

New Huntington's disease drug shows positive effects

DeNDRoN's first industry study of a new drug for Huntington's disease (HD) has reported positive results. The participants found they could control their movements better, and had fewer of the involuntary writhing movements that characterise HD. The treatment was not associated with worsening of other signs or symptoms and did not compromise patient safety.

The drug, Huntexil (pridopidine), is the first in a new class of agents

that stabilise the dopamine system in the brain (which plays a central role in the control of motor and mental functions).

Over 400 patients took part in the trial internationally. This made it one of the largest studies so far conducted in HD in Europe. Recruitment was completed within 1 year. The company that developed the drug (NeuroSearch) is putting forward plans with scientific advisors and regulatory agencies for Huntexil as a novel treatment for HD.

Principal Investigator, Dr Andrea Nemeth, Oxford Radcliffe Hospitals NHS Trust and Oxford University, commented:

"This is an exciting development in the symptomatic treatment of HD and we are very grateful that our patients have so generously participated in the study. We are very fortunate to have DeNDRoN support for running clinical trials which we hope will lead to further progress in treating HD".

Participants who completed the initial 6 months' study (where half of participants were on the drug, the other half on a placebo or dummy pill), were then offered to continue open-label treatment (where all participants take the active drug) for a further 6 months. Close to 90% of the initial participants chose to continue treatment.

Results from this open-label extension study are expected later this year.

£5 million Parkinson's disease project lifting off in Thames Valley



In October last year, Thames Valley researchers were awarded a £5 million grant to study how Parkinson's disease (PD) develops and progresses. This £5 million Monument Discovery Award was funded by the Monument Trust, one of the Sainsbury Family Trusts, and awarded by Parkinson's UK. The Oxford Parkinson's Disease Consortium, led by Dr Richard Wade-Martins, was selected from a shortlist of seven UK research teams by an international review panel. Reacting to this success at the time, Dr Wade-Martins

of the Department of Physiology, Anatomy and Genetics at the University of Oxford, said: "We are absolutely thrilled to have been chosen as the Monument Discovery Award winners. Our team of 13 include world-class scientists from the University of Oxford and two Medical Research Council Units working across a number of different disciplines, including genetics, neurology and imaging."

The researchers are looking at three key areas to:

- Identify specific molecules in cells and use brain imaging techniques to predict whether a person will get PD
- Identify and study alterations in new genes which may be responsible for the development of PD

- Create new animal models with the symptoms of PD to aid the development of new drugs and treatments

"We will undertake a new study to better understand the very earliest steps in developing Parkinson's Disease with the eventual aim of generating drugs to halt the disease before symptoms appear," said Dr Wade-Martins.

"We will be able to take full advantage of the ongoing revolution in human genetics and recent advances in stem cell technology to uncover the genes underlying risk to Parkinson's. We have access to sophisticated analytical and clinical testing facilities, including one of the most powerful magnetic resonance imaging (MRI) magnets in the country here at Oxford."

The clinical part of the study (parts a & b in the above list) is being coordinated by Dr Michele Hu and Dr Kevin Talbot in the Department of Clinical Neurology at the John Radcliffe Hospital, Oxford. Thames Valley DeNDRoN will be helping the clinical research team to recruit 1,700 people with early stage PD, 300 relatives who may be at-risk for the disease, and 300 people without PD of similar ages from Northamptonshire, Berkshire, Oxfordshire, Buckinghamshire and Milton Keynes.

If you're interested in taking part, visit: <http://opdc.medsci.ox.ac.uk/patient-involvement> or call Sally Beauchamp on 01865 231846.

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.

Alzheimer's – A Clinical Research Study (Abbott)

Feature study

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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 07825 356510, or email claire.merritt@nhs.net

This study is running in Northamptonshire, Oxfordshire & Buckinghamshire.

Clinical and Genetic Investigation of Cerebellar Ataxia

'Ataxia' means 'lack of order'. People with ataxia have problems with movement, balance, and speech. Over 10,000 people in the UK have a form of ataxia. This study aims to develop new genetic tests for ataxias, and improve our understanding of genetic causes of ataxia to help find better treatments.

A research team at the John Radcliffe Hospital, Oxford, is looking to involve participants with a likely genetic cause, and onset before age 50. A 'likely genetic cause' may be ascertained if other relatives are affected or the type of ataxia is similar to those that are known to be inherited. Unfortunately, this project is not suitable for people with a confirmed diagnosis of Friedreich's ataxia. Visits for this study will take place in Oxford. For more information please contact Angie Weir on 01865 231543 (please leave a message on the answerphone with your contact details if Angie is unavailable).

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

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 to date has been very successful. For more information call Val Russell on (01865) 234372 or [email val.russell@orh.nhs.uk](mailto:email.val.russell@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 ***

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

The DeNDROn Northampton Team has moved! Gayle Borley and Sandy Hudson (research nurses), Zoe Hutcheson (Northants hub administrator) and Fabia McCoy (assistant research psychologist) are now based in Research & Development at Berrywood Hospital, Berrywood Drive, Duston NN5 6UD.

