

East Anglia DeNDRoN

Autumn 2010 Newsletter

'Research with care'

Welcome to the Autumn 2010 edition of our newsletter, created to keep staff, patients and the public updated on current events taking place within East Anglia DeNDRoN.

"For the times they are a changing"

So said Bob Dylan, and this perpetual truth applies to DeNDRoN today. Having been *Clinical Lead* for the East Anglia LRN since 2006, my title is now changing to *Director*. Essentially this means that I will be more focussed on strategic issues such as the further development of the network and ensuring that participating local NHS Trusts are more closely involved in supporting and facilitating the work of the LRN.

The "clinical" part of my previous role is now going to be taken on and further developed by the appointment of Research Directors in each of the 4 DeNDRoN disease areas (Huntington's Disease, Parkinson's Disease, Motor Neuron Disease and Dementia). We are currently in the process of recruiting people into these posts. These Research Directors will provide local clinical research leadership to the network in their disease area. They will be responsible for overseeing the development and delivery of a balanced portfolio of studies, supporting me in the active management of the network and ensuring the needs of industry are met in their disease area. The aim is to increase the integration of health research and patient care, encourage local clinicians to participate in NIHR portfolio studies and to improve the speed and quality of clinical research in trusts across the network.

Once these appointments have been finalised we will announce their names and we hope to publish short articles to introduce them to the network in future editions of this newsletter.

Other ongoing developments in East Anglia include the recent appointment of Dr Chris Fox to the post of Reader in Old Age Psychiatry at the University of East Anglia and the forthcoming development of a Norfolk Dementia Academy (linked to the construction of a new Dementia Intensive Care Unit on the Julian Hospital site in Norwich) which will focus on research and the training of staff who work in the field of dementia care. DeNDRoN East Anglia has also been working closely with the Cambridge & Peterborough CLAHRC (Collaboration in Leadership in Academic Health Research and Care) on how we can jointly facilitate research in dementia.

I should like to take this opportunity to thank everyone who has supported, participated or assisted in DeNDRoN studies throughout East Anglia. This Local Research Network has developed a strong reputation for bringing research studies to new sites and thereby offering the opportunity for many more people to be involved. Let's keep up the good work!

Dr Andrew Tarbuck
Director, DeNDRoN East Anglia

Debbie takes to the Sky!



Story on next page!

Debbie Takes to the Sky for MND

Debbie Hancock and her sister-in-law, our PPI Panel member Janine Vince, know all too well about the devastating impact that Motor Neurone Disease (MND) has on everyone affected by it. Debbie's family has the familial form of MND, known as FUS1.

As a direct result, Debbie has lost her brother (Janine's husband), along with other family members to the disease. However, despite her devastation, Debbie is determined to raise awareness of MND and earlier this year plucked up the courage to complete a charity sky-dive, raising a total of £1500 for the MND Association, helping them to continue with their research and to offer support to everyone affected by the disease.



Debbie and her family work closely with the specialist medical team at Kings College Hospital, London and, in particular, with Professor Chris Shaw, whose support has proved invaluable.

Well done, Debbie, on completing your amazing sky-dive and for not only managing to raise a significant amount of money but for also continuing to help bring MND to the forefront of health research.

MND Research News

MND is one of 4 diseases covered by the DeNDRoN network, and our research activity in this area looks set to increase.

One new study, supported by a team at Addenbrooke's Hospital, aims to evaluate the safety and tolerability of a new drug that targets a protein known to impair nerve cell regeneration.

Another study, which we hope to support at Ipswich, Norfolk & Norwich and West Suffolk Hospitals, sets out to explore issues around gastrostomy use for patients with MND.

The MNDA DNA bank, was adopted by DeNDRoN in 2007 and is due to close to recruitment in March next year. We have recently had a lull in recruitment to this DNA bank but now are in a position to restart recruitment at Addenbrooke's MNDA Care Centre.

