

***Patients and carers will benefit from
£3 million annual investment in Alzheimer's, Parkinson's,
Huntington's and Motor Neurone Disease research***

Patients and carers are set to benefit from quicker access to the latest treatments following the launch of seven new Local Research Networks in England to support research into debilitating conditions such as Alzheimer's disease, Huntington's disease, Parkinson's disease and motor neurone disease.

The Networks are funded by the Department of Health, as part of the UK Clinical Research Network, to coordinate and deliver research studies which focus on the prevention, diagnosis and treatment of these conditions.

Dementias and neurodegenerative diseases constitute a growing problem. Dementias alone affect over 750,000 people in the UK, creating an associated healthcare cost which is estimated to be around £7 billion.

The range of these disorders and their management is one of the major challenges facing the new Dementias and Neurodegenerative Diseases Research Network (DeNDRoN), which will build on the strengths already present in the UK whilst also aiming to substantially increase general research capacity.

Shirley Nurock cared for her husband for 15 years. She said:

“As a former carer, I know that it is often little changes that make a huge difference to people's lives. Therefore it is vital that people with dementia and their carers have a say on what outcomes of research matter to them. This network is a big step forward in making clinical research more relevant to the lives of people affected by conditions such as Alzheimer's disease.”

Patient groups have also welcomed the establishment of the new Research Networks. Kieran Breen, Director of Research at the Parkinson's Disease Society said:

"The Parkinson's Disease Society welcomes the Dementias and Neurodegenerative Diseases Research Network as it will strengthen clinical research into Parkinson's by resourcing clinical studies, supporting Society-funded research, helping to spread methodological expertise amongst researchers, and ensuring that research undertaken is relevant to the needs of people with Parkinson's.

Strengthening clinical research gives hope to people with Parkinson's that new treatments and a cure will be found and is also a key step to improving the delivery of healthcare services to the 120,000 people living with the condition in the UK."

Neil Hunt, Chief Executive of the Alzheimer's Society also supports this work:

“This is an important initiative which will strengthen research in neurodegenerative diseases, including dementia. It is crucial that effective Networks are in place to support dementia research. Dementia research is severely under funded, and effective research is our best hope of finding a cure.

This Network's role is to facilitate clinical research, and we hope that DeNDRoN will work with people with dementia and their carers to ensure that the outcomes measured in clinical research are relevant to people's lives, as well as reflecting the disease stages. The Alzheimer's Society funds research through our award winning programme Quality Research in Dementia and we look forward to working with the new Network."

The new Local Research Networks are made up of regionally based, collaborative groups in NHS Trusts, Primary Care Trusts, Hospitals and Universities managed within a host organisation. They are based in the following regions:

- East Anglia (hosted by Norfolk & Waveney Mental Health Partnership NHS Trust, led by Dr Andrew Tarbuck)
- North East (hosted by Newcastle, North Tyneside & Northumberland Mental Health NHS Trust, led by Professor John O'Brien)
- North Thames (hosted by Camden & Islington Mental Health & Social Care NHS Trust, led by Dr Craig Ritchie)
- North West (hosted by Manchester Mental Health and Social Care Trust, led by Dr Jane Byrne)
- South Coast (hosted by Hampshire Partnership Trust, led by Dr Clive Holmes)
- South West (hosted by Avon and Wiltshire Mental Health Partnership NHS Trust, led by Professor Roy Jones)
- Thames Valley (hosted by Oxford Radcliffe NHS Trust, led by Dr Rupert McShane)

Each Network will be tasked with widening participation in research as well as supporting workforce development, open and transparent communication and patient and public involvement.

An average of **£400k** will be provided to each Network annually to employ dedicated research nurses and similar staff who will support clinical teams in hospitals to facilitate involvement in dementias and neurodegenerative diseases studies. Networks will be required to work collaboratively, under the guidance of the Dementias and Neurodegenerative Diseases Research Network Coordinating Centre, to utilise this funding to its full effect, and will be encouraged to build on any existing links with clinical and research support services in their local areas.

Additional resources have also been set aside to support research activity for motor neurone disease and Huntington's disease in the Sheffield, Birmingham and London areas.

Professor Ian McKeith, Co-Director of the Dementias and Neurodegenerative Diseases Research Network, said:

"The Dementias and Neurodegenerative Diseases Research Network will forge partnerships between specialists in psychiatry and neurology together with teams in primary care who treat this large group of patients with complex and often long-term diseases. The Network will offer unprecedented opportunities to bring the latest

clinical treatments and trials to people in the UK. The new scheme will operate in close partnership with patient organisations to ensure that we are addressing the research questions that are of most importance to them.”

The establishment of the new Local Research Networks marks the next stage of development in the Government’s £100 million initiative to transform the clinical research environment in the UK. This was reinforced by the recent launch of the NHS R&D Strategy, “*Best Research for Best Health*”, which placed the creation of Research Networks at its core and confirmed the importance of clinical research as a vital component in the development of more effective health care.

Andy Burnham, MP, Minister of State for Delivery and Quality, said:

“The requirement to conduct research for the improvement of health and medical treatments was one of the founding principles of the National Health Service. The NHS has a key role to play in determining the future health and wealth of this country, and the Government is determined to harness its capacity to make the UK the best place in the world for health research.

