

**NIHR South West Dementias and Neurodegenerative
Diseases Research Network**
A study update

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South West DeNDRoN Conference 08/12/08



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Aim of the presentation

- To provide some particular examples of how we are supporting these studies

- **Dementia Studies**
Domino-AD, 020 & 007 Debbie Howcroft

- **Neurodegenerative Studies**
PD Med, Get upChristine Cosby

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Title: DeNDRoN 007 & 020
Observational study of the costs & caregiver burden in Alzheimer disease

Sites in the South West:

Bath, Gloucester, Salisbury & Plymouth

Start Date in the South West:	May 2008
Recruitment up to 30/11/08 (007):	18
Recruitment up to 30/11/08 (020):	73

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DeNDRoN 007 & 020

Rationale for the studies

- Previous studies have shown a link between costs, disease severity and caregiver burden as affected by care setting or impact on quality of life
- The studies aimed to measure the cost of care of patients with AD in relation to disease severity, as measured by cognitive function, ADL-abilities and presence of behavioural disturbances and care setting and the impact on carers

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DeNDRoN 007 & 020

<u>Centre</u>	<u>Recruited</u> <u>007</u>	<u>Recruited</u> <u>020</u>
Holly house Gloucester	18(25)	n/a
RICE Bath	n/a	59
Derriford Hospital, Plymouth	n/a	14
Three swans surgery, Salisbury	0(6)	n/a

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DeNDRoN 007 & 020

Roles of the DeNDRoN funded staff

- Set up and training of two new researchers (PIs)
- Set up of study with local R&D and ethics approval
- Nagging clinicians & their teams
- Identification of suitable patients & carers
- Discussion of study with patients & carers
- Consent process
- Data collection interviews
- Ongoing Site file management
- Making links with local AD groups
- Raise awareness of studies

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DeNDRoN 007 & 020

Opportunities & Challenges

- Significant for clinical practice
 - DeNDRoN staff embedded in clinics
 - Very committed PIs and research teams
 - Support of study coordinating centre : regular teleconference
 - Severity of patients
 - One off interview
-
- Severity of patients
 - Clinicians time
 - New research teams

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Title: Domino-AD Donepezil and Memantine in Moderate to severe Alzheimer's disease

Sites in the UK: 15 sites
Sites in the South West: **Bath & Plymouth**

Start Date in the South West: Feb 08
Recruitment up to 25/11/08: 111(300)
Funded by Medical Research Council
& Alzheimer's Society

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Domino-AD

Rationale for the study

- Evidence is unclear on what clinicians prescribe to people with Alzheimer's disease once they reach moderate to severe transition point.
- The trial will look at whether pharmacological treatment with donepezil alone or memantine alone is better than placebo at maintaining cognitive function and daily activities
- Also consider there are synergistic effects of the two drugs combined.

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Domino-AD

<u>Centre</u>	<u>Recruited</u>
RICE Bath	3
Derriford Hospital, Plymouth	2

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Domino-AD

Roles of the DeNDRoN funded staff

- National training of sites for delivery of rating scales
- Set up of study with local R&D and ethics
- Nagging clinicians
- Identification of suitable patients
- Discussion of study with patients
- Randomisation paperwork & medication
- Follow up visits
- Telephone contact to assist retention in the study
- Making links with local AD groups
- Raise awareness of study with clinicians
- Assist with SAE paperwork
- Ongoing Site file management
- Ran PPI focus group in Bath

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Domino-AD

Opportunities & challenges

- Significant for clinical practice
- DeNDRoN staff embedded in clinics
- Very committed PIs and research teams
- Support by study coordinating centre : regular teleconferences
- Presentations to local AD groups
- Study information in clinics
- Funded by MRC & AS
- Opportunity to access drugs at severe stage

- Placebo
- Prescribing practices
- Severity of patients

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Title: PD Med

A large randomised assessment of the relative cost effectiveness of different classes of drugs for Parkinson's disease

