

# North Thames DeNDRoN Newsletter

Issue 4 • Spring 2010

## A Note from our Clinical Lead

As a researcher, why should you be involved with DeNDRoN? That question has occurred to me many times and been put to me by hard pressed clinical scientists that could do without another meeting with no clear reward.

My view is this: if we truly want the research community to thrive in this country in spite of the financial threats that hang over us, we need to club together. We need to show that what we do positively affects the average Joe. We finally have the national recognition that neurodegenerative diseases are an important area and by forming a network we can be that much more powerful a voice.

DeNDRoN can make a difference. We have the expertise to set up new research sites, to help find patients for studies that are struggling and to unblock gaps where there are difficulties. But we cannot do any of these things without the engagement of researchers in North Thames. We need you to tell us what the difficulties are in conducting research in the NHS environment. We need you to think about whether your next patient might want to go into a study on the pathway; where the direction of research in the area should go; how we might improve things.

There has been much change recently at North Thames DeNDRoN. We are joined by several new faces, some of which introduce themselves in this newsletter. Change is national as well as local: there will be significant restructuring to ensure more clarity and responsibility in disease areas and more communication between regional networks to spread knowledge of best practice in clinical research. What has not changed is our vision to give every patient the opportunity to take part in research and to make sure that excellent clinical research goes hand in hand with optimising clinical practice.

North Thames DeNDRoN as a network includes three world class neuroscience institutions. We can build on that to become an innovative, world beating group if we combine our resources: DeNDRoN can help facilitate that.

There are significant challenges ahead, not least uncertainties over what happens after the election. However, if we work together we can improve research for patients, clinicians and researchers alike by increasing collaboration, increasing access to research, improving clinical practice and future proofing ourselves by becoming a part of the NHS fabric.



Dr Cath Mummy  
Clinical Lead NTDeNDRoN

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# How do I know what studies my patients have access to?

Remember that we have produced leaflets showing Patient Pathways into Research for each of our disease areas. These provide you with a quick and easy overview of the studies we have on the portfolio and details of how to refer patients to them. We hope that you received these with the newsletter, but please contact us if you want more!



For information about the 12 studies currently recruiting in **Dementia**, please contact:  
Jose Trevino  
[jose.trevino@candi.nhs.uk](mailto:jose.trevino@candi.nhs.uk)  
020 3317 4750



For information about the 4 studies currently recruiting in **Parkinson's disease**, please contact:  
Gita Sharma  
[gitanjali.sharma@candi.nhs.uk](mailto:gitanjali.sharma@candi.nhs.uk)  
020 3317 4750



For information about the 3 studies currently recruiting in **Huntington's Disease**, please contact:  
Aakta Patel  
[apatel@ion.ucl.ac.uk](mailto:apatel@ion.ucl.ac.uk)  
020 7905 2993



For information about the 3 studies currently recruiting in **Motor Neurone Disease**, please contact:  
Nicola Maycock  
[nicola.maycock@candi.nhs.uk](mailto:nicola.maycock@candi.nhs.uk)  
020 3317 4755

## Free Training for Staff

Don't forget – if you are involved with a trial that is on the DeNDRoN portfolio, you can access NIHR CRN training free of charge!

Go to:

[http://www.ukcrn.org.uk/index/  
training.html](http://www.ukcrn.org.uk/index/training.html)

for more information on courses available  
and how to sign up.

If you would like to join our mailing list, have any queries or feedback, have a study that you think should be on our portfolio, or if you have something that you want us to inform others in the network about, please get in contact!

**North Thames DeNDRoN, Camden Mews Day Hospital,  
Camden & Islington Foundation Trust, 5 Camden Mews, NW1 9DB  
or email: [ntdendron.admin@candi.nhs.uk](mailto:ntdendron.admin@candi.nhs.uk)**

# NT DeNDRoN HQ

Network Manager Tania Burke will be on maternity leave from May 2010 and during this period Dr Gillian Murphy will be the acting Network Manager. The team would like congratulate Tania on the new addition to her family and we look forward to her return at the end of the year. Gillian has previously worked for the Medical Research Council and at the Thames Stroke Research Network, she is eager bring this wealth of experience to North Thames DeNDRoN.

We are also saying goodbye to Lisa Curry, our Deputy Manager of 2 years. During her time at North Thames DeNDRoN Lisa worked extensively on developing our patient registries, in particular DemReg. She will continue this work in her new role as Research Coordination Team Manager (at Imperial College / WLMHT) focusing on the development of DemReg on a national level. The team would like to wish Lisa the best of luck in her new role.

