

South West DeNDRoN Newsletter

Spring 2010

Issue 5

Following the review of DeNDRoN last year, a decision has been made to change the structure of the Local Networks. Instead of a Clinical Lead and Deputy Clinical Lead, each network will have a Director together with 4 Research Directors, one for each of the disease areas (the Dementias, Parkinson's disease, Motor Neurone disease and Huntington's disease). The Director will have a major role in engaging with the NHS Trusts and Trust management and be part of the National Operational Steering Group. The Research Directors will be part of the relevant Clinical Studies Group with major responsibility for developing new research and ensuring that the LRN is recruiting patients and actively involved in studies. The network will be judged largely on how successful its recruitment to research studies has been and our budgets will be dependent on this – it is vital therefore for each centre and each individual within the network to contribute appropriately in order to continue to receive financial support from DeNDRoN.



The current Clinical Leads have been given a choice of becoming the new Director or to move to be one of the Research Directors. After discussion both locally and nationally, I have decided to take on the Research Director role for the Dementias. This means that SW DeNDRoN will be recruiting a new Director in the immediate future followed later by advertisements for the other Research Director posts. Further information about these positions can be obtained from both local and national DeNDRoN offices. The next few years are going to be very challenging for SW DeNDRoN and the NHS Research Networks and we will all have to work very hard if we are to be successful.

Finally I would like to thank everyone who has contributed to SW DeNDRoN so far and supported me in my role as Clinical Lead since we began, particularly my Deputies (John Zajicek and more recently Steve Pearson), Tony Soteriou and AWP, all of the DeNDRoN staff throughout the SW and the members of the SW Steering Committee.

Roy Jones, SW DeNDRoN Clinical Lead

Local developments



South West DeNDRoN Conference 2009:

Taking Research Forward

South West DeNDRoN held its 2nd annual conference in Taunton on 30th November. A wide range of people were invited to the event.

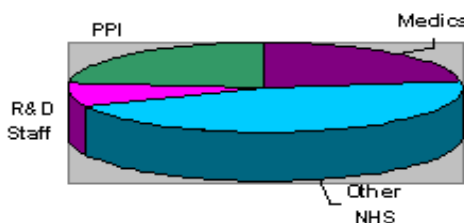
144 people attended the conference. The displays included stands set up by charities and networks and academic posters detailing research work ongoing in the South West.

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

We received 74 conference evaluation forms. Analysis of these has shown that the vast majority of delegates found the event useful and informative.

There was a general consensus that the event had been well organised. It also succeeded in involving patients, carers and professionals.

Breakdown of Audience type for SW DeNDRoN Conference



Comments from respondents included the following:

"The patient and carer perspectives were richly informative"

"This was a really interesting day, thank you very much for organising such a good day"

"I found this programme better targeted than last year and more useful and relevant. Generally an excellent standard of speakers and presenters".

We would like to say thank you to all those who contributed in any way to the success of the day.

Patient and Public Involvement Events

Public involvement in research is central to the National Institute for Health Research (NIHR) strategy. In the South West a scoping study was developed to explore the experiences and practice currently taking place in health and social care research setting within the South West area. 14 stakeholders were involved in the task, including South West DeNDRoN. The study led to 5 possible options for the future collaboration in public involvement. These were further discussed at a 'Public Involvement in Research Event' in April 2010 where it was concluded that a coordinator working across the stakeholders would be the best way to take public involvement in research forward. The funding and responsibilities of this position are currently being negotiated. The report is available to download on <http://hls.uwe.ac.uk/suci/Default.aspx?pageid=9>

South West DeNDRoN Training Event— 19th January 2010

The Clinical Studies Officers (CSOs) and Research Nurses meet every 4 months alternately in Plymouth and Bath to get together to discuss:

- recent study successes and challenges
- share any training events
- to reflect on the way forward with new studies.

The team last met on 19th January in Bath when staff changes, potential new studies, update on our conference in 2009, the workings of the new portal, our latest newsletter and consent issues were all discussed.



The team enjoyed a presentation from Jenny Keylock, a PhD student from Birmingham University who is currently leading a Huntington's disease study entitled 'The familiarity of psychiatric symptoms in Huntington's disease'. This national study is keen to recruit siblings with HD in the family. Any interested parties please find details on the HD Association website <http://www.hda.org.uk/>. For potential recruits please contact Jenny directly at jkeylock@hotmail.com.

Dr Andrea Tales, Research Fellow from BRACE, University of Bristol presented on practical tips for researchers. The next SW team meeting is in May in Plymouth.

