



square Imaging Centre

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Welcome | Professor Nick Fox

Professor of Clinical Neurology | Director of the Dementia Research Centre



The last year has been a positive one for dementia research internationally and locally. Internationally there have been promising results from trials of treatments for early Alzheimer's disease although, as ever, these

findings need to be confirmed in larger studies. New treatment trials have been launched in frontotemporal dementia.

There have been advances in basic science and genetics and in the tools that we have to assess the causes of dementia, such as new markers based upon cerebrospinal fluid, and novel brain imaging tracers that can detect abnormal proteins that accumulate in the brain in different dementias. These tools provide ways of "seeing" and tracking fundamental disease processes in a way that previously was not possible during life. They are already being used to improve diagnosis and they open up new research avenues. Some of these advances involved research and samples from the Dementia Research Centre - so thank you to all those who have helped in those studies.

Research at the Dementia Research Centre has continued to grow with new studies and students. Our research is very clinically based and so all this has only been possible thanks to the very generous participation of research volunteers. As demand on the clinical service continues to grow we are expanding the number of clinics that we provide.

We are keen for our research to make a practical difference to patients and their families: to add to the understanding of these devastating diseases, to improve diagnosis and care, and to help in the search for treatments to slow, stop or prevent the onset of dementia - our overriding aim. Our ability to support testing of treatments has been greatly improved by the opening of the Leonard Wolfson Experimental

Neurology Centre which is a state-of-the-art facility for in-patient and out-patient treatment trials located in the heart of the National Hospital.

In terms of the wider picture we continue to work with both Alzheimer's Research UK and the Alzheimer's Society who are doing an excellent job of lobbying for more support for research into dementia.

Our support groups continue to go from strength to strength. We have strived to make these meetings more accessible, with live streaming now available for those who are unable to attend the London meetings.

Finally, we hope you enjoy reading about the research projects featured in this newsletter, some of which you or a relative/friend may have been involved in. Without your valuable contributions our work would not be possible, and we are very grateful for this.

Research Participant Questionnaire

At the start of 2015, we asked you about your experience at the Dementia Research Centre. We were glad to hear that most of you felt positively about your visit here. Thank you also for the helpful suggestions on how we might improve things.

- Free WiFi is now available for visitors in reception
- People will receive more detailed information about research they are doing each time they visit

If you would like to know more about research at the DRC please visit our website at www.ucl.ac.uk/drc. This newsletter can only touch on a fraction of the projects at the DRC and mention just a small number of the people that make research at the DRC possible.

GENFI - Genetic FTD Initiative



GENFI is led by **Dr Jonathan Rohrer** (pictured) and studies people who have the genetic forms of frontotemporal dementia (FTD) with problems in the genes called progranulin, tau and C9orf72. In

particular we are interested in looking at the very earliest stages of FTD and so the majority of participants in the study are children of people who have developed FTD but do not currently have symptoms themselves.

Helped by our study co-ordinator **Katrina Dick** we work closely with over 20 other centres across Europe and Canada, and have recently shown that changes in brain imaging can be seen around ten years before symptoms are likely to develop.

LIFTD - Longitudinal Investigation of FTD

We continue to study people with all forms of FTD to understand its complex and difficult symptoms, which can include impairments of social conduct or emotional reactions.



Over 100 people and their supporters have very generously agreed to help us with this research. As well as understanding how the disease changes over time, we have also looked at the brain changes that occur as people with FTD understand and react to humour, sarcasm, music, abstract art, flavours, pain, temperature variations, and speech.

This work is currently being led by **Professor Jason Warren** (pictured) and **Dr Jonathan Rohrer**, with **Camilla Clark, Elizabeth Gordon, Chris Hardy, Charlie Marshall** and **Ione Woollacott** helping with the projects as part of their PhDs.

Seeing What They See

Dementia-related visual impairment restricts everyday activities, such as getting around confidently and locating objects around the home. This study aims to understand more about the impact of such impairment on people's function. We hope this will inform the design of aids and strategies that improve the quality of life and the independence of individuals affected by dementia-related visual loss.