Buckinghamshire

Joanne Cross will be joining our team from mid-August, based at the Haleacre Unit (Amersham) and working within memory clinic settings. Joanna Glennon (research nurse) will be working in High Wycombe on the Parkinson's Disease Discovery study.

Oxfordshire

Sarah Murphy (research nurse), Stephanie Robinson (study administrator) and Catherine Whatley (research nurse) have recently joined our team. Joanna Glennon will also be helping with the Study of Chorea in HD.

Berkshire

Siobhan Gardiner, Lynn Rigby (research nurses) and Jack Ayre (assistant research psychologist) are now all based at Fitzwilliam House in Bracknell, Berkshire.

Research study of Mild Cognitive Impairment (MCI) now running in Berks

People with MCI have more memory problems than normal for people of their age, but their symptoms are not as bad as people with Alzheimer's Disease. Heatherwood Hospital (Ascot) is seeking volunteers to take part in a study which is trying to find better ways to predict which people with MCI may or may not develop Alzheimer's disease. To take part, volunteers of 55 years or older must have consulted their doctor about their memory difficulties but not given a diagnosis of dementia, and be willing to take part for at least three years. If you or someone you care for might be eligible, and would like to help, contact: Lynn Rigby on 07554 436726 or email lynn.rigby@nhs.net

CONTACT

For general enquiries, please contact our head office

Thames Valley DeNDROn

Room 4401D, Level 4
John Radcliffe Hospital
Headington
Oxford OX3 9DU

Tel: (01865) 234310
Fax: (01865) 234609

E: k.lucas@nhs.net
E: helencollins1@nhs.net

Staff Profile

Wendy Barrett Research Nurse



Wendy trained in Liverpool and has worked in the neurology field for over 10 years. She has been with DeNDROn for two years and also had a brief stint in stroke research. Prior to this she worked as a community nurse in East Berkshire with a special interest in neurology.

How would your friends describe you?

"I think they'd say that I'm always baking & singing! I'm a keen opera singer. I like live music and reciting epic poems, too. I love cooking for people and having spontaneous gatherings. On Sundays, I like to cook for the whole week, so I have 4 dinners on the go at the same time! Otherwise, I'm a big fan of night walks and herbal teas."

How did you get involved in DeNDROn?

"I saw the advert and knew it was just the job for me – a natural progression. I wanted to get back into

Neurology which I've loved all my professional life. I was also attracted by the idea of helping to bring new understanding and hope through research in a very complex area."

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

"The variety of skills that you need, the variety of circumstances you encounter, and the variety of opportunities for your professional development."

What are you looking forward to this year?

"It will be the 1st anniversary of many of my patients in

the LiCALS (MND) study. I always tell study participants when it's been 1 year since the first visit (no cake though, unfortunately). Retaining study participants is just as important as involving them in the first place. We're all on a journey together along the research pathway. Their commitment to the study in the face of their deteriorating condition is truly inspiring."

How do you like to spend your holidays?

"No time constraints, just free-wheeling, really. I try not to have any routine, any plan. Just being in the moment. All to regain a sense of perspective!"

Study updates

LiCALS

Oxford was the 2nd highest recruiting site in the country for this study of lithium for motor neurone disease, with 25 participants recruited. This achievement was rewarded with a free conference registration for the 21st International Symposium on ALS/MND in Orlando in December 2010 (courtesy of the MND Association). After all her great work on this trial, Wendy Barrett has duly accepted and will be venturing across the pond to enjoy her prize!

CONCERT

Thames Valley DeNDROn is currently the 3rd highest national recruiter to this study of Dimebon, a possible new treatment for Alzheimer's disease. We are inviting participants with mild-moderate Alzheimer's, living at home, who have been taking Aricept (donepezil) for at least 5 months and a stable dose of 10mg 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. For information please contact Claire Merritt on (01865) 231556 or email claire.merritt@nhs.net

Thank you Clare Williams!

The team says a fond farewell to Clare Williams, who managed and championed our rapidly expanding neurology studies portfolio, and will be missed by all.

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 is available to download and view online at:

www.mndoxfordshire.org

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.

BDR (Brains for Dementia Research)



We'd like to thank all of our clinical colleagues for helping to satisfy this demand by offering patients and carers the opportunity to take part.

The team is also very appreciative of the commitment to help research into dementias made by potential donors and their carers.

Congratulations to our colleague Caroline Cox & the BDR team. After just over 1 year, 200 participants have been enrolled across the Thames Valley (700 in UK) into this project involving brain donation after death and assessments every 1-2 years.

This truly reflects a striking public demand to take part in this important study.



BRAINS FOR DEMENTIA RESEARCH

Increasing knowledge - Finding a cure



Use your brain to help untangle dementia

Brain tissue from regularly assessed individuals provides the very best resource for scientists working to understand dementia. If you would like to consider donating your brain after death to help develop future treatments for dementia please visit

www.brainsfordementiaresearch.org.uk

Alternatively call Caroline Cox on (01865) 234309 or 07554 436723 or email carolinecox2@nhs.net

In the next issue: Parkinson's Disease Discovery study, new Alzheimer's drug study and much more...