On 31st August the 1st paper using samples from the DNA bank was published in *Lancet Neurology*. The results confirmed that a region of DNA on chromosome 9 plays an important role in both sporadic and familial MND.

If you are affected by MND and wish to express an interest in participating in research please visit the MNDA website www.mndassociation.org.uk

If you are a researcher you may wish to hear more about the new MND 'Patient Record of Interest in Research' www.dendron.org.uk/cr/mnd_raft.html

Public & Patient Involvement (PPI) Panel If you would like to volunteer to join East Anglia DeNDRoN PPI Panel please contact Tom Rhodes — details on page 3.

Study Update

New Alzheimer's Disease Study to be Launched at Three Locations in East Anglia

Starting in the autumn of 2010, GERAS will take place in three locations in the East Anglian region; Great Yarmouth, Ipswich and Ely. GERAS is a new observational study of resource use and cost in Alzheimer's disease at different stages of the disease. The Principal Investigators will be Dr Ian Shaw at Northgate Hospital, Great Yarmouth; Dr Shamin Ruhi at St Clements, Ipswich; and Dr Katrina Young at St Mary's Surgery in Ely. The study will also be looking at how caregiving and health related quality of life progress for patients and for their carers at different stages of Alzheimer's disease.

Great Yarmouth and Ipswich both have members of staff from their Older People's Community Mental Health Teams on secondment with DeNDRoN. Ralph Woodcock, based at Northgate Hospital, has been working with DeNDRoN since January this year and Cathy Forman (Ipswich) and Adrian Jackson (Cambridge) have recently joined DeNDRoN on secondment. Ralph and Cathy have extensive experience working within Older People's Community Mental Health Teams. DeNDRoN East Anglia has recently contributed to an observational study on Alzheimer's disease, the successful DADE project (Dependence on Alzheimer's disease in England).

The St Mary's Surgery in Ely has been identified as a suitable regional primary care site for this study following close collaboration between East Anglia DeNDRoN and the East of England Primary Care Research Network.

For further information about this study, please contact Ralph, Cathy or Adrian:

Norfolk:	Ralph Woodcock	ralph.woodcock@nhs.net	Tel. 01493 337636
Suffolk:	Cathy Forman	cathy.forman@nhs.net	Tel. 01473 329000
Cambridge:	Adrian Jackson	adrian.jackson@nhs.net	Tel. 01223 746174

New studies are being added to the research portfolio all the time. If you would like to join the distribution list for the full portfolio of current East Anglia DeNDRoN studies then please contact Tom Rhodes on 01603 421850 or t.rhodes@nhs.net.

Would you like to come and see what we do?

We are very keen for anyone and everyone to come and enjoy a research visit with us. If you wish to see a visit, or have a one to one conversation with one of our researchers, or just see where we work, we would be delighted to accommodate you.

So, if you are a Student, Nurse, Practice Nurse, Doctor, Therapist, etc please contact Kim Clipsham, Senior Research Nurse on 01603 421882 or k.clipsham@nhs.net.

Contact Us:

For general enquiries or if you wish to be on our distribution list for this Newsletter, please contact:

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DeNDRoN East Anglia VOWNnet Conference 2010

Over 200 delegates from health and social care backgrounds, in addition to carers and service users attended the conference held at the John Innes Research Centre in Norwich.

Display stands with brochures and information from organisations supporting people with Huntington's disease, Motor Neurone disease, Multiple Sclerosis, Parkinson's disease, Progressive Supranuclear Palsy, plus stands with information about DeNDRoN and the Mental Health Research Network, were popular with delegates.

