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## Thames Valley update

“Well, if it’s going to help others...” Participating in research can give purpose and meaning to people suffering from neurodegenerative disease. But the hope that a new treatment might reduce the decline is a still more powerful motivator. So I’m delighted that our Northants team has been selected as a site in a trial of *bapineuzumab* – an intravenous treatment designed to remove amyloid in Alzheimer’s

disease – and has identified 10 potential participants. This experience in getting complex studies underway bodes very well for the future.

Similarly, recruitment to a trial of a drug to treat the symptoms of Huntington’s disease has gone well and is a tribute to the hard work of the team.

We now have 20 members of staff supporting recruitment to 9 active

studies. Our aim – to provide as many patients as possible with the chance of participating in research – is looking more feasible.



**Dr Rupert McShane**  
Clinical Lead

## Why DeNDRoN matters



**Anne Silk**

People are all so different, genetically and how they respond to environmental stressors. The wide ranging remit and extensive portfolio in DeNDRoN can potentially cover an array of factors that can contribute to neurological disease.

DeNDRoN can also play a vital part by bringing members of the public and patients under their auspices. Patients I have met have generally been very keen to help medical researchers, whether in clinical trials or other types of research studies. It’s vital that clinicians recognize patients’ and carers’ demand to get involved and take part in studies. It’s also important for patients to be aware of what research is taking place locally and grasp with both hands the

opportunities DeNDRoN offers.

I can only hope that we can fill as many gaps in our knowledge as possible through DeNDRoN-supported research. I must say that so far I’ve been very impressed and look forward to continue working with DeNDRoN in a constructive manner.

*Anne Silk is the lay Chair on the Thames Valley DeNDRoN Steering Committee.*

DeNDRoN is a UK-wide initiative funded by the Department of Health. It aims to facilitate research by bringing about focused, effective investment to enhance NHS research infrastructure, and to promote collaboration between academics, clinicians, patients, carers and research funders.

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.

### ACR-16

#### Feature Study: ACR-16 trial

The ACR-16 trial is the first major international drug trial in Huntington's disease (HD). ACR-16 is a compound that stabilizes dopamine systems in the brain so it could help both the movement disorder of HD as well as some of the other cognitive and affective aspects of the disorder. The study will be following participants with mild-moderate HD over a period of 26 weeks. If you'd like to learn more about this study, or if you'd like to register an interest in Huntington's disease research more generally, please contact **Gill Siuda** (tel: **01865 231543** or email: [gill.siuda@orh.nhs.uk](mailto:gill.siuda@orh.nhs.uk)) or Dr Andrea H Nemeth, Consultant and Honorary Senior Lecturer in Clinical Genetics, on (01865) 226020, or by post: Department of Clinical Genetics, Churchill Hospital, Old Road, Headington, Oxford, OX3 7LJ.

### MAG-D

The aim of the MAGD trial is to evaluate whether memantine (Ebixa) can help with symptoms such as irritability and restlessness in people with Alzheimer's disease. Such symptoms are reported in many people with dementia and may cause distress or even trigger admission to hospital. Memantine/Ebixa is a drug prescribed to help memory and everyday functions in people with Alzheimer's disease. This study is being carried out across the Thames Valley at residential care homes, nursing homes and in-patient units. For more information, please call **Claire Merritt** on (01865) 231556 or 07825 356510, or email: [claire.merritt@nhs.net](mailto:claire.merritt@nhs.net). We recently recruited our first participants, with further referrals currently flowing in. Many thanks!

### Long Term Effect of Rivastigmine in Parkinson's Disease Dementia

Rivastigmine/Exelon is currently used to treat patients with dementia. It may also benefit people who have Parkinson's Disease Dementia (PDD). This study is looking at the long-term effects of rivastigmine capsules and skin patches when treating PDD. If you care for someone with Parkinson's Disease and dementia, and would like to hear more about this study, please contact: **Angie Weir** on (01865) 231543 or email: [angie.weir@orh.nhs.uk](mailto:angie.weir@orh.nhs.uk). Patients and carers can claim back their travel expenses for getting to and from the surgery or clinics.

### MND Association DNA Bank

The **MND DNA Bank** is the most ambitious research project ever undertaken by the Motor Neurone Disease Association. This £1million project aims to collect several thousand DNA samples (extracted from blood samples) over five years. The resulting information will be used to investigate potential causes of, and possible treatments for, this disease. Recruitment has so far been very successful this year. For more information call **Val Russell** on (01865) 224372 or email: [val.russell@orh.nhs.uk](mailto:val.russell@orh.nhs.uk)

Our 'Studies currently recruiting' boards are placed in relevant clinical and patient areas across Thames Valley. Look out for these for updates to our studies.

**If you are setting up a new study, looking for participants for an existing study, or for information on all our studies, please contact Claire Merritt on (01865) 231556 or 07825 356510.**

## Berkshire

Our long search for research nurses in Berks is over! After Wendy Barrett joined us last July (see previous issue), enter Ann Greenizan and Gill Stokes who were appointed (both part-time) in January by Berkshire Healthcare NHS Foundation Trust.

## Oxfordshire

- Paula Har is the first nursing student to carry out a placement with us. A medical student will also be conducting her placement with us from April.
- Dr Mary Akinola will be providing 1.5 days/week of medical support for our studies.
- We soon hope to recruit a Neurology Research Worker (Band 6/7 depending on experience). The successful applicant will be employed by Oxford Radcliffe Hospitals NHS Trust and based in Oxford for a fixed term until March 2012, subject to extension.

