Studies for people with Mild Cognitive Impairment or early dementia

Emerge is a new study testing a monoclonal antibody treatment to clear amyloid from the brain, even before strands of amyloid have joined together to form plaques. This treatment, called aducanumab, is for people with Mild Cognitive Impairment who are at risk of getting Alzheimer’s, or people who have mild Alzheimer’s. Participants need to have a PET scan to show up the amyloid in their brains. It is expected that the treatment will clear amyloid early enough in the course of disease to delay the development of cognitive impairment.

CRENEZUMAB is another new monoclonal antibody treatment trial. It is also for people with early mild Alzheimer’s.

The GREAT study is looking at ways of helping people live well with memory difficulties. The study will find out whether a new form of therapy is beneficial for people with memory difficulties, as well as for their friends and family members. This research is for people with any kind of dementia. The treatment is called ‘cognitive rehabilitation’. Cognitive rehabilitation involves working with a therapist (an experienced health professional) to try to manage the impact memory difficulties can have on activities, relationships, and enjoyment of life. Half the people taking part in the GREAT trial will receive the treatment. This will show how helpful cognitive rehabilitation is.

LewyPro Mild Cognitive Impairment (MCI) is a diagnosis for some people receive who have slight changes in their memory and thinking. Not everyone with MCI goes on to get dementia. This study is for people with MCI whose symptoms (such as visual hallucinations or parkinsonism) suggest they might get dementia with Lewy bodies in the future. Participants will have tests and clinical reviews for two years. This will show which symptoms or tests (‘biomarkers’) can predict the development of dementia with Lewy bodies. LewyPro has been running for a few years, and there are over 80 people taking part. These people, and new participants, may be invited to join the SUPERB study. The SUPERB study includes a MIBG cardiac scan, the same kind of scan as in the MIDAS study.

We hope to be able to offer our first preventative study. This is testing treatment with a drug that helps stop amyloid being produced. The drug is called JNJ-54869111 and is a BACE inhibitor, reducing the activity of an enzyme involved in making amyloid. We are calling this the JANSEN study. It is not for people who have dementia or MCI, but is for normal healthy people who have some indication of amyloid by PET scan. We expect to need to screen 9 people for every one person suitable to join this groundbreaking study. Participants will not come from the Case Register, as Case Register members have a diagnosis. We will advertise this study through ‘Join dementia research’ and community organisations to get healthy older volunteers without dementia to take part.

Research Study

Control Volunteers

Some Clinical Studies need control individuals, people without a diagnosis in the same age group as the participants in a study. You can help research if you join the Control Volunteers List

Phone: 0191 223 2740
Email: dendron@ntw.nhs.uk
or Write: Dementias and neurodegeneration (DeNDRoN), St Nicholas Hospital, Jubilee Road, Gosforth, Newcastle upon Tyne, NE3 3XT

Patient, Carer and Public Involvement

Our Patient, Carer and Public Involvement Panel give their opinion about Dementias and Neurodegeneration research. They comment on new research proposals, the research studies we run, and how we go about them. Being on the PPI Panel can be as much or as little involvement as you like. Please get in touch if you would like more information about the PPI Panel.

PPI Outreach

We are delighted to visit any organisations or medical charity groups. The local team of the Dementias and Neurodegeneration Specialty can bring information and give talks. Often we make a newsletter specially for an event. Please let us know about any meetings, events, dementia cafés, carers support groups, or anywhere we can tell people about clinical research. You can see more about our research on the North East and North Cumbria Clinical Research Network website - www.makingresearchbetter.co.uk

Opportunities for research by being a member of the Case Register

The DeNDRoN Case Register is for people with any dementia or mild cognitive impairment, or Parkinson’s, or other neurodegenerative disease. People join the Case Register when their doctor or nurse suggests it to them, or because they telephone us directly. We invite people we meet at community or medical charity group meetings to consider joining the Case Register. We help Case Register members find the right clinical research study for them. At present there are over 1000 Case Register members. There have been 855 approaches to people to consider joining a research study. Most people are able to take up the offer of research when they are asked. Please get in touch if you are interested in any of the studies described inside.

To find out about national opportunities for research, people with dementia and people without a diagnosis can sign up on the ‘Join dementia research’ website https://www.joindementiaresearch.nihr.ac.uk/

Cases Register News

January 2016

Dementias and Neurodegeneration Specialty

Case Register Newsletter

for all the people on the DeNDRoN Case Register and their families

Contact us

Phone 0191 223 2740
or email dendron@ntw.nhs.uk
if you would like to know more about any of the research studies.

If you have had any changes, such as change in diagnosis, GP, or medication, or anything else, please phone us or email, or post back the ‘Change of Circumstances’ form enclosed with this newsletter.

Clinical Research Network

The Clinical Research Network is the research arm of the NHS. Research is supported in 30 different medical specialties. Dementias and Neurodegeneration is one of the Specialties. We carry out research in all dementias, Mild Cognitive Impairment, Parkinson’s, Huntington’s, motor neurone disease and other neurodegenerative disorders. We help doctors and other NHS professionals to do research. Studies can be for improving diagnosis, management or treatment of these different disorders.

