

North Thames DeNDRoN Newsletter

Issue 5 • Autumn 2010

A Note from our Network Manager

Welcome to the latest edition of the North Thames DeNDRoN newsletter.

There has been a considerable amount of change within DeNDRoN over recent months both at the national Coordinating Centre and at the local research network level.

Earlier in the summer, Professor John O'Brien and Professor David Burn joined the Coordinating Centre leadership team as Associate Directors. Professor O'Brien (Newcastle University and Northumberland, Tyne & Wear NHS Foundation Trust) was appointed as National Lead for Dementia, as a replacement for Professor Alistair Burns who has moved on to the role of National Clinical Director for Dementia at the Department of Health. Professor Burn (Newcastle University and Newcastle upon Tyne Hospitals NHS Foundation Trust) was appointed as National Lead for Parkinson's Disease, as a replacement for Professor Andrew Lees who has stepped down following five years in the post.

For local research networks (LRNs), there are changes being made to the network management teams. The role of the Network Clinical Lead is evolving to become the "LRN Director" (see page 2). In addition, LRNs will include disease-specific clinical leadership as part of their management framework. In line with this change, at North Thames DeNDRoN we have recently advertised for Research Directors in both motor neurone disease and Huntington's disease to complement the disease specific leadership already existing in our Senior Management Group.

Finally we hope that you find our newsletter informative and interesting, and we are really keen to hear your views and ideas on what we should and shouldn't include. We've included a short feedback questionnaire and we'd be delighted if you could take a few minutes to fill-in and return it to us.

As our new members of staff settle into their roles, we continuously seek to develop the Network both supporting and raising awareness of research across the region. We continually aim to make the DeNDRoN vision a reality: to give every patient the opportunity to take part in research.



Gillian Murphy
Network Manager
NTDeNDRoN

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Dates For Your Diary

South Coast HD Forum

Friday 19th November

Contact email: liz.james@hantspt-sw.nhs.uk

North East DeNDRoN Conference

Wednesday 1st December

Contact email: dendron@ntw.nhs.uk

North Thames DeNDRoN 4th Annual General Meeting

26th November 2010, London

Registration to this year's AGM will also include an invite to undertake **GCP Training**.

A half day training course provided free of charge for staff working on the DeNDRoN portfolio, followed by the AGM.

Details will be placed on the NTDeNDRoN website

www.dendron.org.uk/rn/nt.html

North Thames Local Research Network Director

As previously reported, Dr Craig Ritchie stepped down as Clinical Lead for NT DeNDRoN in January 2010 and Dr Cath Mummery has been appointed as Acting Clinical Lead for the interim period. We are seeking to appoint a permanent LRN Director. The LRN Director is a key leadership position in both the local and national network. This is a part-time post (2 PAs per week). Joint applications for LRN Director and Deputy Director are also welcome. The Department of Health will reimburse the successful applicant's employer for their time commitment.

Deadline for applications is
15th October 2010

For further information please see
<http://www.dendron.org.uk/vacancies/leadership/ntdirector.html>

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!

Free GCP 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.

GCP Online – Available now
Introduction to GCP – 2nd November 2010, Manchester

For more information and details of how to sign up go to:

<http://www.ukcrn.org.uk/index/training.html>

or contact

ruth.hudson@candi.nhs.uk

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

NT DeNDRoN HQ



For information about the studies currently recruiting in **Parkinson's Disease**, please contact:
Gita Sharma
gitanjali.sharma@candi.nhs.uk
020 3317 4755



For information about the studies currently recruiting in **Motor Neurone Disease**, please contact:
Nicola Maycock
nicola.maycock@candi.nhs.uk
020 3317 4750



For information about the studies currently recruiting in **Dementia and Ataxia**, please contact:
jonathan.anderson@candi.nhs.uk
020 317 4749



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

Goodbye and good luck to Jose Trevino and Alex Holborow, Dementia Clinical Research Officers. Alex has moved on to pastures new and Jose will be taking a career break from October 2010. We would like to thank them both for all their hard at DeNDRoN. We would also like to send best wishes to Network Manager, Tania Burke and her new baby girl Poppy and we look forward to her return from maternity leave.

