

News from the Dementias and Neurodegenerative Diseases Research Network

## North East DeNDRoN

DeNDRoN is part of the NHS, carrying out research in dementia. We help research studies for improving diagnosis, management and treatment of dementia. We do research in all kinds of dementia, including Alzheimer's disease, dementia with Lewy bodies, vascular dementia, and dementia associated with Parkinson's disease.

North East DeNDRoN covers Berwick to North Yorkshire, and links up with research in Yorkshire.



## Join the Patient List

DeNDRoN has a Patient List of people interested in research. You don't have to wait for your doctor or nurse - you can contact us yourself. You get an information leaflet; then if you want to go ahead we visit you at home. After getting your permission to hold information about you, we tell your GP and



consultant that you've joined the Patient List. You can leave the Patient List, or withdraw from any research study, at any time without giving a reason. Patient List Members get newsletters to tell them about research, and invited to join suitable studies. Many dementia patients on the Patient List have been asked about joining a study. However while there is unlikely to be a study for everyone, new studies are being added all the time. The DeNDRoN Patient List is the new name of the Case Register. Just call 0191 223 2740 for more information.

### Latest news

- The Patient List now has over 200 people with dementia
- Half the people on the patient list with dementia have joined a clinical study
- DeNDRoN studies recruiting now are SUSPECTED-AD, CATFieLD, Bapineuzumab, Brains for Dementia Research and DaTSCAN
- New dementia studies are starting all the time. Join the Patient List to get involved

### Recruiting Now :-

#### DeNDRoN 022 The Bapineuzumab Trial

uses ready-made antibodies against one of the abnormal proteins (amyloid) that build up in plaques in the brain in Alzheimer's disease. The antibodies are given by infusion (by drip), with the aim of removing the amyloid. The study includes tests of mental ability and brain scans.

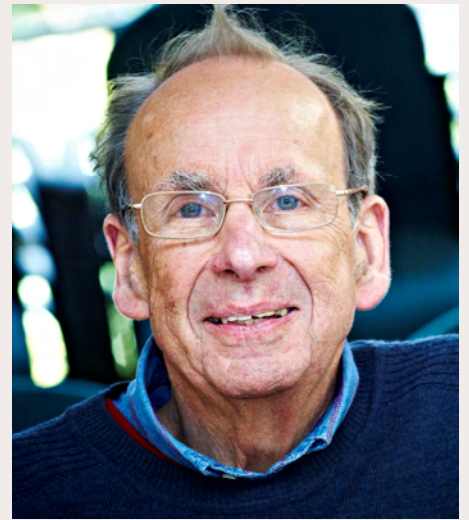
### Volunteers

Some Clinical Studies need control individuals, people who do not have dementia but are from the same age group as the patients in a study. DeNDRoN keeps a list of control volunteers.

## Dementia-themed Call for Research

This year the government has prioritised dementia research, calling for research proposals looking at cause, cure, care and treatment of dementia. There are several new studies going to start next year. We expect to be able to offer several new research studies in our region, about diagnosis of dementia, and about visual problems in

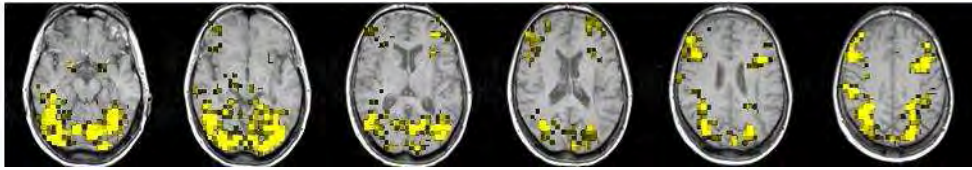
dementia. The Alzheimer's Society supports the dementia themed call and is helping some investigators with their applications. In the North East 12 patient and carers in DeNDRoN formed a focus group to review three dementia themed call applications.



## Research Studies

**CATFiELD** looks at changes in levels of alertness, thinking and attention in Lewy body dementias (Dementia with Lewy bodies and Parkinson's disease dementia). Participants have functional

Magnetic Resonance Imaging (MRI) measures of brain activity and EEG recordings while carrying out a visual test. All patients are compared to Alzheimer's and control individuals.



**SUSPECTED-AD** is comparing two kinds of brain imaging, PET and SPECT, for how accurate and cost effective they are for early diagnosis of dementia. Patients get expert diagnosis through the two methods. Which kind of scan patients and carers prefer is also recorded.

**DeNDRoN 057 DaTSCAN** study is for people with possible dementia with Lewy bodies who have not yet had a DaTSCAN. The study is to test how helpful a picture of the dopamine transporter SPECT brain image is to help diagnose cases of DLB.

## Brains for Dementia Research

Brains for Dementia Research encourages brain tissue donation from anyone over 65 who has a diagnosis of dementia, and from controls also over 65. Patients registered with BDR get an annual home visit. Control donors follow-up is by telephone every other year with a home visit in between. Being registered for brain donation is quite different from having an organ donor card. Donated brain tissue is stored in the Newcastle Brain Tissue Resource. This valuable tissue is distributed to scientists for work in the causes and treatment of dementia.

If you would like to know about brain donation please call DeNDRoN 0191 223 2740

### DeNDRoN PPI Panel

North East DeNDRoN have a Public / Patient Involvement Panel which meets from time to time. The PPI panel discusses aspects of DeNDRoN research. Please call DeNDRoN for more information.

### Contact DeNDRoN

Contact DeNDRoN  
Phone 0191 223 2740  
e-mail  
dendron@ntw.nhs.uk  
about the Patient List,  
the PPI Panel,  
or any of the studies.