NHS

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Parkinson’s Research

AC-DC is a treatment study for hallucinations. It is for people with Lewy body disorders (either Dementia with Lewy Bodies or Parkinson’s with memory impairment). This trans-cranial direct current stimulation treatment is a safe and well-tolerated technique. It can alter the level of activity in parts of the brain. It is applied to reduce activity in the visual part of the brain. It is for people with Lewy body disorders (either Parkinson’s, eye disease, dementia, and dementia plus eye disease. People’s experiences of visual hallucinations will be recorded over 21 months. The study is to find the economic impact of visual hallucinations on NHS services and society as a whole. The effect on patients and carers quality of life, and their satisfaction with treatments will be recorded. The study will describe current pathways to care and NHS service provision across the three groups (Parkinson’s, eye disease, and dementia). The risk factors that predispose people to experience visual hallucinations will be found. The study will help the design of future clinical trials into hallucinations.

The TOLEDO study is being carried out in Newcastle. It is a study to test apomorphine given by under-the-skin injection. Consultants in other parts of the region can be asked to refer patients for clinical care to Professor Burn to allow them to take part. The study requires 5 consecutive daily visits to the Clinical Ageing Research Unit, but taxi fares will be paid, and hotel accommodation if necessary. It is for people who have never tried apomorphine before, and take a levodopa-containing medicine in 4 or more different daily doses but still have ‘off’ periods that average over 3 hours a day.

The Northumbria Parkinson’s disease service team have finished a research study on the effects of exercise on heart and lung fitness. They showed improved fitness in muscles, heart and blood vessels. Another exercise study using the Speedflex training system, originally designed for the rehabilitation of athletes, is being developed. It will test if people with Parkinson’s can exercise at high intensity and how they benefit from this exercise.

SHAPED research is about the impact of visual hallucinations on quality of life and emotional well-being across four groups. The groups are Parkinson’s, eye disease, dementia, and dementia plus eye disease. People’s experiences of visual hallucinations will be recorded over 21 months. The study is to find the economic impact of visual hallucinations on NHS services and society as a whole. The effect on patients and carers quality of life, and their satisfaction with treatments will be recorded. The study will describe current pathways to care and NHS service provision across the three groups (Parkinson’s, eye disease, and dementia). The risk factors that predispose people to experience visual hallucinations will be found. The study will help the design of future clinical trials into hallucinations.

Safinamide promotes dopamine action in the brain by reducing re-uptake and degradation of dopamine. It has other actions that help facilitate movement function too. Safinamide has been approved by the European Medicines Agency for the treatment of Parkinson’s as add-on therapy to Levodopa in people with middle-stage fluctuating disease. This new study is of the long term effect of 100mg per day of safinamide, and is running at Northumbria and Newcastle. We expect to be able to offer other commercial treatment studies in coming months.

Dementia Research Studies

We hope to be able to offer the RADAR (Reducing pathology in Alzheimer’s Disease through Angiotensin targeting) study is a trial to evaluate the effect of losartan on brain tissue changes in people with Alzheimer’s. Losartan is a well-tolerated blood pressure drug. It is an angiotensin receptor II antagonist type of drug. People who have previously taken losartan seem to have a lower risk of developing Alzheimer’s. This trial will see if losartan could complement current treatments for Alzheimer’s. It might slow down the progression of Alzheimer’s by improving brain blood flow. Brain scans will measure if losartan reduces brain shrinkage, and blood samples will be taken. If it is effective, this could be an easy, well tolerated way to slow the progression of Alzheimer’s. RADAR is a pilot study to get the evidence needed to start a much larger trial to prove if there is any benefit of losartan in Alzheimer’s.

VEEG-Stim is to find out what causes hallucinations. It is examining people with Lewy body dementias, including Parkinson’s dementia, who have hallucinations. The study uses trans-cranial magnetic stimulation, which people sometimes experience as a brief flash of light.

Some studies are to improve diagnosis. It is important to tell the difference between Dementia with Lewy Bodies and Alzheimer’s, as treatment may differ. The MIDAS study is using an imaging method (MIBG cardiac scan) to look at separating Alzheimer’s from dementia with Lewy bodies. The MIBG scan is often used for diagnosis in Japan, but there is little evidence about how it compares to other diagnosis methods.

A treatment study for agitation in Alzheimer’s disease, using carbamazepine or mirtazapine, is starting soon. Called SYMBAD, this study will seek people living in their own homes as well as care home residents to join the study. Treatment is for 12 weeks, with the effect on agitation and quality of life recorded at intervals.

Early diagnosis of dementia by blood test

This study is to develop a blood test to help diagnose dementia. Proteins present in blood samples are being compared between people with different types of dementia. For people with vascular dementia, or dementia with Lewy bodies, or age-matched control individuals (without dementia), a one-off blood sample is collected. For people with Alzheimer’s a blood sample is taken before and after starting anti-dementia medication.

The AD Genetics study in early onset Alzheimer’s is open in all parts of the region. This is to map genetic risk in people who are diagnosed with Alzheimer’s before the age of 65. The vast majority of dementia is not caused by genetic factors. But there may be some genes which put people more at risk. This study will help advise families in the future.