“These new Local Research Networks will play a pivotal role in creating a health research system that boasts outstanding individuals, world-class facilities and leading-edge research focused on the needs of patients and the public.”

The Dementias and Neurodegenerative Diseases Research Network will work closely with colleagues in Scotland, Northern Ireland and Wales to support the creation of a UK-wide clinical research infrastructure for dementias and neurodegenerative diseases research.

The Welsh Dementias and Neurodegenerative Disorders Research Network is led by Professor Bob Woods of University of Wales Bangor.

At this time although Scottish UKCRC funds will not be used to establish a separate Network for Dementias and Neurodegenerative Diseases, it is expected that the additional infrastructure funding allocated in Scotland will be available to research in this area, which may also link into the Mental Health Research Network.

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Notes for editors

1. The UK Clinical Research Network was established in February 2005 to lead the development of a UK-wide infrastructure to support clinical research in the NHS. More information on the UK Clinical Research Network is available at www.ukcrn.org.uk

2. The Dementias and Neurodegenerative Diseases Research Network was created in 2005 as part of the UKCRN to support clinical research in a range of dementias and neurodegenerative diseases. More information on the Dementias and Neurodegenerative Diseases Research Network is available at www.dendron.org.uk

3. The UKCRN is working with each of the Topic-Specific Research Networks to develop a high quality and balanced portfolio of clinical research studies. Clinical

Studies Groups have been established in each Network to oversee this development process. Membership of the groups will include experts in a range of areas associated with each topic.

4. More information on the NHS R&D Strategy, “Best Research for Best Health” is available at www.dh.gov.uk/researchstrategy

5. **Dementia** affects over three quarters of a million people in the UK, and with an ageing population this figure is set to escalate. Research is severely under-funded - only £11 is spent on UK research annually per Alzheimer's patient, compared with £289 per cancer patient and there are presently few treatment options available.

The **Alzheimer's Society** is the leading care and research charity for people with all forms of dementia and their carers. It provides information and education, support for carers, and quality day and home care. It funds medical and scientific research and campaigns for improved health and social services and greater public understanding of dementia. The Alzheimer's Society provides a national help line on 0845 3000 336 and website www.alzheimers.org.uk. Please include this information in any publication that uses these comments. For more information contact: Gayle Wing, Press Officer on 020 7306 0839

6. **Parkinson's disease** is a complex, progressive condition resulting from a loss of dopamine in the brain. The three main motor symptoms are tremor, muscular rigidity or stiffness, and bradykinesia (slowness of movement). Other symptoms include tiredness, depression, difficulties with handwriting, speech, and balance. Parkinson's is very individual and the rate and nature of progression varies from one person to another.

There are approximately 120,000 people in the UK who have Parkinson's and 10,000 people are diagnosed with the condition every year. The **Parkinson's Disease Society** is the UK's leading authority on all aspects of the condition. The PDS campaigns for a better quality of life for people with Parkinson's and it invests £3.4 million each year on a wide range of vital medical and welfare research projects. The PDS has over 300 branches and support groups across the UK and a Network of field staff and community support workers and it funds Parkinson's Disease Nurse Specialists.

The general enquiries number of the PDS is 020 7931 8080. The website address is www.parkinsons.org.uk and the free helpline number is 0808 800 0303.

7. The **Huntington's Disease Association** was founded in 1971 as a self-help group with 76 members to support families and individuals affected by Huntington's Disease. It was then known as The Association to Combat Huntington's Chorea. Families at that time lived in complete isolation, unaware of the extent of the disease in the community stigmatised by its hereditary nature. They were further isolated by manifestation of the Disease itself characterised by severe physical, emotional and behavioural problems.

Huntington's disease is a progressive degenerative neurological disorder causing a steady decline of people's physical, emotional and cognitive skills. It is a genetic illness every child born to a parent carrying the Huntington's gene has a 50% risk of inheriting the gene and going on to develop the illness at some stage in their life. It affects both males and females equally, the onset of the symptoms are usually in the prime of a persons life between the ages of 30-55, although there is a juvenile form

of the illness and people have been known to develop the illness later in life. According to the office of health economics up to 50,000 people in Britain are affected by the ravages of the disease with up to 6,000-10,000 sufferers in the UK at any one time.

As yet there is no known cure for Huntington's disease. Carol Carruthers, Chair of the **Huntington's Disease Association** stated, "Sadly there is no treatment which halts the progression of Huntington's disease. However huge strides have been made towards the understanding of the illness. Many symptoms are better able to be controlled with the introduction of new drugs especially in the problematic areas of depression and emotional and behavioural disturbances. We must be hopeful that in the near future progress will be made which will result in the effective treatment. My greatest wish is that in the near future a treatment or cure will be found what a wonderful day that will be. On a positive note hardly a month goes by without the publication of research which takes us a step nearer to that goal" Visit the Huntington's Disease Association website at www.hda.org.uk

8. **Motor Neurone Disease** (MND) is a rapidly progressive, fatal illness. It leaves people unable to walk, talk or feed themselves, but intellect usually remains unaffected. With no cure, half die within 14 months of diagnosis.

The **MND Association** wants to see a world free of MND. We fund and promote research to help bring about an end to the disease. Until then, we do all we can to ensure everyone with MND receives the best possible care, achieves the highest quality of life, and dies with dignity. We are also dedicated to supporting the families and carers of people with MND. Visit the MND Association website at www.mndassociation.org