

## **SW DeNDRoN South West Dementias & Neurodegenerative Diseases Research Network**

**NEWSLETTER - September 2008 – Issue 2**

Dear Colleagues,

Welcome to the second newsletter from South West DeNDRoN. These newsletters are designed to keep you up to date with the developments and changes in the network and to keep you informed about events, training and other DeNDRoN related activities. In the last six months we have moved our research and activity forward, started supporting new studies and recruited a new network manager:

Welcome to Dr Joanne Hartland, our Research Network Manager, who is with us whilst Erica is on maternity leave. Jo has a wide range of experience to bring to the network, in both empirical research, and in research management and support. She has held research posts at the University of Bath, the University of Bristol and the Health Promotion Authority for Wales. Her research management posts include that of Research and Business Development Officer for the Faculty of Social Science at the University of Bath and Research Primary Care Research Manager for the Pan Bath and Swindon Primary Care Consortium. In addition she brings experience of large scale project management – gained with the South West Strategic Health Authority.



### **Recent Achievements & Successes**

- Thank you to all those who have contributed to the Added Value Questionnaire sent out by Debbie and the interviews organised by Jo. There will be a full report on this in our next newsletter.
- The RICE Centre in Bath has recruited the largest number of patients in the country to the SCODA trial so far this year. Congratulations to the staff involved.

### **Events and Dates for the diary**

- **DeNDRoN National Conference** took place on **Tuesday, 14th October** in Newcastle. Presentations are available here: <http://www.dendron.org.uk/newcastle2008.html> . On the previous day, **Monday, 13th October**, a Staff Development Day aimed at research nurses, clinical studies officers and other study support staff, was organised in Newcastle and all our staff were encouraged to attend.
- **South West DeNDRoN Conference** Registration is now open and all our staff, partners and collaborators have been invited. Details of the event, which takes place in Taunton on **Monday, 8th December**, are available near the bottom of this web page: [http://www.dendron.org.uk/rn/south\\_west.html](http://www.dendron.org.uk/rn/south_west.html) . We have set up on-line registration at this site: [www.aquavenuesolutions.com/swdendron](http://www.aquavenuesolutions.com/swdendron) . One of the aims of the day is to give patients and carers an opportunity to understand and influence the research agenda. As such we are keen to invite a wider range of service users, carers, and voluntary groups. If you have links with people you think we need to invite, please let Sarah have contact details ([sarah.mercer@awp.nhs.uk](mailto:sarah.mercer@awp.nhs.uk)). This event is free.

### **Meetings & Training**

- **CSO Team meeting, 9th July, Plymouth Hospitals NHS Trust** – our regular four-monthly meeting was very well attended. Prof John Zajicek opened the meeting; Helen Quinn, Manager of the Peninsula Comprehensive LRN made a presentation outlining changes in funding for R&D; Terry McGrath, DeNDRoN PPI Coordinator then talked about patient and public involvement, looking at ways in which we can involve these groups more in our work. Dr Joanne Hartland introduced herself as new Network Manager and discussed recruitment targets and challenges facing the Network in the coming year. The date of the next meeting is to be Wednesday, 4<sup>th</sup> February 2009 at the RICE Centre in Bath.

In addition the CSOs will have a chance to meet at both the Dendron National Conference and the SW Dendron Conference.

- **Huntington's Disease study day** - Thursday, 16<sup>th</sup> October in Weston-super-Mare. Please contact [carol\\_dutton@hda.org.uk](mailto:carol_dutton@hda.org.uk) for more information.

#### UKCRN training

By now all of you will have all accessed the UKCRN training database. It has a range of online and taught courses. Below we have picked out courses which seem very relevant to us as a group. Also we have tried to find the dates when courses are being run in the South West. If we can all make an effort to attend these courses in South West venues it will support the need for running the courses in our part of the world.

- UKCRN training on Standard Operating Procedures (SOP) 20<sup>th</sup> November, Manchester 2008 and 26<sup>th</sup> January, Bristol.
- GCP and EU directive for experienced staff - 20<sup>th</sup> November 2008 Bristol.