Participants with posterior cortical atrophy (PCA) or Alzheimer's disease are being invited by **Amelia Carton** and **Keir Yong** (pictured) to take part. The research includes trying to identify what the optimal conditions for perceiving things is, and how to navigate a room and locate objects. We also perform more in-depth interviews with people in order to work out coping strategies that can support those with dementia-related visual impairment.

C-PLACID



From late Summer 2015, we will be starting a new study called *C-PLACID*. This is led by **Professor Sebastian Crutch** (pictured) **Emilie Brotherhood**. *C-PLACID* stands for '*Computational PLatform for the Assessment of Cognition In Dementia*'

Standard cognitive tests have been performed using pen and paper but new technology is now available. The aim of this study is to improve current cognitive assessments using the latest technology such as eye-tracking, voice-recording equipment, and virtual reality. We hope this can help to diagnose individuals with rarer dementias such as PCA and FTD much earlier than the current tests, which focus heavily on assessing memory.

YOAD - Young Onset Alzheimer's Disease

This study is led by **Dr Jonathan Schott** and aims to find out more about people who develop their first symptoms of Alzheimer's disease before the age of 65. **Catherine Slattery** (pictured), **Alex Foulkes** and **Ross Paterson** are the research fellows working on the study which aims to improve our understanding of young onset Alzheimer's disease (YOAD).



Alzheimer's disease can cause different problems in people who develop symptoms at an early age, such as difficulties with language, spatial awareness or problem solving. By looking in detail at the symptoms, performance on psychological tests, brain imaging and spinal fluid of people with YOAD we hope to understand it better. Over 40 people with AD and 20 control participants have completed their first visit so far.

FAD - Familial Alzheimer's Disease study

Co-ordinated by **Natalie Ryan** (pictured) and **Phil Weston**, this study investigates people who have the genetic form of Alzheimer's disease. Our main aims are to look at whether we can detect very early changes using brain scans and new memory tests. We hope that this will allow us to identify Alzheimer's disease earlier than is currently possible.



The DRC is a member of the multicentre *Dominantly Inherited Alzheimer's disease Network* (DIAN), which has recently begun the first drug trial in people with FAD. The DRC is the only UK centre involved in this trial.

We are also planning to start using brain PET scanning to visualise the two abnormal proteins (amyloid and tau) that are involved in FAD, allowing for earlier and more accurate diagnosis.

Insight 46 - MRC 1946 Birth Cohort

In March 1946, 5,000 babies born in the same week in England, Scotland and Wales were recruited into the Medical Research Council (MRC) National Survey of Health and Development study. Researchers have tracked these study members multiple times throughout their lives.



As the study members approach their 70s, researchers at the DRC are collaborating with the UCL Unit for Lifelong Health and Ageing to begin a detailed investigation of their brain health. For this brain imaging substudy, **Dr Jonathan Schott** (pictured) with **Chris Lane** and **Tom Parker** will assess 500 study members, using MRI and PET scans to identify the brain changes that accompany healthy ageing. From these scans, we will gain important insights into the factors that lead to Alzheimer's disease and other forms of dementia.

Other imaging studies at the DRC



Dr Jo Barnes (pictured) and **Cassy Fiford** are using brain imaging to look at changes in the white matter areas of the brain. White matter is a structured network of cells which act like cables to link up communicating brain regions. We hope that better understanding of how these cells can become disorganized and dysfunctional, and lead to impaired cognitive function will help in the development of improved treatments for people with dementia.

Professor Jason Warren and **Jennifer Agustus** are looking at how the brain functions in people with different dementias using a technique called functional MRI scanning. This allows us to look at which areas of the brain are active when a particular task is performed.

Cerebrospinal fluid studies at the DRC



In recent years we have started to study how changes in the cerebrospinal fluid (CSF) of people with dementia may help us to understand what is happening in the brain.

“CSF is an extremely valuable resource for researchers interested in untangling the complicated biological processes that lead to dementias such as Alzheimer’s disease and frontotemporal dementia”, explains **Dr Ross Paterson** (pictured) who is involved in the study. “Using this information in tandem with MRI scans and cognitive tests can help us to understand how the disease develops and may also help us to diagnose neurodegenerative diseases earlier”.

