We felt there's always a chance (even a small one) of improvement, of it helping a bit. We'd certainly appreciate the offer of taking part in other studies in future."

The following is a sample from our portfolio of high-quality, nationally important studies. Taking part in any of these studies is entirely voluntary. Participants can withdraw at any point before or during a visit without giving any reason why. This does not in any way affect their care or treatment. Taking part may, however, contribute to improving knowledge and standard of care for future generations.

### Feature study: **Functional MRI Study**

This study aims to develop new procedures (known as 'biomarkers') that allow the detection of changes in the brain associated with memory impairment. The research uses a brain scanning technique called functional magnetic resonance imaging (fMRI), which helps to visualize changes in the brain during the performance of tasks. We would like to invite people with a diagnosis of early Alzheimer's disease, mild cognitive impairment, frontotemporal dementia, vascular dementia or Lewy Body Dementia. You may consider participating if you are aged 50 years or above, and have a carer, relative or close friend who knows you well and can come with you. Participants are asked to attend the John Radcliffe Hospital, Oxford, for one or two days in one week only. Assessment will include memory testing and a MRI brain scan. For some patients it will also include a physical examination and a blood sample.

**CONTACT OPTIMA:** (01865) 231453 or (01865) 231270.

### **Parkinson's UK Discovery Study**

Thames Valley DeNDROn is helping the Oxford Parkinson's Disease Centre clinical research team to recruit 1,700 people with early stage Parkinson's disease (PD), 300 relatives who may be at-risk for the condition, and 300 people without PD of similar ages from Northamptonshire, Berkshire, Oxfordshire, Buckinghamshire and Milton Keynes. If you're interested in taking part, please visit <http://opdc.medsci.ox.ac.uk/patient-involvement> or call Sally Beauchamp on 01865 231846.

### **Challenge FamCare**

'FamCare' is investigating whether training community mental health team (CMHT) staff in an evidence-based assessment and treatment method improves the care and in turn quality of life for both people with dementia who are living at home and their family members. The study aims to reduce distressing behaviour in people with dementia and decrease carer stress.

All people with dementia living at home who have local family carers, and are referred to CMHTs are eligible to take part. The study involves 3 visits (lasting 1-2 hours each) from a researcher at first referral, 8 weeks later and after a further 4 months. Visits involve an interview and some questionnaires to assess challenging behaviour, quality of life, and other relevant care received. **CONTACT Bina Kerai:** 07798 882 580 or [bina.kerai@obmh.nhs.uk](mailto:bina.kerai@obmh.nhs.uk)

### **Alzheimer's – A Clinical Research Study (Abbott)**

#### **Is someone you care for living with Alzheimer's?**

Your loved one may be eligible to take part in a research study of an investigational drug for mild-to-moderate Alzheimer's. The person in your care may be eligible for this research study if he or she:

- Has mild-to-moderate Alzheimer's
- Is 55 or older, and is not currently taking a prescription medication for Alzheimer's
- Has a caregiver (yourself, a family member, a nurse, etc.) who can provide support during the study.

To learn more, and to see if your loved one may be eligible to participate, please contact Claire Merritt on (01865) 231556 or email [claire.merritt@nhs.net](mailto:claire.merritt@nhs.net)

### **Study of Chorea in HD**

This study aims to find out if a new drug is safe and effective for people who have Huntington's disease (HD) with involuntary movements (chorea). The treatment acts by blocking receptors (in this case mGlu5) in the brain that affect movements. Participation lasts approximately 11 weeks and involves 12 or 13 visits to the clinical site. The treatment period will last 32 days. For more information about this study or other current HD research, please contact Gill Siuda on 07825 681042 or (01865) 231543 or email [gill.siuda@orh.nhs.uk](mailto:gill.siuda@orh.nhs.uk)

**\*\*\* If you are setting up a new study, looking for participants for an existing study, or for information on all our studies, please call Helen Collins, Network Manager, on (01865) 234607 or 07825 356499, or email [helencollins1@nhs.net](mailto:helencollins1@nhs.net) \*\*\***

Thames Valley DeNDRoN covers a geographical area that includes Berkshire, Buckinghamshire, Milton Keynes, Northamptonshire and Oxfordshire. The coverage of our network is focused around 3 hubs in Northampton, Reading and Oxford. Here's the latest news from across our four counties.