We would also like to welcome a few new additions to our team. Ruth Hudson will be our new Deputy Manager commencing May 2010 and Jonathan Anderson, Clinical Research Officer will be in post from April 2010. Jonathan will be supporting research across the Dementia and Ataxia portfolio. New Network Administrator Mala Thakore is another valuable addition to the team. Mala will working alongside Francesca Opaleye, based at our Camden office.



**Gillian  
Murphy**



**Ruth  
Hudson**



**Jonathan  
Anderson**

## NT DeNDRoN Team

<b>Senior Management Group</b>	Clinical Lead		Dr Cath Mummery
	Research Network Manager		Tania Burke
	(Maternity cover)		Gillian Murphy
	Deputy Manager		Ruth Hudson
	Advisor	Neurology	Dr Cath Mummery
	Advisor	Psychiatry, C&I	Prof Gill Livingston
	Advisor	Parkinson's Disease	Dr Sophie Molloy
<b>Research Staff</b>	Clinical Research Officers	Dementia and Ataxia	Jonathan Anderson
		Dementia	Alex Holborow
		Dementia	Jose Trevino
		Motor Neurone Disease	Nicola Maycock
		Parkinson's Disease	Gita Sharma
	HD Researcher	Huntington's Disease	Aakta Patel
<b>Administration</b>	Network Administrator/PA		Francesca Opaleye
			Mala Thakore



# EVIDEM-EoL:

## Changing practice for people with memory problems in care homes; developing and testing evidence-based interventions

### **EVIDEM** towards the end-of-life

by Professor Claire Goodman &  
Natasha Baron, on behalf of the Evidem Team

There are approximately 560,000 people living with dementia in the UK, of whom an estimated 244,000 are resident in care homes; furthermore these figures are set to rise.<sup>1</sup> The difficulties surrounding recognition of when people with dementia are approaching end-of-life are well documented and this can lead to sub-optimal end-of-life care, unnecessary interventions and unplanned hospital admissions.<sup>2,3</sup>

Evidem End-of-Life study is a four year study that is part of the wider NIHR funded Evidem Programme ([www.evidem.org.uk](http://www.evidem.org.uk)). It aims to understand the need for support and end-of-life care of older people with dementia living in care homes. Phase one tracked over two years the experiences of 133 older people with dementia across six Hertfordshire care homes. Using 4-monthly case note reviews, and interview data, we collected information about the experiences and health of participants and services they received.

Recruitment to the study was resource intensive. Firstly, to introduce the study and address concerns about research focusing on this sensitive area, multiple meetings with care home managers, staff, residents and relatives were held. Secondly, in collaboration with the care home staff, we identified people with dementia who had capacity to consent to an interview and their notes being reviewed. Thirdly, for those people who lacked the capacity to consent, we consulted their relatives/consultees asking if they thought that, if their relative could make the decision themselves, participation in the study would have been something they would have chosen. Funding from North Thames DeNDRoN enabled employment, for seven months, of an additional researcher. With this support we achieved a response rate of 62.1%, higher than that reported elsewhere.<sup>4</sup> The funding allowed data collection to continue according to the protocol during phase one.

Preliminary findings show that this population has a range of complex needs, with few opportunities for discussion with NHS and care home staff surrounding choices and planning care for end-of-life. People with dementia experience similar problems and care needs, but their pathways to death vary, and are influenced by the culture/context of the care home, how dying is recognised by NHS and care home staff, and the availability of particular health services. Phase two, from June 2010, will use this data, and existing palliative care frameworks, to develop and test a dementia-specific intervention to support care home and primary care staff to work together to provide dementia-sensitive palliative care.

#### References

<sup>1</sup> Commission for Social Care Inspection. (2008). *See me, not just the dementia: Understanding people's experiences of living in a care home*. London: Commission for Social Care Inspection

<sup>2</sup> Mitchell, SL, Kiely, DK, Hamel, MB. (2004). Dying with advanced dementia in the nursing home. *Arch Intern Med*, 164: 321–326.

<sup>3</sup> Goodman, C., Evans, C., Wilcock, J., Froggatt, K., Drennan, V., Sampson, E., Blanchard, B., Bissett, M. and Iliffe, S. (2009) End of life care for community dwelling older people with dementia: an integrated review *International Journal of Geriatric Psychiatry published online 17.08.09* DOI: 10.1002/gps.2343US: <http://dx.doi.org/10.1002/gps.2343>

<sup>4</sup> Zermansky, A.G., Allred, D.P., Petty, D.R., Raynor, D.K. (2007). Striving to recruit: the difficulties of conducting clinical research on elderly care home residents. *Journal of the Royal Society of Medicine*. 100: 258-261.