Staff Changes

We would like to say goodbye and good luck to Erica Marriage, who has now left SW DeNDRoN as Network Manager. Erica plans to dedicate her time to looking after her young daughter. Debbie Howcroft, currently Senior Research Nurse for the north of the area, has kindly agreed to step in as Acting Network Manager for the next few months.

Goodbye also to Professor John Zajicek who has resigned his post as Deputy Clinical Lead for SW DeNDRoN. Dr Stephen Pearson, Consultant in Older Age Psychiatry with Devon Partnership NHS Trust, continues to cover in this role. Welcome to:

- Alison Harding, CSO/Research Nurse, who has taken up the post in Gloucester Hospitals NHS Foundation Trust.
- Alison Potter, a PenCLRN nurse currently working with Royal Devon & Exeter NHS Foundation Trust, is covering the SW DeNDRoN post in Exeter.
- Leanne Walker, newly appointed Assistant Psychologist based in Plymouth, from 29th March 2010.
- Julie Frost, newly appointed CSO/Research Nurse based in Truro, who will support the SW DeNDRoN activities in Cornwall from 1st March 2010.

Disease Registers

Motor Neurone Disease: Members of the DeNDRoN MND Clinical Studies Group in collaboration with the Motor Neurone Disease Association (MNDA) have formulated a method of bringing together researchers and volunteer participants. A system has been developed that will allow patients to record their interest in taking part in research. This list allows the MNDA to identify suitable participants and provide them with information about approved researcher's studies.

Patients with a diagnosis of any form of MND are eligible to join this and are asked to provide details which will

aid researchers to carry out a basic review of eligibility. This record will help researchers to recruit people with MND across England, Wales and Northern Ireland.

For researchers to know how to apply: http://www.dendron.org.uk/cr/mnd_raft.html

For patients: http://www.mndassociation.org/research/get_involved_in_research/register_your.html

Parkinson's Disease: The PRO-DeNDRoN Parkinson's disease register is a way of bringing together research in PD (Parkinson's disease), connecting patients and researchers. We are maintaining a patient register in order to offer people the opportunity to participate in research projects and keep them up-to-date with the latest developments. The PRO-DeNDRoN research team is collecting data from people living with Parkinson's disease. This information will allow doctors to contact patients easily when new research is set up in the area which they may wish to participate in.

Since October 2007 the PRO-DeNDRoN PD Register was successfully piloted in Devon and Cornwall. Due to significant interest in the register, the South West DeNDRoN team have extended the register to the rest of the South West. The counties we have extended into so far are: Avon, Somerset, Gloucestershire and Wiltshire. Almost all of these areas are ready to assist in recruitment now. To date, we have 463 patients recruited to the register. If you would like to take part please contact the coordinating office on 01752 342048.

Spotlight—Dr Tony Soteriou, Research & Development Director (AWP)

Dr Tony Soteriou, Director of Research & Development with Avon Wiltshire Mental Health Partnership Trust (AWP)



Our Trust holds the contract with the Department of Health for hosting the South West DeNDRoN, working closely with the core DeNDRoN team, Clinical Lead and the DeNDRoN Coordinating Centre.

As part of this, as Director of R&D, I strongly believe that the Topic support AWP's role in providing HR, Specific Research Networks finance and other systems to enable purpose is in supporting research SW DeNDRoN to function effectively, and development in the including agreeing and holding NHS. AWP also hosts the South service level agreements with many West Mental Health Research Trusts around the South West through Network and I personally am a which DeNDRoN provides staffing member of the Western and financial support. We also Comprehensive Research support the core team, based in Bath, Network's Executive Group, so all with the necessary financial and in all I get a full range of performance information. involvement with research networks across the region.

My own personal involvement goes further. I am a member of the SW DeNDRoN Executive Group which I am always happy for people to contact me directly if there are any issues connected with hosting the DeNDRoN aims and objectives, and a SW DeNDRoN. My email is member of the SW DeNDRoN tony.soteriou@awp.nhs.uk. Board. I very much enjoy my involvement with SW DeNDRoN.

Training Update

The NIHR CRN ran a training day in London in December 2009 on Informed Consent for Vulnerable Adults. Debbie Howcroft and Abi Wright attended. The day covered issues surrounding consent including the Mental Capacity Act. Debbie and Abi talked about the issues raised at the team meeting in January. A summary of information can be found on the portal.

Kudzai Mugweni and Bev Hayward hosted the SW DeNDRoN stand at an MND study day in Newport in September 2009. The day included talks from clinicians and a talk from a carer on her experience of MND. There was a lot of interest in the South West DeNDRoN stand.