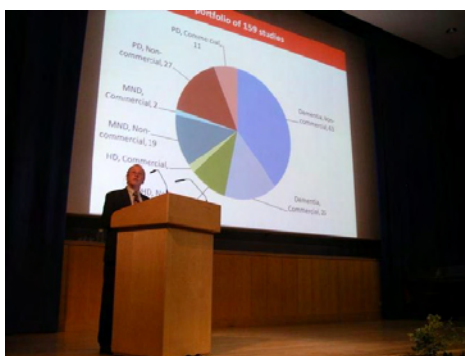
The speakers were informative and their input was well received. Professor Steve Iliffe, Associate Director of DeNDRoN spoke of the DeNDRoN vision that "all patients with a neurodegenerative disease have the opportunity to participate in and benefit from high quality clinical research". Key recommendations for DeNDRoN include the development of a balanced portfolio and further integration between research and clinical care. DeNDRoN has proved to be comparatively successful at opening research sites for recruitment to commercial interventional trials and at recruiting to trials adopted to its portfolio.

Dr. Roger Barker, Consultant Neurologist from Addenbrooke's Hospital, followed with a presentation outlining developments in the treatment of Huntington's disease. After providing valuable background information for those of us with less experience of people with Huntington's disease, the developments taking place were outlined. Huntington's disease can be increasingly better modelled in the lab. New therapies for the treatment of Huntington's are now the subject of increasingly more clinical trials including trials of disease modifying drugs.

Dr. Brian Dickie, Director of Research Development for the MND Association spoke of the advances in creating new disease models in the lab and identifying bio-markers for Motor Neurone Disease. Of the 20 MND studies on the DeNDRoN portfolio 11 are funded or co-funded by the MND Association.

Fiona Matthews, from the MRC Biostatistics Unit in Cambridge, delivered a presentation of the statistical analysis of the prevalence and possible protective and risk factors in Alzheimer's disease. Dr. Matthews stated the importance of population based studies in providing a foundation to inform health, economic and social policy; and to assist in identifying the impact and distribution of the disease, and risk factors that contribute to disease pathogenesis.

The final presentation was by Dr. Kieran Breen, Director of Research Development for Parkinson's UK who presented recent developments in Parkinson's disease research. Brain banks have provided a valuable resource to study the effects of the disease on the brain when compared with a brain of someone who does not have Parkinson's. Dr. Breen also spoke of the importance of bio-markers in the early identification of Parkinson's disease in individuals.



There was also an opportunity for delegates to participate in one of three parallel workshops. Dr. Craig Ritchie presented a workshop outlining the dynamics of setting up a database or registry of people willing to be contacted about participation in research studies as part of a clinical trial. This would serve to facilitate the recruitment of trial participants and also as a feasibility tool in proposed clinical trials. The prototype of DemReg is being developed in the North Thames area and is designed to be a useful source of information for use by clinicians in patient management, as well as for those directly involved in research. This provides a means to connect patients directly with high quality research studies.

A second group heard a 'Dragon's Den' style session where three people working in the field of dementia and neurodegenerative diseases outlined their research proposals. The panel of 'dragons' then questioned and provided input and suggestions to develop the proposals under discussion.

The third group looked at using the observational method Dementia Care Mapping (DCM) in research. The session was a team effort, from speakers Judith Farmer and Mary Aldridge, both Approved DCM Trainers from the trust, Nicola Crook, Clinical Psychologist and Juni West, DeNDRoN Research Nurse and Approved DCM Trainer. It began with an overview of DCM the tool, then delegates had a go at 'speed mapping' two of the DCM trainers 'in role' as characters with dementia. This gave the audience a short experience of what using the tool in practice may offer. An overview of the various ways DCM can be used as an outcome measure in research provided a backdrop for two interesting presentations on studies which have used the tool, investigating the use of Life Story Books and Rummage Boxes as well as Cognitive Stimulation Therapy.

Feedback from the evaluation sheets was overwhelmingly of the opinion that the content of the day had been very informative and that the venue, organisation of the day and the quality of the speakers had been excellent. The excellent catering was also appreciated and unsurprisingly mentioned on many of the forms. As always there are some lessons to be learnt but overall it was a thoroughly informative and enjoyable day.



Carolyn Garrett – Research Nurse
East Anglia DeNDRoN