

# DeNDRoN South Coast

Dementia and Neurodegenerative Diseases Research Network

## January 2009 Newsletter

### The Arrival of Twins

South Coast DeNDRoN are thrilled to announce, on behalf of Dr. Naji Tabet, the birth of identical twin girls.

#### **Baby Grace and Baby Joy.**

Our congratulations to Dr. Tabet and his wife wishing them every health and happiness for the future.

### **DeNDRoN National Conference 2008**

as written by research nurse Angie Hare

The Annual DeNDRoN Conference took place on 14<sup>th</sup> and 15<sup>th</sup> October at The Hilton Hotel Newcastle. The first of this two day conference was set up as a study day aiming to inform staff of dementia related topics they wish to learn more about.

Many of the South Coast DeNDRoN staff attended and below is some feedback from Angela Hare, Research Nurse.

"When I attended my first study session, 'An Introduction to Research in Dementia', I was really impressed by the speakers, who believed in what they were aiming to achieve in finding a cure and more effective treatments / interventions for Alzheimer's disease. I've worked in many areas with Alzheimer's and seen how it affects patients and their families.

The conference was just as motivating. I thought it was really good to have the range of speakers and topics, to reiterate how wide the network topic area is. It reminded me of the hope and ideas developed at the study session.

I am really quite proud that when I visit and see people, patients and their families, I try to pass on the enthusiasm and optimism for what DeNDRoN stands for to me. Added to that is the Department of Health working with our NHS Trusts, which also validates and instills confidence in the research we are undertaking.

I am well aware I'm doing my ever so enthusiastic 'I love DeNDRoN' bit, but it means a lot to me."

<http://www.dendron.org.uk/newcastle2008.html>

Thanks to Angie for her continued enthusiasm and commitment to DeNDRoN!

**We are pleased to announce the next DeNDRoN Annual Conference is to be hosted by South Coast DeNDRoN at the beginning of October. Date to be confirmed.**

### Plans for 2009

The start of 2009 is an exciting time for South Coast DeNDRoN. With the additional support of our 3 new clinical trials officers we will be able to build momentum in our mission to give every patient, in the South Coast, affected by dementias and neurodegenerative diseases the opportunity to take part in research.

To help us achieve this Yvette Lycett will take the lead in patient and public involvement and is available to give talks to any patient/carers groups. Please contact Yvette as below. We also intend to be more visible with information stands at prominent sites across the South Coast.

Early in the New Year we will be conducting a patient survey on research topic areas. **Is the research being conducted the research that patients want?** Please contact us if you would like to take part in this survey or be involved in any aspect of South Coast DeNDRoN.

On 29<sup>th</sup> October 2008 with MARC (Memory Assessment Research Center) we held a **clinical trials information event** over lunch time. This was so well attended and received we intend to make this a regular happening. **Please contact Liz James for future dates.**

### Trials Update

Following the hard work of Anne Martin, **PD MED** is now open in Poole Hospital under Dr. Harries-Jones. Diane Haig-Brown will be the South Coast DeNDRoN link for recruitment

Vanessa Pressly has successfully established Winchester under Dr. Chris Gordon, as another site for **PD MED**. Marek Czeladzki will be the South Coast DeNDRoN link for recruitment.

Despite strong competition we are pleased to report two South Coast DeNDRoN sites were accepted to undertake the **PDNovartis** study. Dr. Khaled Amar in Bournemouth, supported by research nurse Anne Martin and Dr. Steve Simpson, North Dorset, supported by research nurse Caroline Coleman are now undertaking this study. Dr. David Wilkinson, MARC, is an original site for this study linking in with Dr. Helen Roberts for recruitment.

Two other new studies in **AD**, adopted by DeNDRoN are also now recruiting under Dr. David Wilkinson who continues to work closely with Dr. Carol Trotter at St. James Hospital to give patients in Portsmouth opportunity to take part in research.

**Please contact us for further information.**