NT DeNDRoN Team

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

North Thames DemReg Progress Update

By Gillian Murphy

Although Dr Craig Ritchie and Lisa Curry have both stepped down from their original roles with North Thames DeNDRoN, they are both still very much involved with the Network. Supported by DeNDRoN, they are continuing development of DemReg, the pilot project for the North Thames registry for dementia research.

There are approximately 300 patients and carers consented to DemReg across three Trusts: West London Mental Health NHS Trust, Barnet, Enfield and Haringey Mental Health NHS Trust and South Essex Partnership NHS Foundation Trust. In addition, a new data manager will shortly be in post to develop the registry at Central and North West London NHS Foundation Trust and Imperial College Healthcare NHS Trust. Development of the website application continues, and the team is currently liaising with external advisors to ensure appropriate Information Governance is in place for the registry.

As part of the initial development testing, the team have started to recruit to a few studies through DemReg. Results have been promising so far: for example Danielle Wilson is a researcher based at West London Mental Health NHS Trust who has been coordinating recruitment to the DADE study (Dependence in Alzheimer's Disease in England). This is a questionnaire-based study, on the DeNDRoN portfolio, looking at the financial cost and unknown burden associated with caring for a person with Alzheimer's disease. Through using DemReg, Danielle was able to recruit a further 25 patients and carers to the study. "It helped a great deal that for these patients I had an electronically-generated list, and that I did not have to wait for their clinical care team to contact them first as they had already consented to me doing so" commented Danielle.

Dementia Advisory Service

by Kate Moffat

Following the publication of the National Dementia Strategy *Living Well with Dementia*, a new Dementia Adviser Service has been commissioned to be delivered by Age Concern Camden. This service is primarily for people with dementia, as well as their supporters and carers. It provides people with a named contact throughout their journey with dementia.

The main aims of the service are:

- Provision of a quality information and signposting service which is tailored to individual need. This will be supported by the work of committed, trained volunteers who will enable people with dementia to understand the information they are given and to access the services to which they have been referred.
- Focus on the individual – empowering them to access the information they need, promoting independence, self-help, well-being, choice and control.
- Collaboration with other health and care professionals and active development of these partnerships to maximise the outcome for the person with dementia.
- Monitoring – cases will not be closed, but will be regularly reviewed (frequency depending on the person's situation)
- Accessibility – seeking to increase the proportion of people with dementia who receive a diagnosis by carrying out dementia awareness outreach work amongst groups of people living in the community who we have traditionally found it hard to reach

A Dementia Adviser Service Coordinator has been recruited, who is currently working to induct and train a group of volunteers to support her work.

The service will be run from Camden Memory Service's base at Queen Mary's House, 23 East Heath Road, London NW5 1DU.

The service began to accept referrals from Monday 17th May 2010. Referrals to the service may come from health and social care professionals, voluntary organisations, the friends, family or carers of people with dementia or memory problems or self-referral.

For more details please contact
Kate Moffatt
Dementia Adviser Service Coordinator
Age Concern Camden
Camden Memory Service
23 East Heath Road
London
NW5 1DU
Tel: 020 3317 6655
Email: k.moffatt@ageconcerncamden.org.uk

New Clinical Guidelines for the Management of Ataxia

The second edition of Ataxia UK's clinical guidelines, 'Management of the ataxias – Towards best clinical practice' is now complete. The updated guidelines were put together in consultation with ataxia experts from different fields of medicine, including neurology, cardiology, neuro-ophthalmology and neuro-urology. The new version of the guidelines also contains sections on physiotherapy, occupational therapy and speech and language therapy, to provide more rounded guidance.

An electronic version of 'Management of the ataxias – Towards best clinical practice' is available on the Ataxia UK website, under the 'for professionals' section http://www.ataxia.org.uk/data/filesataxia_guidelines_web.pdf. For hard copies please contact research@ataxia.org.uk.

