

Network update

My first few months in post have been very exciting. The team has continued to grow, now counting 25 members of staff. We are well placed across a number of NHS Trusts to engage patients and clinicians with research opportunities, but there is plenty more room for growth!

I've been inspired by the increasing numbers of patients and carers taking part in our studies since 2006/2007 (see graph), and by our growing portfolio of studies across all disease areas.

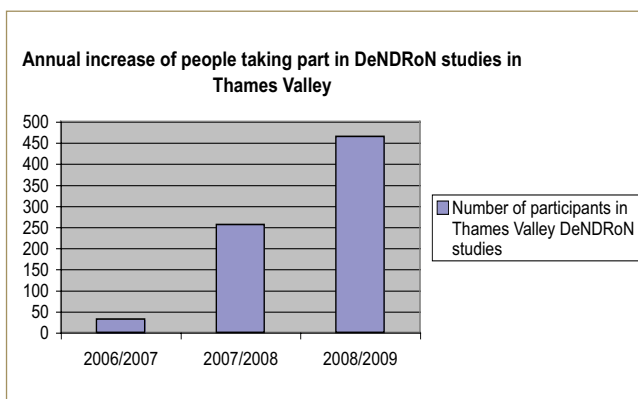
We've recently been covering new ground with studies of Dimebon (CONCERT) and Bapineuzumab for

Alzheimer's disease, and lithium for motor neurone disease (LiCALS). We will soon be embarking on an exciting new study for

Parkinson's disease dementia (MUSTARDD-PD). At a national level, we are delighted to announce that funding for the DeNDRoN Coordinating Centre will be extended for a further five years.

This is great news for everyone involved and should allow us to continue to provide patients (and carers) with the opportunity to participate in high quality research.

Helen Collins, Ph.D
Network Manager



Dementia: a carer's perspective

An interview with John Forrest, husband of Barbara, lovingly cared for at Southerndown Nursing Home, Chipping Norton, Oxfordshire

How would you describe your experience as a carer?

Demanding would be the word that sums it up. In the early years of my wife's condition, she became very angry and frustrated. I learned never to argue with her as she was losing her power to reason. I sought help from others. We were able to get through some very difficult times but eventually I couldn't cope anymore. I was receiving quite a bit of help but I realised I had to bring her into a care home.

How has dementia affected you and your life with your partner?

Initially it appeared to strain our marriage because I was dealing with a different person. But I realised she

was only different because of her condition. Yet, after some very difficult times, we've actually grown closer to each other again as I learned how to communicate better with her. When I saw her recently she uttered "Oh, I do love him"... These words will echo in my mind forever. We have developed a real love and understanding through the mist of dementia.

How has your life changed since your wife's condition?

We often used to go for walks in the countryside. That has obviously changed. My life at home has changed. I don't get out to events as much. I do attend church regularly and find I get a lot of help from

other members of church.

What next?

That's a difficult one to answer. I am bereaved in many ways yet I still have to face the final bereavement. In many ways I see it as a relief for my wife and myself, but the prospect is still painful.

Do you have any advice to people who've recently begun their journey as a caregiver?

To really try to understand the illness. This way, I gained an ever increasing sympathy for my wife. Seek help from others: only someone who's had a loved one with the condition can understand what you're going through. I belong to my local Alzheimer's Society support group - this is a real

help. I've also been getting involved with my wife's nursing home. I've actually grown to love many of the other patients there.

How can research help?

We've been involved with the OPTIMA project in Oxford for many years. Involvement in research can ease the situation by at least helping to bring some benefit to others in years to come. It can also bring a sense of purpose and help you find ways of protecting yourself whilst supporting your loved one. I fully support organisations like DeNDRoN in raising the profile of dementia and neurodegenerative disease research up to the level of cancer research. This should be our aim.

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.

