

South West DeNDroN Newsletter

March 2009

Issue 3

Welcome to the Spring Newsletter from South West DeNDroN. This publication outlines developments over the last six months and plans for the immediate future. If you would like information on any topics not covered here, please get in touch with our office – our contact details are shown on the back page.

Special Points of interest:

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National developments

In December the DeNDroN Coordinating Centre submitted the triennial (2005-2008) review to the National Institute for Health Research (NIHR).

The review was designed to assess the progress and performance of the DeNDroN Coordinating Centre and concentrated on three criteria:

- development of a balanced portfolio of high quality commercial and non-commercial studies
- accrual of study participants
- speed of study cohort to pre-defined timetable.

Following a review meeting in mid-January, the Coordinating Centre has been informed that the funding will be extended for a further five years. This is very good news for everyone involved in DeNDroN work and will allow us to develop our future plans to ensure we meet our key aims.

Local developments



**South West DeNDroN Conference
2008: Networking, Updating and
Influencing the Research Agenda**

South West DeNDroN held its first annual conference in Taunton on 8th December. A wide range of people were invited to the event – clinicians, nurses, academics, patients and carers as well as representatives from a variety of charities.

115 people attended the conference. The displays included seven stands set up by charities and academic posters detailing research work ongoing in the South West. The Network Manager, Dr Joanne Hartland, introduced the day and chaired the first session. Professor Roy Jones, Clinical Lead, introduced the second session on Clinical Trials & Research, and Professor John Zajicek, Deputy Clinical Lead, took charge of the final session on South West DeNDroN and the future.

All presentations can be found at http://www.dendron.org.uk/rn/south_west.html.

We would like to say thank you to all those who made presentations, brought along posters, stands and other materials or contributed in

any way to the success of the day. We received 80 conference evaluation forms. Analysis of these has shown that the vast majority of delegates found the event useful and informative. There was consensus that the event should be run annually, and on that basis we are now planning the 2009 event. If you would like more information about this event, please let us know.



Patient and Public Involvement Events

Focus group

In September 2008 South West DeNDRoN staff held a focus group in Bath for patients, carers and our Patient and Public Involvement representatives. The aim of the group was to discuss DOMINO-AD, which is a study investigating the use of donepezil and memantine in moderate to severe Alzheimer's Disease, and how to improve recruitment to this study. The afternoon was very successful and generated many useful ideas. One of the main

outcomes was that participants highlighted the need to increase patient and carer knowledge of all research in the local area.

As a follow-up event, we held a second focus group on 24th March in Plymouth. This was with local patients and carers and helped us to plan our local research and gather ideas that will improve dementia research in the South West. The group also helped to raise awareness of DeNDRoN and the

opportunities currently available. Carers, ex-carers and patients with mild dementia were all invited to take part in the group. For more information please contact Corinna Chambers or Katie Stocker on 01752 315264, or email corinna.chambers@phnt.swest.nhs.uk A big thank you to everyone who took part in these events.



The Alzheimer's Research Trust (ART)

Bristol & Bath Network Centre held an event on 25th February at the Hilton Hotel in Bath entitled: *Research Into Alzheimer's Disease – A Local Perspective*. A series of short lectures was chaired by Professor Roy Jones. The evening was of interest to the general public and anyone involved with Alzheimer's disease, including patients and their families, carers, care workers and local charities. South West DeNDRoN staff were in attendance and set up an information stand at the event.

South West DeNDRoN CSO Training Event

In February 2009 we had the latest in a series of regular CSO training days at our Bath office. These events allow our CSOs to share ideas, trade successes and discuss local challenges at their Trusts. We also invited Helen Jones (Manager of the Western Comprehensive Local Research Network) to attend and give us an overview of the work of the WCLRN and how it overlaps with the work of South West DeNDRoN.

Staff Changes

Our thanks goes out to Helen Lewis, Nick Pilkington, Lynn Oxborough and Liz Burrows for their hard work over the last couple of years and their contribution to the success of the South West Network. Helen, Nick and Lynn are moving on to new jobs and Liz, on the other hand, is planning her retirement. We wish them all the best of luck in the future.

Living well with dementia: a National Dementia Strategy

The first ever National Dementia Strategy was published by the Department of Health in February 2009. The Strategy is backed by funding of £150 million over the first two years. The aims of the strategy are to increase awareness of dementia, ensure early diagnosis and intervention and radically improve the quality of care that people with the condition receive. Proposals include the introduction of a dementia specialist into every general hospital and care home and plans for mental health teams to assess people with dementia.

