

www.dendron.org.uk

INFORMATION ABOUT POSSIBILITIES FOR PARTICIPATION IN RESEARCH STUDIES

Participation in Research Studies means when individual patients participate in a piece of clinical research testing new varieties of drugs, new clinical methods, etc. The DeNDRoN research studies which have so far been adopted onto the NIHR (National Institute for Health Research) portfolio are included on the following website: http://www.ukcrn.org.uk/index/clinical/portfolio_new.html

- In response to enquiries from individuals around the country who are hoping to find out about specifically relevant research, the enclosed information has been prepared and may hopefully be of some help.
- Unfortunately, there will not always currently be any suitable research study. This can understandably be disheartening for people keen to consider possibilities for research participation. It can be difficult to accept for oneself, and sometimes even more difficult emotionally, if there is no research study suitable for a friend or relative. Sometimes, people say they are prepared to travel long distances, but that is usually not appropriate for a study.
- Although hopefully the enclosed information is useful, it is not a substitute for consulting a specialist doctor. Consultants and specialist nurses caring for a patient are best placed to know what research studies there might be in any part of the UK.

Research is important in helping to find the best possible treatments, improving quality of life, or finding the best possible new approach to care. It is worth remembering that being in research does not in any way guarantee better health outcomes.

One potential advantage of taking part in research for a new treatment or approach is that research participants may have their treatment and progress monitored even more closely than normal. New treatments or models of care also tend to be compared alongside the best currently available.

However, being 'in research' is absolutely no guarantee of better outcomes. It is always important to talk over any potential advantages and disadvantages with your doctor or nurse.

RESEARCH REGISTERS

Some registers of research studies are mentioned below, but:...

- **Not everyone can use the internet themselves. Even so, these websites may contain some information which a patient's doctor or nurse, who will be able to use the internet, may find of some help. If you are able to look through these sites, it might prompt some questions to raise when seeing a local specialist.**
- **Some information is hard to understand. It's often geared towards health professionals rather than participants, and contains technical jargon.**
- **Also, at the moment there is no easy way to work out what research studies might be suitable for a particular person.**
- **These are not complete lists of all the clinical studies currently recruiting participants in the UK. Occasionally, a local specialist might be aware of others, or studies in the early planning stage**
- **Many are no longer recruiting, but still on the register**
- **Some are open to one or two centres only**

DeNDRoN.....http://www.ukcrn.org.uk/index/clinical/portfolio_new.html

The DeNDRoN research studies which have so far been adopted onto the National Institute for Health Research portfolio are included on the above website.

The number and range of research studies on our portfolio will increase over time. It can be also reached via links from the DeNDRoN website: www.dendron.org.uk

MRC Clinical Trials Unit www.ctu.mrc.ac.uk/TakePart.asp

It describes studies that the Medical Research Council's Clinical Trials Unit runs, but unfortunately it doesn't currently have much detail of dementias or neurodegenerative disease-specific studies. However, it is useful because it contains excellent, thought-provoking general advice about clinical research.

Current Controlled Trials website..... www.controlled-trials.com

This is a complicated website and not at all 'patient-friendly'. It is useful for giving a picture of all the different research going on around the world, and can do a very broad INTERNATIONAL search across lots of clinical research registers. It is published by a medical publishing company. The information is geared towards health professionals and researchers rather than participants.

All research studies have guidelines about who can take part – ‘inclusion and exclusion criteria’ for who is and isn’t suitable. For example, studies may exclude people who are already taking a drug that may interact with the treatment being studied. Some trials only include people of a certain age, or at a particular stage in their illness. Many are restricted to specific types of people and sometimes only certain hospitals or parts of the UK. Some of the sites included provide links to views which DeNDRoN won’t necessarily agree with.

AN EXPLANATORY NOTE ABOUT THE DIFFERENT PHASES OF CLINICAL RESEARCH STUDIES

DeNDRoN’s focus is on “Phase 2” and “Phase 3” clinical research studies, but is also concerned with trying to push forward the frontiers for new ideas for good quality clinical research of relevance to patients and carers.

Phase 1 studies are very small early research; they only involve a tiny number of people who try out a new drug, or a new approach to improving quality of life, such as a type of medical equipment or a “model of care”. Any new drug is tested on people only if extensive laboratory work shows promising results, and the participants are monitored extremely closely for side effects.

Phase 2 studies come next, if Phase 1 results are good. They’re bigger, aiming to confirm whether a promising new drug or model of care actually helps, without causing unexpected events or adverse side effects. New treatments or models of care tend to be compared against the best currently available.

Phase 3 studies follow next, and are much larger still. They could even involve thousands of patients over many years. This research looks at the effects of a drug or model of care over time, to assess just how beneficial the outcomes are. Phase 3 studies are also used to work out the best dose of a drug, or best method of using a new model of care. Patients are sometimes divided randomly into groups to detect small differences between the overall effects over time.

RELATED WEBSITES

Much helpful information about relevant research is available on medical charity websites:

Alzheimer's Society www.alzheimers.org.uk

Parkinson's UK (*formerly the Parkinson's Disease Society*) www.parkinsons.org.uk

The Cure Parkinson's Trust www.cureparkinsons.org.uk

Motor Neurone Disease Association www.mndassociation.org

Huntington's Disease Association www.hda.org.uk

Lewy Body Association.....www.lewybody.org

Progressive Supranuclear Palsy Association www.pspeur.org

NHS Direct Online..... www.library.nhs.uk/forpatients/

General Health Information for patients. This is a list accredited by NHS Direct Online of websites of value to patients and non-clinicians. It includes, for example, some of the larger medical charities concerned with dementias and neurodegenerative diseases.

One section of this site includes some good clear pages about how clinical trials work generally, and what to expect if you take part in a trial, but doesn't provide information about specific trials:

www.library.nhs.uk/knowledgemanagement/Page.aspx?pagename=CONCLINTR

PATIENT AND PUBLIC INVOLVEMENT GROUPS

DeNDRoN..... www.dendron.org.uk

Enclosed please find some sheets about DeNDRoN (Dementias and Neurodegenerative Diseases Research Network). Patient and public involvement (PPI) means patients or carers having a say in the overall planning of dementias and neurodegenerative disease research – e.g. sitting on a committee in one of our 7 local networks in England, or helping to decide research policies at a UK-wide level. This is different from being a participant in research as such. DeNDRoN is involved with both aspects of research.

INVOLVE www.invo.org.uk

INVOLVE aims to promote and support active public involvement in NHS, public health and social care research generally. It is not specifically connected to any particular disease. I've included a leaflet about them.

People in Research website www.peopleinresearch.org

This is supported by the NHS. It lists organisations which want to actively involve members of the public in all aspects of planning research priorities to make clinical research more relevant to people's needs and concerns.