More than 120 individuals have already donated samples over the past 2 years and the samples are now being studied in a range of departments across UCL and in other research institutions.

Support groups

We have a number of support groups which meet throughout the year to provide support and advice to carers and individuals with dementia.

The main groups we run are for people with:

- Posterior cortical atrophy
- Frontotemporal dementia
- Primary progressive aphasia
- Familial Alzheimer’s disease
- Familial frontotemporal dementia

For more information about upcoming meetings, or for any general information about the support groups, please contact **Jill Walton** (pictured):



✉ jill.walton@ucl.ac.uk

☎ 07592 540 555

Clinical trials

The clinical trials team at the DRC are busier than ever, with 7 clinical trials open in Alzheimer’s disease and frontotemporal dementia, and several more in set up. These are exciting times in trials work in dementia with increasing focus on biomarkers that enable testing of new therapies early in the disease when symptoms and damage are mild.

A major focus is in looking for treatments for at-risk individuals with familial Alzheimer’s disease and other dementias, the results of which we hope may translate to all affected by these diseases. The



DIAN-TU study examines the possibility of preventing onset of disease in familial AD. Our team are the second highest recruiters in the world to the study, and the only participating centre in the UK.

Other studies examine the ability of drugs to slow progression in the behavioural variant of FTD and in sporadic AD. We have recently started the FORUM study in patients with mutations in the progranulin gene that causes familial FTD. The drug aims to normalise the abnormally low levels of progranulin back to normal levels and therefore halt progression of the disease.

Dr Cath Mummery (pictured top) leads the unit as chief investigator and we welcome our new clinical trials nurse, **Claire Jarvis**, who joins **Jane Douglas** (pictured below) and the expanding team with a wealth of experience in clinical trials.



We are continually looking for new ways to move forward in the clinical trials field and so we are starting to look at new drug targets such as those that affect inflammation in the brain.

We will be running observational studies alongside the clinical trials to develop markers of treatment success and to ensure we are at the frontline of new treatments in dementias.

Thank you

We would like to thank all of the people who have participated in our research and clinical trials over the last year. If you would like more information about taking part in any of our studies please contact drcresearch@ucl.ac.uk.

We would also like to thank the funding for research that we receive from funding bodies such as the Medical Research Council (MRC), National Institute for Health Research (NIHR) and Wellcome Trust, and research charities such as the Alzheimer's Society and Alzheimer's Research UK.

We are extremely grateful to all of the people who support our research through fundraising, donations and wills. If you would like to make a charitable donation to support the work of the DRC this can be done through the National Brain Appeal (www.nationalbrainappeal.org) stating that your donation is for dementia research. Alternatively, you can send cheques payable to Dementia Research to the Dementia Research Centre, Box 16, National Hospital for Neurology and Neurosurgery, Queen Square, London, WC1N 3BG.

CANDID

CANDID (Counselling And Diagnosis In Dementia) is a nurse-led information and advice service that has been run from the DRC for more than 10 years.

It offers a wide range of advice on how to access information such as legal and financial matters. We can also help to explain the role of other support services in the care of people with dementia.

CANDID is available to patients and families registered with the Specialist Cognitive Disorders Clinic at the National Hospital for Neurology and Neurosurgery.

To contact CANDID please call our Consultant Nurse Katy Judd (pictured):

 katy.judd@uclh.nhs.uk

 0203 448 3467



Professor Martin Rossor

Director of the NIHR Queen Square Dementia Biomedical Research Unit

2015 has been a busy year for Martin. He has been key in setting up the Join Dementia Research collaboration to allow volunteers and researchers to link up for research.



The www.joindementiaresearch.nihr.ac.uk website offers a secure and easy way for someone to register their interest, discover studies that interest them, and ultimately connect with researchers to take part in their studies.

As Director of The Queen Square Dementia Biomedical Research Unit (BRU) Martin is pushing forward research with a focus on young onset dementias in order to achieve the aims of developing new methods of diagnosis and treatment.