Of particular interest for the research community is Objective 16 of the Strategy which asks for a clear picture of research evidence and needs. Evidence is

to be made available on the existing research base on dementia in the UK and the gaps that need to be filled. DeNDRoN is specifically mentioned. The Medical Research Council with the Department of Health will be convening a summit with all relevant stakeholders to discuss how research funders, charities and industry could work more effectively together to begin to deliver the research needed on prevention, causes, cure and care of dementia.

<http://www.dh.gov.uk/en/socialcare/deliveringadultsocialcare/olderpeople/nationaldementiastrategy/index.htm>



A day in the life of a Clinical Studies Officer (CSO)

I joined the South West DeNDRoN team in September 2008 as a CSO. Early on in my research career I realised that low study recruitment was responsible for derailing even the best funded research studies.

Spotlight

Along with other DeNDRoN funded CSOs and Research Nurses throughout the South West, recruitment forms a key part of our role.

I start the day with an 'IT hat' on; promoting studies to new investigators via email or telephone and, designing leaflets/ posters. This work often leads to the setup of a meeting with doctors to establish their research interest and/or setup a new research site. The next part of the day is best tackled with the 'Tourist/ Clinic hat'. One has to embark on scenic drives from Bath to Bristol, or anywhere else between Gloucester and

Truro. I get to meet and talk to clinic staff, patients and carers. I then assist with screening notes, giving information as part of the consent process, taking consent, and carrying out study procedures such as taking blood samples or doing memory tests.

A quick change, and it's back to the office to check emails and follow-up honorary contracts, R&D applications and adverse event reports. So ends another busy day in the life of a CSO.
Kudzai Mugweni.

'Added Value' Investigation

A key aspect of ensuring the network is succeeding is to regularly assess how the Network is perceived by the people involved with it. The 'Added Value' project, carried out in the Autumn of 2008, was designed to find out how those people view South West DeNDRoN, and to use that information to shape our future work plans.

A two-pronged approach to the work was taken: (i) a questionnaire was distributed to a wide range of stakeholders, to gather data about individuals, their involvement with and knowledge of South West DeNDRoN, whether their contact with South West DeNDRoN had been useful or not, which areas of work they had either received help with, and a range of other issues. (ii) More detailed information was collected from specific researchers, using a semi structured interview. The aim was to get an all-round view from a range of clinicians, including established researchers, researchers who are inexperienced in research and have been supported by South West DeNDRoN in recent months, and more established researchers who have not become involved with DeNDRoN.

A full report of the work is available, but, to summarise, the results of the questionnaires showed that South West DeNDRoN supports a wide range of activity, but that patient involvement in study development could be improved. Issues around clinicians' lack of time and lack of funding also emerged. Comments were also made about a lack of knowledge of research governance processes. Beyond this, the results showed that newer researchers were keen and very supportive of DeNDRoN, recognising and accessing the support that the network offers, whereas established researchers did not rely on us as much as they could. It was agreed we can now build this information into our future planning.

Training Update

IRAS System

Peninsula Comprehensive Local Research Network are holding training sessions for the Integrated Research Application System (IRAS) once a month throughout 2009. These aim to introduce researchers to the IRAS system. Forthcoming dates are 9th April at North Devon District Hospital and 24th April in Exeter. Contact Andrena Lynes if you would like to attend

Andrena.Lynes@phnt.swest.nhs.uk

Huntington's Disease

A conference is being held on 24th April 2009 from 10.00 – 4.00 pm at The Thistle Hotel, Exeter. Contact Andrea Clark or Emma Metherell on millaton@barchester.com for a booking form or more information.

The United Kingdom & European Huntington's Disease Network (UKHDN/EHDN) meeting will be held on the morning of Thursday, June 18th 2009 at Austin Court in Birmingham followed by one and a half days of Huntington's Disease clinical research training on the afternoon of Thursday, 18th and all day on Friday, 19th June. The

programme, accommodation and registration details will be issued shortly on <http://www.ukhdn.net/meetings.html>

There are training days being run regularly in Plymouth for professional carers working with Huntington's Disease. The next one is in April 2009. Please contact 01752 434535 for more information.

Dementia

The Journal of Dementia Care will hold a conference on 24th April 2009 at the University of Surrey. For more details visit www.careinfo.org and follow the Journal of Dementia care link.