Future training events:

- PD Awareness day on 13th July 2010 in Exeter.

For more information contact the Learning and Development Service 01392 405171 or LDS.Heavitree@rdefn.nhs.uk

- WCLRN are running study days—see www.crnc.nihr.ac.uk/index/networks/comprehensive/clrns/western
- The HD Association have an HD training day at Austin Court, Birmingham on Friday, 9th July for beginner raters and individuals new to working with HD. To register email mccorriana@cardiff.ac.uk by 31st May with name, job title, LRN and email address.

Conferences:

- The Parkinson's Disease Society are holding a research conference on 1-2 November 2010 in York. www.parkinsons.org.uk

SW DeNDRoN Studies Update— April 2010

The following studies are underway in our area:

Disease Area	Study Acronym/name	Site (sites in brackets in setup)
Dementias	DeNDRoN 022 & 023	Swindon
	DeNDRoN 031	Bath & Swindon
	DeNDRoN 032	Swindon
	DeNDRoN 037	Bath, Gloucester, Plymouth
	DeNDRoN 038	Swindon
	DeNDRoN 041	Bath, Swindon
	DOMINO-AD	Bath & Clevedon
	Semantic Dementia Project	Bath
Huntington's Disease	Euro HD Biobank	Bristol, Exeter, Gloucester, Plymouth
	Euro HD Registry	Barnstaple, Bristol, Exeter, Gloucester, Plymouth
	The familiarity of psychiatric symptoms in HD	Bristol
Motor Neurone Disease	LiCALS	Plymouth
	MND Association DNA Bank	Bristol, Plymouth
Parkinson's Disease	DBS of the PPN in PD	Bristol
	PD GEN	Barnstaple, Bristol, Bath, Cheltenham, Exeter, Gloucester, Taunton, Torquay, Yeovil
	PD Rehab	Exeter, Gloucester, Plymouth, Taunton, (Torquay), Yeovil .
	PRO-DeNDRoN Register	Barnstaple, Bath, Exeter, Gloucester, Plymouth, Taunton, Torquay, Yeovil.

How to get support from DeNDRoN for research

SW DeNDRoN resources can only be used to support studies that have been adopted onto the NIHR portfolio. For a list of all current portfolio studies see <http://public.ukcrn.org.uk/search/>

- SW DeNDRoN can support randomised controlled trials and other well designed studies within the topic areas of Dementia, PD, HD and MND.
- SW DeNDRoN nurses, clinical studies officers & administrators can provide practical assistance with research. They work alongside Clinical teams, screening and recruiting patients and carers to studies, undertaking the consent process, carrying out practical tests and follow up procedures.
- SW DeNDRoN staff can also provide advice and assist with the timely set up and process for ethical and NHS Trust R&D approvals for research studies.

If you would like further information on how to get your study adopted, please contact Debbie or Christine.

Forthcoming Studies:

- **Brains for Dementia Research Project**— Brains for Dementia Research project is a cooperative venture between five centres (based in London, Oxford, Newcastle, Manchester and Cardiff universities) funded jointly by the Alzheimer's Society and Alzheimer's Research Trust. The project will be inviting people diagnosed with a memory impairment (or dementia) to participate in monitoring of memory, thinking and behaviour prior to brain donation. They will also invite those who do not have a memory impairment to take part as normal tissue is essential for comparison.
- **ALS biomarker** - This study will evaluate the expression of neurofilaments and of other relevant molecules in blood samples taken from individuals with amyotrophic lateral sclerosis at different time points during the development of the disease. The aim is to validate easily accessible disease biomarkers functioning as reliable predictors of disease severity and capable of providing information about the stratification of the disease phenotypes.
- **Result study**—Review of Epidemiology and Service Use in Rare Long Term Neurological Conditions (LTNC). People with rarer progressive neurological conditions have complex needs requiring specialist expertise and resources, yet little is known about the incidence, prevalence, course of disease and burden to patients, families, health and social services. The findings will provide the information required to assist service planning and inform the implementation and audit of the National Service Framework for LTNC.
- **The Familiarity of Psychiatric Symptoms in HD**— Jenny Keylock, PhD student who is currently working in Birmingham, is looking at brothers and sisters affected by Huntington's disease, including psychiatric symptoms. This is a national study and she is keen to recruit from sites with sibling pairs and happy to go to people's homes to undertake the 2 hour cognitive assessment with them. Jenny is also keen to interview negative predictive siblings. She has until November for this with possible extension to February 2011. Her study is on the HD Association website <http://www.hda.org.uk/>. Please contact Jenny directly at jkeylock@hotmail.com if you are able to assist with this.

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