#### **Network Developments**

South West DeNDRoN is monitored by the UKCRN via the DeNDRoN National Coordinating Centre. During June and July we prepared our annual report for the Coordinating Centre in which we were asked to describe all our activities during the previous year and to demonstrate the ways in which we have helped to recruit patients to trials. The report also asked for an outline of our future plans – in the short-term (1 year) and the medium-term (3 years). In addition to this SW DeNDRoN is currently preparing an operational plan, setting out how we will achieve our objectives, which will be submitted to the Coordinating Centre in the next few weeks.

#### **SW DeNDRoN Developments**

**SW DeNDRoN Website:** the national DeNDRoN website now links to our SW website, where we have been able to load information about the local network, factsheets, contact details, study details and newsletters. To get to our site click here: [http://www.dendron.org.uk/rn/south\\_west.html](http://www.dendron.org.uk/rn/south_west.html) and bookmark the page.

**SW DeNDRoN Leaflet:** we have also produced a succinct and compact leaflet describing the local network and our activities. We will be able to email this to you soon for you to print. If you do not have access to colour printing, please ask Sarah to send hard copies in the mail. Please ensure you distribute these to everyone who is keen to find out more about the work of SW DeNDRoN.

**New Staff:** we are pleased to welcome Louise Jones to SW Dendron in Yeovil. Louise is an experienced acute care nurse and has now taken over from Clare Buckley whilst she is on maternity leave. Welcome also to Amy Stabb, the new Trials Administrator based in Plymouth. Welcome also to Corinna Chambers an Assistant Psychologist based in Plymouth. Corinna recently graduated from Cardiff University following a year working on clinical trials with Cardiff Memory Team. We would also like to welcome Kudzai Mugweni who recently joined our SW DeNDRoN Bath office team as a Clinical Studies Officer. He brings in significant experience in Community/Clinical Trial Setup, participant accrual and follow-up to regulatory and GCP requirements. He has worked on multiple projects with the University of Zimbabwe – University of California Collaborative Research Programme on Women's Health (UZ-UCSF), The World Health Organisation (WHO) and the Ministry of Health Botswana – Harvard School of Public Health Public Private Initiative (PPI). This brings our complement of support staff in the south west to 22.

#### **Spotlight**

In future editions we will focus on one of our colleagues and their activities in a typical week. Dr Stephen Pearson, SW DeNDRoN's Research Champion, has kindly offered to go first:

I am a Consultant in Older Adult Psychiatry working in South Devon for Devon Partnership Trust. I have always been interested in research and the delivery of high quality patient care. I am a member of the SW DeNDRoN Steering committee and was appointed DeNDRoN Research Champion in March 2007 to help develop dementia research on the peninsula. I now



have a funded research session from the Peninsula Comprehensive Research Network to take things forward.

Our research unit works from Tamar Science Park in Plymouth and with the support of Dr Rupert Noad, Clinical Neuropsychologist, and DeNDRoN staff, we have set up 2 clinical trials and have another 2 trials about to start. One of the current trials, DeNDRoN 020, is looking at carer stress and disease severity in Alzheimer dementia. The other trial is an MRC drug trial DOMINO-AD that we are undertaking with RICE in Bath looking at late stage Alzheimer dementia and seeing whether the addition of memantine can help relieve symptoms. Since developing my research interests I have undertaken UKCRN/DeNDRoN training in GCP and Huntington's Disease.

I have high hopes for developing a Peninsula dementia research group as part of the DeNDRoN research network. We are still trying to think of a name for our group which captures all aspects of its dynamism. We will keep you all posted.

*Stephen Pearson*

### Studies update

#### Recruitment to studies:

- Good news for Dendron 020 – the site in Bath is currently the highest recruiter to this study in the country.
- Steve Pearson is now up and running and recruiting to two studies: Domino and DeNDRoN 020 (see separate article from Steve).
- Cupid is now closed to recruitment and is in follow-up.
- Exeter and Frenchay have now opened to recruitment for the DeNDRoN 024 study which is a commercial drug study in PD.
- Long term neurological conditions, support for carers: Devon, Taunton and Frenchay are about to start contributing to this study with referral of suitable carers.