### Northamptonshire

Many thanks to Sandy Hudson, whose secondment with our team finishes in February. We're very grateful for her contribution to Northampton being the highest recruiting site for GERAS, and her support with the 'Abbott' study (see page 2). Sandy's enthusiasm for research means she will continue to support our work as much as possible.

### Oxfordshire

The Parkinson's UK Discovery study team is opening a new site at Horton hospital. This will offer even greater opportunities for involvement in this £5 million project.

### Buckinghamshire

Many thanks to Joanne Cross for her excellent work building links with memory clinic teams in Bucks. She is leaving us in mid-Feb and will be sadly missed.

### Berkshire

Many congratulations to staff in Berkshire for recruiting the first GERAS participant in the UK!

**Brains for Dementia Research (BDR)** has also been very well received, with 20 Berkshire residents having enrolled onto the project to date. BDR participants have regular assessments of memory and thinking and donate their brain after death as a legacy to dementia research.

**Parkinson's UK Discovery study:** participants will be offered the opportunity to attend clinics at Newbury community hospital, as well as Royal Berkshire Hospital.

**MAIN-AD:** This trial is still in great need of participants! This important study is looking at memantine (Ebixa) as an alternative to neuroleptics for the treatment of irritability, restlessness and agitation in Alzheimer's disease. We are inviting people with Alzheimer's disease who are living in a care home and taking a neuroleptic medication (e.g. haloperidol/Haldol, risperidone/Risperdal, Zyprexa/olanzapine or Seroquel/quetiapine). For information please call 01344 415829 or email [lynn.rigby@nhs.net](mailto:lynn.rigby@nhs.net)

## CONTACT

For general enquiries, please contact our head office

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## Staff Profile

### Jack Ayre

Assistant Research  
Psychologist



Jack studied Psychology at the University of Wales, Bangor. After working for the Alzheimer's Society in Bedford for 18 months, he moved to Reading to join the DeNDRoN team in Berkshire.

### How and why did you get involved in DeNDRoN?

I previously had experience of working with people with dementia at the Alzheimer's Society, carrying out home support work (visiting people in their homes, offering respite time). I'm also working to be accepted onto a clinical psychology course. I hope my time with DeNDRoN will give me the experience I need for my plans to materialise!

### What does your role of Assistant Research Psychologist involve?

My role involves raising awareness of local research among people with neurodegenerative disease (e.g. Alzheimer's or Parkinson's disease), their families, doctors, nurses and clinical colleagues. I help patients and carers take

part in studies and carry out some of the assessments for the study team (e.g. assessments of memory and thinking, behaviour, or ability to carry out everyday activities).

### What has surprised you in your work in NHS-based research?

I've been really pleasantly surprised at the number of people interested in the Brains for Dementia Research (BDR) project. Their passion in helping to find ways to combat the condition has been truly inspiring. There's been a really positive response to the project so far. Long may it continue!

### What are you looking forward to this year?

I'm obviously keen to continue gaining valuable

experience. A specific project I'm excited about is the SHIELD study, in which experienced family carers of people with dementia will provide support for people who are at an earlier stage in their caring journey.

### What would you say is your greatest achievement?

That could be my black belt in taekwondo, which I was awarded at the age of 18. Since then, I've practiced kung fu for 18 months, and subsequently moved onto capoeira, a Brazilian form of dance fighting.

### Do you have any New Year's resolutions?

I'd like to run a half-marathon. I ran a good 10k race in September with my colleague Siobhan Gardiner. I'd like to go one step further next year!