## Northamptonshire

- David Jones was formally appointed in January 2009 as DeNDRoN Research Nurse in Northamptonshire Healthcare NHS Trust following a 1-year secondment.
- Gayle Borley (see profile below) and David Jones have been actively involved in driving forward Northamptonshire Healthcare NHS Trust's 10 year research strategy.
- There are ongoing discussions as to the inclusion of DeNDRoN as a nursing student placement in Northants.

## Buckinghamshire

We have recently advertised a Research Nurse post (Band 6). The successful applicant will be employed by Oxfordshire & Buckinghamshire Mental Health NHS Foundation Trust, for a fixed term until March 2011 subject to extension.

## Staff Profile

### Gayle Borley

Research Nurse



Gayle has been working for Northamptonshire Healthcare NHS Trust for 13 years. She is now a full-time DeNDRoN research nurse based at the Princess Marina Hospital in Northampton.

#### How would your friends describe you?

"I think (hope!) they'd say I'm a loyal friend, good for a laugh and enjoy the odd tittle... But also that I'm caring and tend to put other people first before me."

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

"I heard about DeNDRoN in my dissertation year when I was doing a MSc in Mental Health. My tutor knew Rose Streeton (then Network Manager) and put me in touch with her. At the time, I was a CPN (community psychiatric nurse) with a growing interest in research. Shortly after my chat with Rose, I knew I wanted to apply for the job and one thing led to another! So I was in the

right place at the right time really!"

#### What has surprised you in your work as a research nurse in the NHS?

"Firstly that there are a lot of people out there who want to get involved and actively participate in research. I've also been surprised by how complex the processes are before you can actually get any study going! But ultimately, I'm also a bit surprised by how much I'm enjoying my work. I love it!"

#### What are you looking forward to in the bapineuzumab study (decried in our next issue)?

"I'm mainly looking forward

to the idea of trialling an innovative new drug and being involved in a project that could potentially change many people's lives."

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

"Well, two Summer holidays for starters (chuckle)! I'm going to Disneyland in America and Greece for a friend's wedding. With DeNDRoN, I'm also looking forward to further developing the research team in Northants."

#### What do you like doing on a Sunday?

"Watching football in the pub with my other half, some friends and a nice glass of red wine!"

## Thames Valley DeNDRoN welcomes five new members of staff to their team

- Helen Collins has been appointed as our new full-time Research Network Manager and will be in post from 6 April.
- Caroline Cox joined us in January as our new full-time Assistant Research Psychologist. She will be working predominantly on Brains for Dementia Research (BDR), a brain donation registry, as well as other studies.
- Don Ramage is working 2 days/week with us as Finance Manager. Don is also continuing his role as Management Accountant for commercial studies in the ORH Research & Development department.
- Ann Greenizan and Gill Stokes both joined our team of research nurses in January and are based in Reading, Berks.

## TRAINING

NIHR CRN training courses are offered free of charge to all staff and public representatives working on or affiliated with the NIHR CRN portfolio of studies and can be booked online via the Learning Management System (LMS) at:

[www.ukcrn.org.uk](http://www.ukcrn.org.uk)

## Thanks to Rose and Paula!

Many thanks to our previous Research Network Manager, Rose Streeton, and Finance Manager, Paula Lloyd-Chamberlain, for their vital contributions in launching and establishing our network over a period of 18 months. Best of luck in your future endeavours!

## STUDY UPDATES

**'Cost of Illness and Caregiver Burden' and 'Study of the Costs of care by Disease severity in Alzheimer patients' (SCoDA) recruitment completed!**

We recruited 77 patients in Northamptonshire Healthcare Trust and 99 patients in Oxfordshire & Buckinghamshire Mental Health Trust for these two questionnaire studies recently. Thames Valley was the leading recruiter nationally for both studies combined! Congratulations and many thanks!

### Milton Keynes Parkinson's Disease (MKPD) study

Many thanks and congratulations to our colleagues Michele Hu and Lesley Catterall for their fantastic work in recruiting 247 patients for this study! The MKPD study aims to inform the planning and provision of better care for patients with Parkinson's disease in the Milton Keynes and wider UK community.

## USEFUL LINKS

[www.dendron.org.uk](http://www.dendron.org.uk)  
[www.ukcrn.org.uk](http://www.ukcrn.org.uk)  
[www.ukcrc.org](http://www.ukcrc.org)  
[www.nihr.ac.uk](http://www.nihr.ac.uk)  
[www.myresearchproject.org.uk](http://www.myresearchproject.org.uk)

An electronic copy of this newsletter will be available to download and view online at:

[www.mndoxfordshire.org](http://www.mndoxfordshire.org)

## CONTACT ☎

For general enquiries, please contact our head office

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## And finally...

- Many thanks to Christopher Button (DeNDRoN Co-ordinating Centre) for all the interim management assistance provided over the past few months!
- Congratulations to our colleague Rohan Vanderputt (Haleacre Unit, Amersham Bucks) and his wife Emma! Emma gave birth to 6lbs 13oz baby Lara on 7 November 2008 (photo opposite).
- Coming up in the next issue: bapineuzumab study & possible dimebon studies. Watch this space!



**Baby Lara Vanderputt !**