



News from the Dementias and Neurodegenerative Diseases Research Network

Welcome from LRN Director Dr Peter Brindle



I have spent my first 6 months in post meeting colleagues around the network and hearing about the activity, the challenges and the opportunities. I have been incredibly impressed with the enthusiasm for research I have found that is grounded in a desire to improve patient care, and in particular the almost universal wish to look at ways of doing more research.

Compared with many in the public sector, medical research is relatively well protected in the current financial climate due to the benefits it brings to society. However there is no escape from the challenge of increasing patient participation in studies but from within a limited budget. To do this, we need to refocus on our core role around supporting the set up and recruitment to studies, while also ensuring we attract a balanced range of study types to the region. More than ever we need to strengthen our relationships with industry and deliver on quality. Supporting local research teams to build their portfolio will ensure a long term flow of studies to the region and close alignment with clinical services will improve efficient access to our population.

I do hope you find this snapshot of SW DeNDRoN activity interesting, and that you enjoy the rest of the summer.

Introductions

Research Network Manager

Mary Griffin

I joined SW DeNDRoN in January 2011 after previously working at the Institute of Psychiatry for 2 years as the Trial Manager for the DOMINO-AD Trial. I originally trained as a Registered General Nurse. I have had several years in clinical trial research before that, working as a Trial Coordinator in Bath and am looking forward to this new challenge.

I would like to take this opportunity to thank Deborah Howcroft, who was the Acting Research Network Manager until January. Without Debbie's help and support, the transition from Trial to Network Manager would have been extremely difficult.

Avon and Wiltshire Mental Health Partnership NHS Trust (Host Trust) Research and Development Director

Dr Julian Walker

I started as AWP R&D Director in February 2011 following Dr Tony Soteriou's departure to take up a 2 year secondment with the Department of Health. I am responsible for overseeing the Trust's research activities, working towards the Trust R&D strategy and ensuring good research governance and financial management. My goals as part of the new R&D strategy are to support high quality, sustainably funded research which positively impacts on patient care. I am particularly keen to foster collaborations between Universities and Trust's to achieve this. Dementia research is a particular priority and I hope to work in this direction with DeNDRoN for the future benefit of patients and carers.

I also work as a Consultant Forensic Clinical Psychologist, at Blackberry Hill Hospital in Bristol. My research interests are closely linked to my clinical interests in personality disorders and violence.

Staff Changes

Since our last newsletter in December 2010, there has been several staff changes in SW DeNDRoN.

We would like to say goodbye and thank you for your hard work to: Kudzai Mugweni who has taken up a post as Research Assistant in London, Katie Stocker who has retired and Sonia Wilding who has moved on to pastures new.

Thank you to: Debbie Howcroft for her hard work as Acting Network Manager. Debbie has returned to her post as Senior Research Nurse for the North of the region.

Welcome to: Kingsley Powell, Clinical Studies Officer in Bristol; Mary-Jo Trimmer, Research Nurse in Plymouth; Kaye Fenton, Research Nurse in Gloucester; Hannah Hewitt, Clinical Research Lead in Somerset Partnership NHS Foundation Trust.

National Network Developments

INTERACT Project

Integrating NeTworks and Embedding ReseArch in Clinical Practice

Projects are the means by which DeNDRoN will introduce change and improvement to the network.

The Ministerial Advisory Group for Dementia Research identified the need to strengthen the links between the research network and the national dementia strategy. They also highlighted the need to create a robust, consistent support network across the country to support initiatives emerging from the group's work, and to deliver the increased volume of dementia research expected as a result of the Government's prioritisation of research in this field.