BAPINEUZUMAB study

Bapineuzumab is a new compound currently being tested in clinical trials as a potential new treatment for Alzheimer's disease. Bapineuzumab is a 'passive' vaccine: it supplies anti-amyloid antibodies (amyloid is a protein found in the brains of people with Alzheimer's disease) directly to the immune system rather than stimulating the immune system to produce its own. This study has a site in Northampton. If you are aged 50-88 years, suffer from Alzheimer's disease and have a reliable caregiver who will accompany you to each study visit, we would be interested in hearing from you. For more information, please call Gayle Borley on (01604) 595134 or 07768 151214, or email gayle.borley@nhs.net

LiCALS study

The LiCALS trial is looking at whether Lithium (taken alongside Riluzole) is of benefit in slowing disease progression in Amyotrophic Lateral Sclerosis (ALS)/Motor Neurone Disease. The study will last 18 months for each patient and is looking to recruit 220 participants across the UK (22 participants from the John Radcliffe Hospital, Oxford). Those eligible will have had ALS for at least 6 months and have been taking riluzole (100mg/day) for at least 4 weeks. For more information and full details on eligibility criteria, please call Wendy Barrett on 07827 083787 or email wbarrett@nhs.net

CONCERT study

'CONCERT' is a study of Dimebon, a possible new treatment for Alzheimer's disease that has already shown benefit in previous research. We are now inviting participants with mild-moderate Alzheimer's disease, living at home, who have been taking Aricept (donepezil) for at least 5 months and a stable dose of 10 mg for at least 4 months. We are also inviting their (unpaid) caregiver who sees them at least 15 hours per week. At the end of the 12-month study, all participants will be offered Dimebon in a follow-up study until it gets a license. This study is being carried out across Oxfordshire, Buckinghamshire and Northamptonshire. If you would be interested in taking part, or for more information, please contact Gayle Borley on (01604) 595134 or 07768 151214 or email gayle.borley@nhs.net

MKPD

The Milton Keynes Parkinson's Disease (MKPD) study has been extended for a further 5 years. This 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. For more information please telephone Lesley Catterall on 07917 554687 or e-mail her at Lesley.R.Catterall@mkgeneral.nhs.uk

ACR-16

The ACR-16 trial is the first major international drug trial in Huntington's disease. This study is now in follow-up and some participants are now taking active treatment. We look forward to learning the outcome of this exciting study!

MAIN-AD study

Almost half of people with memory problems in UK care homes are treated with sedative medications called neuroleptics. These are usually given to help unpleasant symptoms like irritability, restlessness and agitation. However, this type of medication can cause unpleasant side-effects. The MAIN-AD study is looking at whether memantine (also called Ebixa) is better than neuroleptics for the treatment of such unpleasant symptoms in Alzheimer's disease. Memantine is a safe drug that has already been shown to help people with Alzheimer's disease. We are inviting eligible participants 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 more information, please contact Claire Merritt on (01865) 231556 or 07825 356510, or email claire.merritt@nhs.net

**If you are setting up a new study, looking for participants for an existing study,
or for information on all our studies, please contact
Helen Collins, Network Manager on (01865) 234607 or 07825 356499.**

Thames Valley DeNDROn covers a geographical area that includes Berkshire, Buckinghamshire, 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.

Berkshire

DOMINO & MAGD now recruiting in Berkshire!

- MAGD is being carried out in residential care homes, nursing homes and in-patient units. The study is evaluating whether memantine (Ebixa) can help with symptoms like irritability and restlessness in people with Alzheimer's disease.
- The DOMINO trial has been funded by the Medical Research Council and the Alzheimer's Society to look at whether donepezil (Aricept) or memantine (Ebixa) are of benefit to people with Alzheimer's disease once they reach the moderate to severe point in their disease and whether taking both donepezil and memantine has more benefits compared with taking either drug alone.

Northamptonshire

David Jones – Nurse of the Year!

Congratulations to our colleague David Jones (Princess Marina Hospital, Northampton) on receiving the Nurse of the Year award for his contributions to Older People's Mental Health Service in West Northants and beyond. His commitment and enthusiasm are truly unparalleled!

Oxfordshire

Congratulations to Meg Barbour on being appointed 'Public Governor' for Oxfordshire and Buckinghamshire Mental Health Foundation Trust! Meg will sit on the Foundation Trust Members' Council and represent Public Members in Oxfordshire. Her tenure started in April and will last 3 years.

Buckinghamshire

Our new team member Chrissie Dransfield is now based at the Haleacre Unit on the Amersham Hospital site.

CONTACT

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Staff Profile

Lesley Catterall
Research Nurse



Lesley has lived in Milton Keynes since she was 11 years old. She qualified as a nurse 25 years ago and has been working in neurology for 9 years. She currently works at Milton Keynes General Hospital and has

been a DeNDROn research nurse for the past two years.