#### Contact Details for the South West DeNDRoN team:

<p>Professor Roy Jones Clinical Lead Phone: 01225 476437 <a href="mailto:R.W.Jones@bath.ac.uk">R.W.Jones@bath.ac.uk</a></p> <p>Professor John Zacijek Deputy Clinical Lead Phone: 01752 315 271 Secretary: 01752 315 252 <a href="mailto:John.Zacijek@phnt.swest.nhs.uk">John.Zacijek@phnt.swest.nhs.uk</a></p> <p>Dr Joanne Hartland Research Network Manager Phone: 01225 476431 <a href="mailto:Joanne.Hartland@awp.nhs.uk">Joanne.Hartland@awp.nhs.uk</a></p> <p>Debbie Howcroft Senior Clinical Research nurse Phone: 01225 476434 <a href="mailto:Deborah.Howcroft@awp.nhs.uk">Deborah.Howcroft@awp.nhs.uk</a></p>	<p>Christine Cosby Senior Clinical Studies Officer <a href="mailto:Christine.Cosby@phnt.swest.nhs.uk">Christine.Cosby@phnt.swest.nhs.uk</a> Phone: 01752 315 264 Fax: 01752 315 254</p> <p>Sarah Mercer Research Network Administrator Phone: 01225 476430 <a href="mailto:Sarah.Mercer@awp.nhs.uk">Sarah.Mercer@awp.nhs.uk</a></p> <p><b>General Enquiries: 01225 476430</b> Fax: 01225 463403</p> <p>South West DeNDRoN The RICE Centre Royal United Hospital Bath BA1 3NG</p>
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## South West DeNDRoN Study Portfolio –September 2008

Study - Commercial	Site	Area of interest
DeNDRoN 001 (closed - finished)	(Bristol)	Parkinson's Disease
DeNDRoN 002 (closed – in f/u)	(Bath & Swindon)	Dementias
DeNDRoN 003 (closed - finished)	(Swindon)	Dementias
DeNDRoN 004 (closed – in f/u)	Bath & Swindon	Parkinson's disease dementia & dementia with Lewy bodies
DeNDRoN 007	Gloucester	Dementias
DeNDRoN 009 (closed)	(Swindon)	Dementias
DeNDRoN 020	Bath & Plymouth (DPT)	Dementias
DeNDRoN 022 & 023 (in setup)	(Bath & Swindon)	Dementias
DeNDRoN 024 (in setup)	(Bristol & Exeter)	Parkinson's Disease
DeNDRoN 027 (in setup)	(Swindon)	Dementias
DeNDRoN 028 (in setup)	(Bath)	Dementias
Study – Non-Commercial		
CUPID (closed – in f/u)	(Bristol, Gloucester, Plymouth, Taunton, Truro)	Multiple Sclerosis
DOMINO	Bath & Plymouth	Dementias
DBS of the PPN in PD	Bristol	Parkinson's Disease
Euro HD Biobank	Exeter, Gloucester, (Bristol)	Huntington's Disease
Euro HD Registry	Exeter, Gloucester, (Bristol)	Huntington's Disease
Falls in PD / GET uP	Exeter, Plymouth, Torquay	Parkinson's Disease
MND Association DNA Bank	Bristol, Plymouth	Motor Neurone Disease
PD GEN	Barnstaple, Bristol, Bath, Cheltenham, Exeter, Gloucester, Taunton, Torquay, Yeovil	Parkinson's Disease
PD MED	Barnstaple, Bath, Bristol, Cheltenham Exeter, Gloucester, Taunton, Torquay, Yeovil	Parkinson's Disease
PD SURG (Closed – in f/u)	(Bristol)	Parkinson's Disease (Neurosurgery)
PRO-DeNDRoN Register	Devon and Cornwall	Parkinson's Disease
LTNC, support for carers	Bristol, Devon and Taunton	Neurodegenerative Disease

The full DeNDRoN portfolio can be viewed at [www.ukcrn.org.uk](http://www.ukcrn.org.uk) (click on “search the UKCRN portfolio database” and select area of interest).

[www.dendron.org.uk](http://www.dendron.org.uk)  
[http://www.dendron.org.uk/rn/south\\_west.html](http://www.dendron.org.uk/rn/south_west.html)