The National Institute for Health Research (NIHR) has agreed that DeNDRoN should work in partnership with the Comprehensive Clinical Research Network (CCRN) to develop a working model to meet this need. As a result DeNDRoN is leading on: INTERACT. The key outcomes of this project are:

- Leadership & coordination: DeNDRoN local leadership and management that is linked in to local NHS clinical leadership and management; regional leadership and management of implementation of National Dementia Strategy; and national DeNDRoN support networks;
- Integrated research networks: Clear and simple local processes, coordinated between CLRN's and DeNDRoN LRN's for planning and delivering NHS Support infrastructure for DeNDRoN portfolio studies that is linked into national coordination;
- Research embedded in patient care: The capacity, systems and support in place to enable local clinical services to signpost patients to research and allow patients to give prospective consent to be contacted about future research;
- Patient, carer & public involvement: Local arrangements for active patient and public involvement in research that is integrated with local PPI arrangements in NHS trusts and local voluntary groups.

As part of this project, we were asked to produce a 'local research map', in the form of a detailed report identifying the current research, support systems that are already in place to support dementia and neurodegenerative diseases research in the region. This report, undertaken by Judith Headley on our behalf, documents what we are doing well as well as opportunities that we can explore further and changes we may want to make to meet the desired outcomes. The recommendations within the report will help to inform our work plans over the next year. Thank you to all those that contributed to this.

Locally the SW DeNDRoN Steering Committee has been contacted and it was agreed that it would change it's purpose to a Project Board for INTERACT (and any other future DeNDRoN projects).

PRO-DeNDRoN Register

The PRO-DeNDRoN Parkinson's disease register is a way of bringing together research in PD (Parkinson's disease), connecting people 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.

The register has been running from Plymouth since 2007 and following being successfully piloted in Devon and Cornwall, was extended to cover the rest of SW DeNDRoN from Summer 2009 due to significant interest. At the end of April 2011 there were 710 patients that had been recruited to the register. A business case has now been completed for the register to be evaluated against similar models with a view to a final recommendation being made.

Please contact the Coordinating Centre team for more information about the PRO-DeNDRoN Register: PRO-DeNDRoN Coordinating Centre, N13, ITTC building 1, Tamar Science Park, 1 Davy Road, Plymouth, PL6 8BX. Tel: 01752 432048.

Patient and Public Involvement (PPI)

Are you a person with a diagnosis of dementia, Parkinson's disease, Motor Neurone disease or Huntington's disease or are you caring for someone who has? Would you like to be more involved with the work of South West DeNDRoN?

South West DeNDRoN want to support clinical research that is of direct relevance to people affected by these diseases. We would like to involve patients and the public in having a say in how we work and move forward with this objective.

There are a number of ways you can contribute to this process: at a national level you can sit on a Clinical Studies Group and contribute to the adoption process and design of research studies; at a local level you can contribute by sitting on our Regional Project Board or becoming involved with a Focus Group to consider a range of issues relevant to research. You can also help to review research information sheets or be a research study participant.

If you are a patient, carer or a member of the public who would like to be more involved with SW DeNDRoN please contact Vicky Page (please see the Contacts page for details).

Thank You Dr Dileas Sweetenham



Dr Dileas Sweetenham has stepped down from her role of Patient and Public Involvement Representative. Professor Roy Jones, SW DeNDRoN Research Director for dementias had this to say about Dileas' contribution to SW DeNDRoN: "Dileas has been a great advocate for research participation (for herself and others) and support for DeNDRoN both locally and nationally. She has recently retired as Chairman of the Bath Parkinson's Society branch and invited several speakers from DeNDRoN in the South West to address this very active group. She helped in the development of the programme for the SW DeNDRoN conference in Taunton in 2009, and has contributed to PPI both locally and nationally including as a speaker at the first National DeNDRoN conference in London. As a person with PD but also a retired GP, she has been able to offer a very useful perspective for doctors and others about what it is like to have a condition like Parkinson's disease."

SW DeNDRoN would like to thank Dr Dileas Sweetenham for her contribution over the last 4 years and wish her all the best for the future.