Ataxia UK Conferences

The Annual Conference will be held on 9th October in Stansted, Essex. Details can be found on the Ataxia UK website. (www.ataxia.org.uk)

Ataxia UK conferences typically feature research updates, talks from people with ataxia about their experiences of living with their condition, information about Ataxia UK services, break-out and therapy sessions and a Drs' Question and Answer session. They are aimed at people with ataxia, although there may be limited spaces for healthcare professionals (if you are interested in attending please contact: research@ataxia.org.uk)

Clinical Trials: A Patient's Point of View

by Colin Knight

After the shattering diagnosis of MND, back in January 2008 I can honestly say my life at that point had hit rock bottom. The thought of this incurable disease slowly but surely wearing me down was to say the least very difficult to come to terms with. My wife and I decided to try and put a positive spin to the problem and looked into ways I could be part of ongoing research which will hopefully lead to a cure for MND one day.

In early 2009 I read about a Lithium Carbonate trial in Italy that had shown to support the theory that the drug slowed progression, but the trial criteria was found to be flawed and the MND Association were looking to contribute to such a trial in the UK. With the help of Jan Clarke and Dr Robin Howard at The National, Queens Sq, I put myself forward for the double blind placebo study and in August 2009 met Dr Richard Orrell to find out if I met the research criteria. Within the month I nervously started my trial and the weekly visits down to The National from Bedfordshire. I must say, the visits were a little tiring to start with, but as the weeks passed the routine became the norm and in a strange way the experience was quite exciting.

I have been involved in the trial now for 11 months and the visits coincide with my regular three monthly clinic appointments. The thought that you are actually helping to make a difference to the understanding of such a terrible disease makes me feel so proud. Also not giving in without putting up a fight is immensely satisfying. I understand the research into this and other treatments have many bridges to cross and in my heart of hearts I know it would be naive to believe this will bring a cure for myself, but if my input to this and other studies means others do not suffer the devastation my family and I felt back in 2008, then it will all have been worth it.





EVIDEM: Evidence-based Interventions in Dementia, 2007-2012

Changing practice in dementia care in the community: developing and testing evidence based interventions, from timely diagnosis to end of life.

This NIHR funded programme is currently in the third of its five years. The EVIDEM research and development programme contains a series of research projects designed to change practice in dementia care in the community. The programme will develop and test evidence-based interventions that address dementia diagnosis and management, continence management, behavioural and psychological symptoms, end-of-life care and the implementation of the Mental Capacity Act. More detail on the five studies contained in the programme can be found on: www.evidem.org.uk. **Currently, three of the five projects are seeking more participants and would value your input.**

EVIDEM-E is exploring the potential of exercise as a non-pharmacological treatment of the behavioural and psychological symptoms commonly experienced by people with dementia. The exercise will take the form of supervised and graded walking, tailored to individual ability. The randomised controlled trial will assess the impact on behaviour, sleep and quality of life.

Contact for referrals or information:

Arlinda Cerga Pashoja, Research Worker on tel:020 3214 5886 or e-mail:acerga-pashoja@nhs.net; and/or Dr David Lowery, Trial Manager on tel: 020 3214 5889, or e-mail:d.lowery@ucl.ac.uk

The double stigma of memory problems and incontinence is being addressed in the **EVIDEM-C** study. It is estimated that up to a third of people with memory problems living at home have difficulties in remaining continent. There is lack of detailed knowledge of the most appropriate management strategies, which is reflected in the lack of guidance for health and social care professionals to help address this problem.

This study explores

- 1) the experience of people with memory problems and their carers in managing incontinence at home
- 2) the feasibility and acceptability of interventions to reduce the impact of incontinence for people with memory problems and their carers living at home.

The researchers are keen to talk to people (and/or their carers) who have problems with their memory and have incontinence, toileting problems or the 'occasional accident' as well as those who use pads or other absorbent products to manage their incontinence.

Contact for referrals or information:

Laura Cole, Research Worker on tel:020 8725 3867 or e-mail:laura.cole@sgul.kingston.ac.uk; and/or Prof Vari Drennan on e-mail:v.drennan@sgul.kingston.ac.uk

EVIDEM-MCA focuses on the implementation and practice of the Mental Capacity Act 2005, a law that came into operation in late 2007 to enable people to make arrangements, if they wish, for a time when they may lack capacity. It sets out the principles to be followed when consenting to any act of care and treatment for someone who is unable to make this decision or to express a view. Professionals in health and social care and the voluntary sector have been interviewed already. The research team are currently interviewing people with dementia and their carers, if they have them, about their everyday experiences of making plans and decisions as well as any plans they have made for later life.