**For more information please contact,  
Professor Claire Goodman; [c.goodman@herts.ac.uk](mailto:c.goodman@herts.ac.uk)  
Natasha Baron; [n.i.1.baron@herts.ac.uk](mailto:n.i.1.baron@herts.ac.uk)**

# PREDICT-HD

by Aakta Patel

PREDICT-HD (Neurobiological Predictors of Huntington's Disease) is a worldwide longitudinal observational study of predictors of HD onset in presymptomatic mutation carriers. Conducted by the Huntington Study Group (HSG) and funded by the U.S. National Institutes of Health (NIH), PREDICT-HD has so far recruited over 1000 participants worldwide since 2002 and though initially planned for seven years, a second version of the study has recently been launched with extension until 2013.

PREDICT is currently conducted at 21 North American sites, 4 centres in Australia and 7 in Europe. Of the 5UK sites (Cardiff, Aberdeen, Manchester, Cambridge & London), the latter is based at the Royal Free Hospital / National Hospital for Neurology & Neurosurgery. The London site is one of 7 HD studies on the North Thames DeNDRoN portfolio with 22 gene-positive subjects and 4 controls enrolled in the study. All subjects undergo various clinical assessments and an MRI scan annually, and retention at the London site has been excellent.

The overall aim of PREDICT is to examine the earliest signs of HD so emerging treatments to slow disease progression or delay disease onset can be initiated at the optimal time-point. To date, the PREDICT-HD Investigators have identified over a dozen markers of very early HD, which will help clinicians and researchers to track disease progression in patients enrolled in future clinical trials.

## Recruiting patients for Dementia Clinical Trials: Ethnic Obstacles and solutions

by Jose Trevino

The number of studies adopted onto the NT DeNDRoN portfolio is growing steadily. Currently, our Dementia portfolio has a substantial number of high profile research projects comprised of 80% non commercial and 20% commercial clinical trials. This February, the GE Healthcare-GE-067-005/amyloid PET imaging in mild cognitive impairment study, led by Dr Richard Perry, was opened at Charing Cross Hospital. In March, the DOMINO AD study closed to recruitment.

The last auditing report on study progress from the DeNDRoN Coordinating Centre (January 2010) has shown that a number of studies from our portfolio are having difficulties achieving their accrual targets within their agreed timescales. The studies scoring red remind us once again of the challenges that recruiters often face to achieve their objectives within their deadlines.

In my experience some of these problems appear to be linked to ethnic factors. In multicultural societies such as the UK, recruiters often have to face cultural differences when approaching other ethnic groups and there can be major obstacles for recruiting and retaining participants in clinical trials, especially in Dementia trials. There are multiple factors which can have an adverse effect on the recruitment process including poor knowledge about the condition being studied, distrust of the research process itself and the researchers, cultural and religious beliefs, moral prejudices, socioeconomic constraints, language barriers and perceptions about help-seeking behaviour.

Researchers need to have the right knowledge, skills and appropriate resources to effectively approach these ethnic groups in order to build positive strong and lasting relationships with them. The strategies used to approach potential participants from these communities should equally address their social environment (friends, relatives and carers).

Successful strategies might be achieved by researchers that are prepared to invest additional resource in educating ethnic minorities' organisational leaders - despite that these efforts might not produce immediate results. The use of user-friendly information leaflets in health centres translated into different languages in conjunction with bilingual, bicultural recruiters that are sensitive to cultural norms are crucial tools. I really believe that by just incorporating these few ingredients recruiters can have a substantial positive impact in the recruitment process when approaching potential participants from these ethnic communities.



# Characterisation of a panel of disease biomarkers in peripheral blood from individuals with Motor Neurone Disease

by Nicola Maycock

The Biomarkers study has been successfully recruiting at Basildon University Hospital and Barts and the London for the past 6 months and we are keen to continue to recruit to this study in order to reach the target of 130 patients. Dr Malaspina has done a fantastic job of recruiting 58 patients to date. The National Hospital for Neurology and Neurosurgery is now up and running and eager to recruit as many patients as possible.

The aim of this study is to identify changes in the blood concentration of specific molecules that we think are associated with the progression of MND. To do this, we need to compare the blood from people with MND (index cases) with the blood from people who do not have MND (control cases). Control individuals should ideally share the same environment as the patients group and be of a similar age.

Patients will be asked a series of questions and a full neurological examination will be conducted. Questions will relate to present neuromuscular symptoms but there also will be questions about any previous illnesses or medical problems. We will also review medical records to obtain information that may be relevant to the development of the study. At the end of the interview, a blood sample of 30 ml (2 tablespoons) will be obtained and we will then ask for a blood sample every three months as part of the follow-up visits.