SW DeNDRoN Studies Update - August 2011

Disease Area	Study Name	Site (sites in brackets in set up)
Dementia	BDR - Brains for Dementia Research Project	Barnstaple, (Bath), (Exeter), (Cheltenham), Swindon, (Taunton), (Truro), (Yeovil)
	Categorising AD	Bath, Bristol, (Cheltenham), Swindon
	Dendron 022/23	Swindon
	Dendron 031 extension	Bath, Swindon
	Dendron 045	Bath, Gloucester, Plymouth
	FT Connectivity	Bath
	InTouch	Bath
	Semantic Dementia Project	Bath
Huntington's Disease	Euro HD Biobank	Bristol, Exeter, Gloucester, Plymouth
	Euro HD Registry	Barnstaple, Bristol, Exeter, Gloucester, Plymouth, (Swindon)
	Euro HD Registry v3	Barnstaple
Motor Neurone Disease	ALS Marker	Taunton
	LiCALS Extension	Plymouth
	MND Association DNA Bank	Plymouth
	PROGAS MND	Plymouth
Parkinson's Disease	DBS of the PPN in PD	Bristol
	Dendron 059	Exeter, Plymouth
	Molecular Genetic Studies of Neurodegenerative Disorders - PD DNA	Barnstaple, Bath, Bristol, Gloucester, (Swindon), Plymouth, Taunton, Torquay, Truro, (Weston-Super-Mare), Yeovil
	PD Gen	Barnstaple, Bath, Bristol, Cheltenham, Exeter, Gloucester, Plymouth, Taunton, Torquay, (Weston-Super-Mare), Yeovil
	PD Rehab	Barnstaple, Exeter, Gloucester, Plymouth, Taunton, Torquay, Weston-Super-Mare, Yeovil
	PD SAS Scales	Plymouth

Spotlight - George Stothart, Principal Investigator for Categorising AD

We are currently helping with the recruitment for a research study at Bristol University. The study measures and compares visual and auditory pre-attentive and attention related brain function in relation to the ability to lay down new memories in healthy ageing, mild cognitive impairment, vascular dementia, Lewy body dementia and Alzheimer's disease. The aim of this study is to find new tests of abnormal brain function that will ultimately improve the early and differential diagnosis of dementia.

We have worked with George Stothart, the Principal Investigator, to set up new Patient Identification Centres in Bath and Somerset and we are in the process of setting up approvals in Gloucester. We have helped to identify suitable patients and healthy volunteers who have been happy to travel to Bristol University to take part. Participants that agree to take part in the study make a one-off visit to the School of Experimental Psychology where they are asked to complete a range of tasks designed to measure their audiovisual processing.



George said: "Recruiting clinical populations when working in an academic environment can often be one of the most challenging aspects of a research study. The aid and cooperation of SW Dendron and AWP in identifying and approaching potential participants for my research has been invaluable. Patients often seem happier to be approached by someone they have already met during their involvement with a memory clinic, rather than an unknown researcher, and this without doubt aids recruitment."

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 Howcroft or Christine Cosby (please see the Contacts page for details).

Forthcoming Studies:

- **CHDI CAB HD** - Cognitive Assessment Battery study to identify a 60 minute cognitive test set for future use in clinical trials that detects reasoning shortfalls in early Huntington's disease and established Huntington's disease compared to those with no Huntington's disease in their family.
- **DeNDRoN 032 Extension** - Continued efficacy and safety monitoring of a study drug in patients with Alzheimer's disease. This is currently in set up in Swindon.
- **DeNDRoN 037 Extension** - Continued study of dependence in Alzheimer's disease in England (DADE): A cross-sectional study of the impact of patient dependence on others on costs and caregiver burden in Alzheimer's disease in England. This is in set up in Bath and Gloucester.
- **DeNDRoN 060** - Study to evaluate the efficacy and safety of a study drug in patients with mild to moderate Alzheimer's disease. This study is currently in set up in Bath and Swindon.
- **DeNDRoN 066** - Study to evaluate the efficacy and safety of a study drug in patients with mild to moderate Alzheimer's disease. This study is currently in set up in Swindon and Bath.
- **Mustardd** - Multi centre study of the Acetylcholinesterase inhibitor Donepezil in early dementia associated with Parkinson's disease. This study is in set up in Bath, Bristol and Gloucester.
- **PROBAND** - Prospective observational multicentre study of first degree relatives of patients with recent onset or young (under 50 years) onset PD, comparing relatives of gene test positive patients, with relatives of gene test negative patients.

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