SW DeNDRoN Studies Update

The following studies are underway in our area:

Disease Area	Study Acronym/name	Site (sites in brackets in setup)
Dementias	DeNDRoN 022 & 023	(Bath)
	DeNDRoN 022 & 023	Swindon
	DeNDRoN 027	Swindon
	DeNDRoN 028	Bath
	DOMINO-AD	Bath & Plymouth
	MAGD	Plymouth
Huntington's Disease	Euro HD Biobank	Exeter, Gloucester, (Bristol)
	Euro HD Registry	Exeter, Gloucester, Plymouth (Bristol)
Motor Neurone Disease	LiCALS	(Plymouth)
	MND Association DNA Bank	Bristol, Plymouth
Parkinson's Disease	DeNDRoN 024	Bristol & Exeter
	DBS of the PPN in PD	Bristol
	PD GEN	Barnstaple, Bristol, Bath, Cheltenham, Exeter, Gloucester, Taunton, Torquay, Yeovil
	PD MED	Barnstaple, Bath, Bristol, Cheltenham, Exeter, Gloucester, Taunton, Torquay, Yeovil
	PRO-DeNDRoN Register	Exeter, Torbay, Plymouth, Launceston, Truro (we have plans to extend this to other sites in the near future)

Recent Successes

- The local DeNDRoN networks across the country have been praised for the support provided for two major Parkinson's Disease studies - PD Med and PD Gen. Professor Carl Clarke from the Birmingham CTU commented on the fantastic contribution made by DeNDRoN Local Research Network managers and staff on the ground who work closely with researchers. He believes that DeNDRoN staff are making a real difference to the delivery of the trials and passed on his thanks for all their support. PD Med was set up in 2001 so Professor Clarke has a good perspective on the impact DeNDRoN staff have had over time. He also commented on the helpful assistance he is receiving from DeNDRoN for the set up of the PD Rehab study.
- The Bristol site at Frenchay Hospital were congratulated on being the first UK site to screen a patient for the DeNDRoN 024 study. They were also complimented on the helpfulness of their prescreening logs. These are used to identify issues in recruitment when patients are being considered for their suitability to enter a study.
- The Long Term Neurological Conditions: Support for Carers study was undertaken in the latter half of 2008. Recruitment at all the South West sites was impressive.

Forthcoming Studies:

PD Rehab: At present there is little available research evidence around the use of occupational therapy and physiotherapy in long-term neurological conditions and without this evidence it is very difficult for service users and professionals to be able to judge what they need, when they need it and what they can expect the outcomes to be. Without research evidence it is also difficult to plan services when little is known about the cost of therapy or the benefits that can be expected. This study, called PD Rehab, will assess both the clinical and the cost effectiveness of occupational therapy and physiotherapy in Parkinson's Disease. Several sites across the South West will be taking part in this study—if you would like to find out more about becoming involved, please contact Dr Joanne Hartland on joanne.hartland@awp.nhs.uk or on 01225 476431.

Professor Carl Clarke will be presenting a discussion on “PD REHAB – what's next” on 30th March at 5.30 at the Lecture Theatre, Postgraduate Education Centre, Exeter. For more information contact Tim Malone on 01392 406462 or T.J.L.Malone@exeter.ac.uk.

LiCALS: Is a randomised placebo-controlled trial of Lithium Carbonate in Amyotrophic Lateral Sclerosis (LiCALS). The Motor Neurone Disease Association has funded this study to determine the explicit benefits and safety of Lithium Carbonate use for Motor Neurone Disease patients. A total of 220 patients will be recruited. Plymouth Hospitals/Peninsula Medical School is one of the 10 UK sites with Prof Oliver Hanemann as Principal Investigator. The SW DeNDRoN team attended the LiCALS investigators' meeting in London on Friday, 13 March 09. The study is now in the set up phase; it will be opened to recruitment later in May 09. For any additional information about LiCALS, please contact: Corinna.chambers@phnt.swest.nhs.uk, Tel: 01752 315240.

MAGD: This study which will evaluate the effects of memantine on agitation in Alzheimer's Disease patients. The study will recruit people who are in hospital or care homes and the aim is to recruit 164 people in the UK. The study site for the South West is Plymouth where Dr Stephen Pearson is the Principal Investigator. For more information please contact Katie Stocker at Katie.stocker@nhs.net or on 01752-315264.

Patient registers: PRO-DeNDRoN Parkinson's Disease Register has been successfully piloted in Devon and Cornwall. The register was designed to list people with Parkinson's Disease who may be interested in taking part in future research – should any suitable studies arise. Due to significant interest in the register the South West DeNDRoN team have decided to extend the register to the rest of the South West area and will be taking this forward over the next few months. For more information please contact: PRO-DeNDRoN Co-ordinating Centre on 0800 015 3430 or email deborah.howcroft@awp.nhs.uk or amy.palmer@phnt.swest.nhs.uk .

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