Basic requirements to the study are:

- Diagnosis of definite or probable ALS according to the El Escorial Criteria (Appendix 2: Ross et al. 2001)
- > 16 of age

With regards to the exclusion criteria:

- ALS/MND patients unable to consent

Control groups will include:

- Patients with a diagnosis of acute and chronic compressive radiculopathy
- Healthy sex and aged-matched individuals

**For more information please contact :**

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# Getting Involved as a Carer

by Jaleh Van Wagner

DeNDRoN like all forward-thinking government and privately funded research groups wisely seeks the input of the public – the users – when forming its strategies and initiating the programmes it considers essential to support. As a volunteer lay member on DeNDRoN's steering committee, and a participant in several of its information-gathering programmes, I have been impressed and heartened by the quality and scope of its outreach. DeNDRoN is dedicated to seeking broad based comprehensive, practical, relevant, high quality input in order to shape, inform and endorse its future strategies.

For example, I recently attended a forum in which the availability and need for assistive technology was explored. Participants, all former or current carers, practicing service providers and professional researchers, discussed the usefulness of various available devices. The forum also voiced "wish lists" for practical, yet unmanufactured, devices that would assist the functional independence and quality of life of the user/patient and/or provide practical aids for the family/carers/service provider. Surely a win-win situation for all!

DeNDRoN is worth supporting. It relies on patient/public input. Contributing to its work provides essential support to excellent research in a field of vital importance to us all. Essentially as lay people, we are, in fact, the ones with first hand, hard-won specialist experience and knowledge of the diseases which have attacked those we love and care for. It is precisely this kind of insight which is so desperately needed and sought by excellent research organisations such as DeNDRoN.

# No Working Group for PD?... Time for a change

by Gita Sharma

You may recall within the January edition of the North Thames DeNDRoN newsletter, there was some information available on Working Groups for some of the other disease topic areas (Dementia and MND) but no information about a Working Group for PD. At NT DeNDRoN we are in the process of trying to set one up, and are therefore trying to reach out to those of you who would like to be part of this "Working Group"....

**"But what is a 'Working Group' exactly?" .....**

A Working Group is a chance not just for specialists, but **anyone** working with a particular patient group to communicate and share their knowledge along with any ideas about research. This can open up doors for best practice and be informative about what is going on in the topic locally.

**"So, why a Working Group for PD?" .....**

It would be an excellent opportunity for professionals from all backgrounds from Care of the Elderly, Neurosurgery, Neurorehabilitation, Nursing, Physio and Occupational Therapy, in addition to Neurology and any other related therapeutic areas, to communicate. This could facilitate research by creating an improved infrastructure for supporting PD research locally as well as generally enhancing patient services in the North Thames region.

**"How?" .....**

**We need to establish who in the region works with and has an interest in developing patient care and research in PD.**

Since we aim to include a variety of professionals, this means we need **you** to contact us to register your interest. We will then arrange an introductory meeting to establish how this can progress. If successful, Working Group meetings can take place at least annually, aiming to start with a general introduction, explanation of what DeNDRoN can provide, description of what it already does and identification of how it can be utilised locally to facilitate further research and resource building. The first meeting is scheduled for September 2010.

Some people have indicated an interest in a PD Working Group already but the greater the interest generated in response to this article, the more progress we can make in moving this proposal forward. We will also directly contact those of you who we already know.

Please therefore, if not already known to DeNDRoN, contact either Dr. Sophie Molloy, Clinical Lead for PD at NT DeNDRoN, who is based at Central Middlesex Hospital and Charing Cross Hospitals or me. We look forward to progress!

**For more information please contact**

**Dr. S. Molloy:**

[sophie.molloy@nwlh.nhs.uk](mailto:sophie.molloy@nwlh.nhs.uk)

**Gitanjali Sharma, PD CRO:**

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**Tel: 0203 317 4755**

## DemReg gains public and patient interest

by Lisa Curry

On February 24<sup>th</sup>, I presented information about DemReg to the DeNDRoN National Patient and Public Involvement Forum, as part of a workshop on how PPI can help to increase recruitment of participants to DeNDRoN research studies. There was a lot of interest – and a lot of questions! – from patients and carers, as well as DeNDRoN team members working in other regions of the country. Overall, feeling was very positive about the research registry, and the opportunity it provides for people to put their hands up and say that they want to be involved in research. People were also positive that people on the registry would receive newsletters, which may be helpful in preparing them for the experience of taking part in research, as well as informing them of what research is going on.

There were, of course, concerns raised too – in particular about the security and ownership of people's personal data. These are concerns that have been born in mind continually while developing the system. Next month, the web-based application of DemReg will be up and running, and it is for reasons of security and protection that this has taken a long time to develop. All data will be held within the NHS, governed by NHS standards, and systems are in place to ensure that no-one but a patient's usual clinic team will be able to identify patients. We have just received our first specific request to use DemReg regionally to identify people and encourage referrals into a study, so it is an exciting time. The main purpose of DemReg is to increase the number of people entering research studies, so this will be a good test of how well we are achieving that aim.