How would your friends describe you?

"Hmm...I reckon they'd say I laugh a lot and am sometimes even a tad loud! I'm very sociable and don't like being on my own. They'd probably say I was good fun (I hope!), sometimes over-sensitive and a good cook."

How did you get involved in DeNDROn?

"I heard about DeNDROn through a colleague. I was working 3 days a week at the time and DeNDROn were offering a really exciting research nurse post for 2 days/week. It was another case of the right place at the right time!"

How is being a research nurse different to being a nurse in clinic?

"In some ways, not that different. Having good patient skills and knowing how to develop a good rapport is obviously important and transferable across the two. My biggest challenge as a research nurse was getting to grips with computers and the extra admin involved! The research team in MK have always been very supportive and we get on very well, amidst the long and deep conversations and occasional banter!"

What would you say is your greatest achievement?

"My 2 children, Jamie (19) and Jemma (17)! My second

greatest achievement must be MKPD (the Milton Keynes Parkinson's Disease study). It's my "baby" and I'm very proud of it! It all felt out of my comfort zone initially but ended up loving the contact with patients and recruited over 250 participants!"

Which research project are you next working on?

"Well, MKPD has been extended for a further 5 years. I'll be able to see the participants again which I'm very happy about (as well as meeting new patients of course!...). Also, MUSTARDD-PD should be starting next year. This is a new project involving memory assessments, which I'm really looking forward to."

Thames Valley DeNDRoN welcomes new members of staff to their team!

- Michelle Thomas joined our team in May on a 6-month secondment from Oxfordshire and Buckinghamshire Mental Health Trust. Michelle will be helping to run the CONCERT study of Dimebon for Alzheimer's disease.
- Clare Williams joined us in July as Senior Research Nurse. Clare will work predominantly on neurology studies and will be primarily based in Oxford.
- Chrissie Dransfield started working with us in September as a research nurse covering Buckinghamshire. Chrissie will be mainly based at the Haleacre Unit.
- We also welcome two new Assistant Research Psychologists. Nathan Collicot and Malika Pavey will be primarily working on the MAIN-AD study in the first instance, and will be based at the Warneford Hospital, Oxford.
- Jayne Wright is also working with us 1 day a week from September. Jayne will be carrying out patient assessments across a number of our studies.

USEFUL LINKS

www.dendron.org.uk
www.ukcrn.org.uk
www.ukcrc.org
www.nihr.ac.uk
www.myresearchproject.org.uk

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

www.mndoxfordshire.org

DOMINO-AD update

Top recruiting site! Half-way there!

Thanks to our colleagues' on-going referrals, we've now recruited 31 participants across Thames Valley for this study of people with moderate-severe Alzheimer's disease living at home and taking 10mg donepezil (also known as Aricept). This means we are now the top recruiting site in the UK! We have also reached over half our total target. Many thanks and congratulations to all for this fantastic achievement! Let's keep up the good work!

The results of the DOMINO study will hopefully provide clear guidelines as to what should be prescribed to people with Alzheimer's disease once they reach a more severe point in their condition. For more information, please call Claire Merritt on (01865) 231556 or 07825 356510, or email claire.merritt@nhs.net

BDR (Brains for Dementia Research) – new study

Congratulations to our colleague Caroline Cox and the BDR team. After just 6 months, a total of 84 participants have already been successfully enrolled into this project involving brain donation after death and assessments every 1-2 years (more info in next issue). What a start!

LICALS

Congratulations to Wendy Barrett, Clare Williams and team, who recruited 5 participants to this MND study in a single day! Phew! This is definitely a new record for us!

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.

And finally...

HD awareness week 2009: Gill and Olivier go gliding

Back in June, Gill Siuda and Olivier Bazin ventured up to Sherington Gliding Centre (Banbury, Oxon) for Huntington's disease awareness week 2009. Having only ever sat in large commercial airplanes, this was a new experience for both DeNDRoN team members. Despite a rainy forecast and the dark shadow of grey clouds, conditions remained dry and the afternoon was a total success. Gill even went one step further, doing a full-blown loop with pilot and Chair of the HD Association Oxfordshire branch Mike Cuming. Many thanks to Mike & co. for organising such a fun day out!



Team Brief



Olivier and Mary before lift-off

In the next issue: MUSTARDD-PD, Brains for Dementia Research and more Dimebon studies!