Sites in the UK: 109 Hospitals

Sites in the South West:

**Exeter, Torquay, Barnstaple, Taunton, Bath,
Bristol, Cheltenham, Gloucester, Yeovil**

**Start Date in the South West: December 2000
with DeNDROn December 2006**

**Recruitment up to 30/11/08: UK : 1813
SW: 422**

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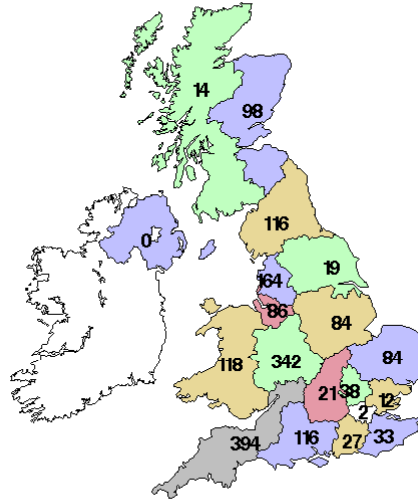
PD Med

Rationale for the study

- PD MED is a large 'real life' trial which aims to determine which class of drugs provide most effective control with fewest side effects for both early and late PD
- 1500 early stage, 1000 late stage
- Closing recruitment End Dec 09

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UK Recruitment to PD MED up to 30 November 2008



Recruitment from overseas centres: 45; Total 1813

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PD Med: 422

<u>Centre</u>	<u>Randomised</u>
Cheltenham Delancey Hospital	25
Bristol, Frenchay Hospital	4
Gloucester Royal Infirmary	18
Barnstaple, North Devon District Hospital	37
Exeter Royal Devon & Exeter Hospital	217
Bath Royal United Hospital (St Martin's)	34
Taunton & Somerset Hospital	25
Torbay Hospital, Torquay	17
Yeovil Hospital	45

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PD Med Roles of the DeNDRoN funded staff

- Support study with local R&D
- Identification of suitable patients
- Discussion of study with patients
- Randomisation paperwork
- Assist with SAE paperwork
- Follow up visits
- Telephone contact to assist retention in the study
- Making links with PDNS and local PD groups
- Raise awareness of study with clinicians
- Discussion about PD GEN study

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Get Up

**Title: The effect of targeted exercise on falls
and function for people with PD**

DeNDRoN sites in the South West: 4

Exeter, Torquay, Barnstaple, Plymouth

Start Date in the South West: May 2007

Recruitment up to 25/11/08: 130 SW D 92

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Get Up Rationale for the study

Falls are common among people with PD

1. Injury
2. Fear of further falls
3. Activity restriction
4. Carer burden

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Get Up:
92

<u>Centre</u>	<u>Start Date</u>	<u>Referred</u>	<u>Recruited</u>
Royal Devon & Exeter Hospital	05/2007	72	44
Torbay Hospital, Torquay	03/2007	38	27
Plymouth Hospital	05/2008	9	7
North Devon District Hospital	08/2008	43	14
+ 6 Other sites Non DeNDROn			
Honiton	07/2008	17	4
Torbay care Trust	03/2007	15	4
Tiverton	08/2008	7	1
Budleigh Salterton	07/2008	11	1
Blackdown surgery Heymyock	08/2008	6	1
Brunel surgery Torquay	08/2008	13	7

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Get Up Roles of the DeNDRoN funded staff

- Identification of suitable patients
- Referring potential patients for recruitment
- Discussion of study with patients
- Making links with local PD groups
- Raise awareness of study with clinicians

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Summary:

Description of 5 of the studies supported by DeNDRoN in the South West
in order to give a flavour of clinical research in our area,
bringing real examples of site organisation, recruitment and level of
support provided.

We hope we have demonstrated how we are widening the opportunity
for patients and carers to take part in
high quality research in the South West.

**Thank you to the patients and carers taking part in the studies
and who are also with us today.**

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