

March 08 Newsletter

Official Launch

March 26th saw the official Launch of South Coast DeNDRoN. An informative event held at the Solent Hotel, Whiteley, Hampshire. South Coast DeNDRoN now have an established, enthusiastic team who are looking forward to an exciting and successful future.

Piers Kotting the Assistant Director of DeNDRoN Coordinating Centre gave an insight into the background of DeNDRoN and future plans.

Judith Headley, Study Support Coordinator for DeNDRoN gave an explanation about how trials are adopted by DeNDRoN and therefore placed on the UKCRN portfolio database.

Clinical Lead – Dr. David Wilkinson gave an interesting presentation about the changes in Dementia care and treatments over the past 50 years. Dr. Wilkinson stressed how these changes and improvements had only been achieved through research and clinical trials outlining the importance of creating a successful local research network.

Clinical Lead – Dr. Helen Roberts presented an overview of current Parkinson's disease trials supported by South Coast DeNDRoN and reported how the network intended to support research into Huntington's disease and Motor Neurone disease.

Sandra Lawton – Network Manager, chairing the event, took the opportunity to announce the Launch of the South Coast DeNDRoN web site.

www.dendronsouthcoast.org.uk

The meeting was drawn to a close with a toast to the successful future of South Coast DeNDRoN.

Progress

Trials in Parkinson's disease and Alzheimer's disease continue to be successfully conducted in our research sites across the South Coast and we aim to keep our website up to date with all current trial information.

In the South Coast we have Dr. Helen Roberts who has a particular interest in Parkinson's disease. Dr. Roberts, supported by Lead Research Nurse, Vanessa Pressly, has recently established a working party to look at possible research areas in Parkinson's disease. The first meeting took place at the end of February and was very successful and positive. Small groups were established to look at the feasibility of suggested studies. The group will meet again in April.

Dementia research is always prominent in the South Coast as we are fortunate to have the Memory Assessment Research Centre (MARC) established by Dr. David Wilkinson which has continual activity in dementia trials.

We are also delighted to note, that Angie Hare, research nurse with Dr. Naji Tabet in Brighton, was noted at a recent National meeting to be the most successful recruiter for SIROCCO (a drug trial in Alzheimer's disease).

There is always less research available for other neurodegenerative diseases such as Motor Neurone disease (MND) or Huntington's disease (HD) but South Coast DeNDRoN is taking the responsibility to cover all disease areas seriously.

Following the very successful working party meeting for Parkinson's disease we are planning the same for HD and MND. Dr. David Wilkinson and Dr. Helen Roberts will be using their research expertise and experience to lead the working parties forward.

The first HD working party meeting is on 3rd April and will begin with a presentation about the Euro HD project by the team from Cardiff.

Anyone wishing to be involved in any of the working parties, please do contact us.

Patient and Public Involvement

South Coast DeNDRoN is looking at ways to improve patient and public involvement in the Network. Two public meetings were held during March, but although highly publicised were not well attended. We are available to give talks/presentations or you can request an information pack.

CSIP (Care Services Improvement Partnership) held a recent conference at Farnham Castle and we were delighted to be invited to exhibit our literature and newly developed information packs.

We have tentative plans to do road shows throughout the area and would welcome feedback as to where we should base ourselves and if this is thought to be a useful idea. Just as a reminder, South Coast DeNDRoN covers Hampshire, Dorset, Sussex and Guildford.

Please let us know how we can keep you informed and involved.

Contact details below or contact us through our web site.

DeNDRoN South Coast Coordinating Team

David Wilkinson – Clinical Lead
Helen Roberts – Deputy Clinical Lead
Sandra Lawton – Network Manager
Karen Carnell – Lead Research Nurse AD
Vanessa Pressly – Lead Research Nurse PD
Liz James - PA