### Leading national recruitment to GERAS

Thames Valley DeNDRoN (Drs Koranteng, Loughlin & McCleery) have enrolled 36 out of 85 participants across 20 sites in the UK to this study of the costs of Alzheimer's disease – a fantastic effort! One participant's carer stated that she had appreciated the opportunity to take part in the study. This had allowed her to express her feelings about the experience of dementia with professionals whom she felt had a more complete understanding of the issues than her friends or relatives (even though she welcomed their time and attention too!).

### New Staff

A very warm welcome to new team members who joined us in January:

- **Edna Gonzalvo & Stephanie Gallehawk**, neurology research nurses (Oxford Radcliffe Hospitals Trust)
- **Sue Vera**: clinical trials nurse (Oxfordshire & Buckinghamshire Mental Health Trust)

### Research Directors appointed

We are delighted to announce the following Research Director appointments for Thames Valley DeNDRoN:

- **Dementias**: Prof. Gordon Wilcock
- **Huntington's disease**: Dr Andrea Nemeth
- **Motor neurone disease**: Prof. Kevin Talbot
- **Parkinson's disease**: Dr Michele Hu

We look forward to building on our long standing relationships with our new Research Directors.

### Mild Cognitive Impairment research gathering pace

Memory problems are one of the first signs of a condition called Mild Cognitive Impairment (MCI). People with this condition have more memory problems than normal for people of their age, but their symptoms are not as severe as for people with Alzheimer's Disease.

We're delighted that MCI is now receiving increased attention in research. Current study opportunities for people with MCI include Brains for Dementia Research, Cognitive Archaeology (see below), the fMRI study and LEAD. Participation in LEAD involves a schedule of six-monthly assessments for the first two years and an annual assessment thereafter. Assessment visits will vary according to the schedule but include brain scans, medical examinations, giving blood samples, cognitive testing, and questionnaires with a study partner.

The 'MCI Support Tool' study is looking at the best way to support people who have just been diagnosed with MCI, as well as their families / close friends. Participation involves a one off, audio-recorded interview with a researcher lasting between 1 and 2 hours. If you would like to hear more about opportunities in MCI research, please call Claire Merritt on (01865) 231556.

### TRAINING

All staff and public representatives involved with studies on the DeNDRoN portfolio can access NIHR CRN training free of charge!

Visit <http://www.ukcrn.org.uk/index/training.html> for more information on courses available and how to sign up.

## Helping DeNDRoN: patient, carer and public involvement

Do you want a say in how neurodegenerative disease research is carried out locally?

#### Interested in research?

Thames Valley DeNDRoN is looking for local people to offer help and advice (mostly from a lay perspective) on making research more relevant and sensitive to patients, carers and the wider public.

There are many ways you can be involved. This can include advising on patient information materials, how to widen participation in research, helping to identify important and relevant research, or promoting awareness of studies.



Members of the public take on an active role with DeNDRoN

Training will be offered. Involvement is voluntary but expenses are reimbursed. You can do as little or as much as you like. You can make a difference! To find out how, call Olivier Bazin on (01865) 234608 or email [o.bazin@nhs.net](mailto:o.bazin@nhs.net)

### Cognitive Archaeology

Language problems are a common early feature of Alzheimer's disease, and are detectable in spoken and written language preceding the recognition of symptoms. Samples of writing (letters, diaries etc.) produced from middle age onwards, are sought by research teams at the Universities of Oxford and Southampton to try to identify the onset of earliest change in Alzheimer's disease. If you, or a member of your family have stored diaries, letters or other writings dating back over 30 or 40 years and would like to contribute to this research project, we would like to hear from you! **CONTACT Dr Celeste de Jager**: by post to OPTIMA, Level 4 (Room 4403), John Radcliffe Hospital, Headley Way, Oxford OX3 9DU; by phone: (01865) 231453; by email: [celeste.de-jager@ndm.ox.ac.uk](mailto:celeste.de-jager@ndm.ox.ac.uk)



**In the next issue:** new dementia studies, interview with BDR participant and much more...