Contact or referrals or information:

Kritika Samsi, Research Worker on tel:020 3214 5886 or e-mail:kritika.1.samsi@kcl.ac.uk; and/or Prof Jill Manthorpe on e-mail:j.manthorpe@kcl.ac.uk

Eligibility criteria to all 3 studies are detailed in the NT DeNDRoN Pathways document.

PD Working Group Interest By Gita Sharma

In our last edition of the newsletter, there was some information provided about the PD Working Group Meeting which we are organising for October 2010. There has been some interest and we are hoping for more. This working group would be the perfect opportunity for persons from all related therapeutic backgrounds to conjugate, discuss and share their knowledge, thereby assisting research by enabling a better infrastructure between health professionals for PD research.

If you would like to attend this meeting in October, please contact either myself

gitanjali.sharma@candi.nhs.uk or

Dr. Sophie Molloy, sophie.molloy@nwlh.nhs.uk

Research on the Organisation Management and Delivery of Specialist Neurological Rehabilitation

This particular study is being run from Kings College with Dr Richard Siegart as Chief Investigator; four North Thames sites are taking part. The study is investigating the type and the amount of rehabilitation that patients receive in the community, and their level of satisfaction with these services. The study aims to evaluate the cost effectiveness of the rehabilitation services and whether the level of rehabilitation received is related to better outcomes for patients. This investigation is suitable for patients with any long-term neurological disease where rehabilitation might be considered an appropriate part of the care pathway.

For further information please contact Gita Sharma,

gitanjali.sharma@candi.nhs.uk

Tel: 020 3317 4755

Please give us Your Feedback

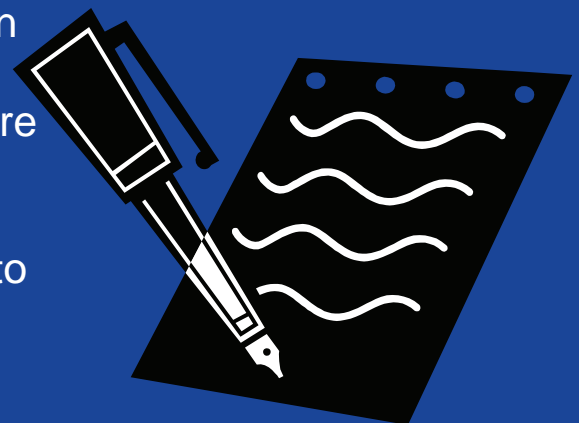
NT DeNDRoN would like your feedback on
our Newsletter.

You can complete the enclosed questionnaire
and return it to us

Or

Email any comments about the newsletter to
ntdendron.admin@candi.nhs.uk

Thank You



The PD REHAB study is being run from Birmingham University, with Prof. Carl Clarke as Chief Investigator. It focuses on providing both physiotherapy and occupational therapy to Parkinson's Disease patients without any change to their routine medication.

PD REHAB Update By Gita Sharma

It was during autumn 2009 that Central Middlesex Hospital agreed to participate in the PD Rehab trial, along with 40 other national sites. As soon as the study set-up paperwork was underway, Dr. Sophie Molloy (Principle Investigator), worked closely with the Willesden Centre for Health & Care to get a team of therapists on board to assist with the study. A departmental database of PD patients, who had indicated an interest in research, was also a useful tool for ensuring the success of this study.

**For more information please
contact**

Gitanjali Sharma, PD CRO:
gitanjali.sharma@candi.nhs.uk,
Tel: 020 3317 4755

With all this groundwork completed the site was ready to open in March of this year. Three patients were randomised in the first month alone, with a further three patients randomised since, meeting our minimum, annual target of 6 patients in just a few months.

North Thames DeNDRoN has received much interest in this trial across the region. Watford General, working closely with the rehabilitation team at Jacketts Field, opened the study in May 2010 with Dr. Syed Rizvi as PI. We anticipate Dr. Rizvi and his team will meet with similar success to that of Central Middlesex Hospital. Finally, the National Hospital of Neurology & Neurosurgery is another site in set-up, hopefully opening soon.

