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**Alzheimer's  
Society** | Leading the  
fight against  
dementia

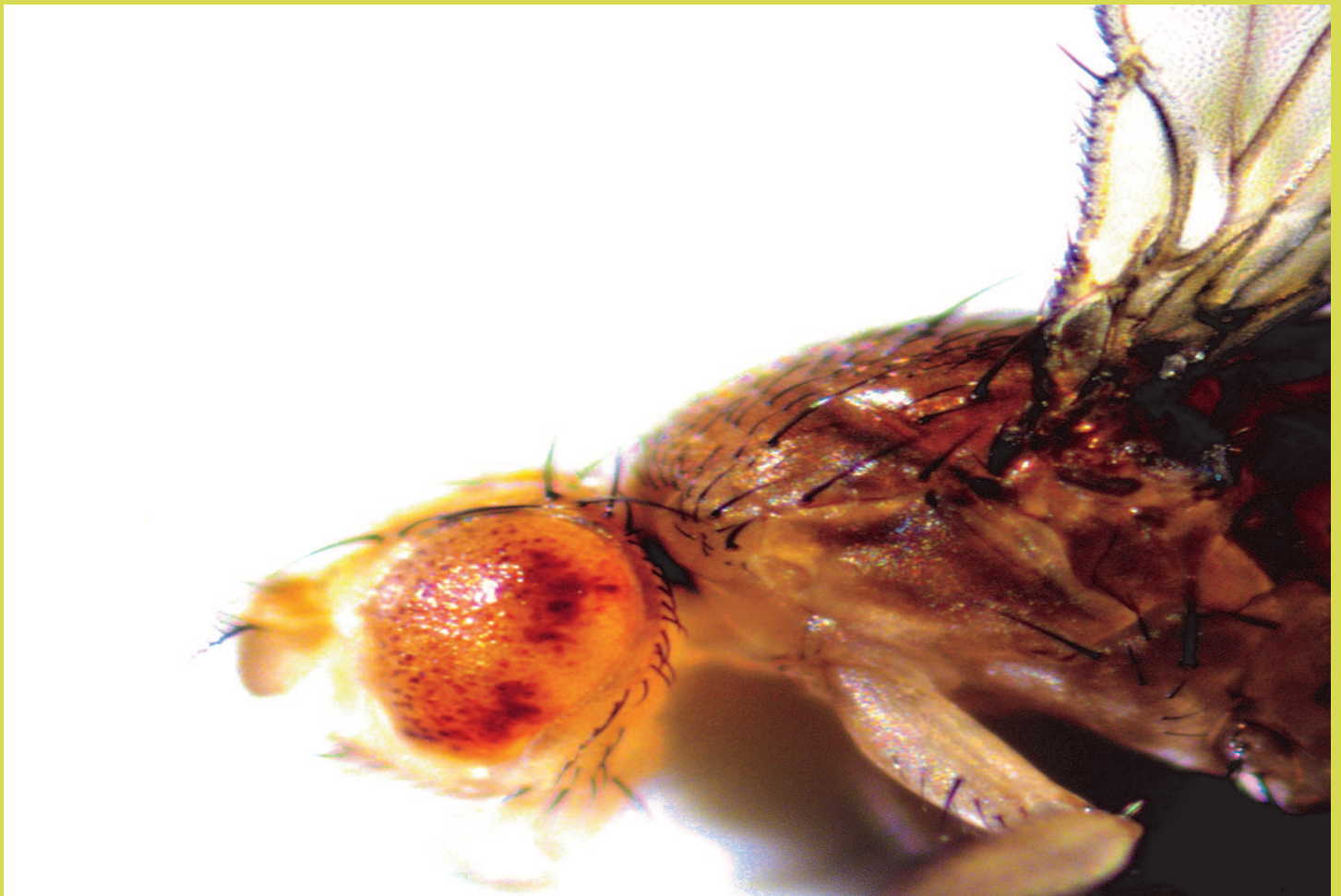
# Research newsletter

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Quality Research in Dementia

July 2012  
Issue 119

Research into fronto-temporal dementia | FITS programme launched



# Notes from the editor

Jess Smith, Research Communications Officer



This month we highlight a research project by one of our funded PhD students. Ryan West is supervised by Dr Sean Sweeney

at the University of York, and is using fruit flies to conduct research into fronto-temporal dementia. Alzheimer's Society is committed to building the dementia research community of the future, and funding PhD students to begin their careers in dementia research is vital. This project is also an example of our funded research into rarer forms of dementia.

Alzheimer's Society Research has launched its new FITS (Focused Intervention Training and Support) programme, which is a

person-centred care training programme for care home staff. An earlier research project funded by Alzheimer's Society found that this particular training programme reduced antipsychotic prescriptions for people with dementia by 50 per cent.

The development of the original research into the FITS programme demonstrates how progress has already been made as part of the new prioritisation of research within the Society's new five-year strategy.

## New resource for Cochrane database on dementia reviews

A website for the ALOIS Community project has been launched. The project is run by the Cochrane Collaboration, and focuses specifically on the reviews that they have conducted into dementia-related research.

The Cochrane Collaboration conducts systematic reviews of research studies. It collects all of the available evidence on a topic, and further analyses the results to establish whether a specific intervention or therapy has positive or negative effects, or whether the current data is inconclusive.

To find out more about the ALOIS Community project and to read the reviews in the database, go to [alois.cochrane.org](http://alois.cochrane.org)

### On the cover

*A Drosophila melanogaster* (fruit fly), genetically altered to express proteins relating to fronto-temporal dementia in its eye. The dark parts of the eye are due to damage caused by these proteins, which helps researchers to understand more about the proteins and fronto-temporal dementia. Image courtesy of Ryan West.

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# Research in the press



An overview of research stories that have made the national press in the last month and how Alzheimer's Society commented on them.

A study from the United States has been one of the first to see laboratory results reporting the benefits of caffeine in reducing the risk of developing dementia translated into benefits for people. The study measured the amount of caffeine in participants' blood and tested them to determine whether they were cognitively normal, had mild cognitive impairment or had dementia. After two to four years, they found that the participants in the MCI group who had higher levels of caffeine in their blood were less likely to progress to having dementia than those with lower levels.

Professor Clive Ballard, Director of Research, commented, 'This small study adds some further weight to the emerging evidence suggesting caffeine could prevent or delay the onset of Alzheimer's disease.'

As one of the first studies to include people with mild cognitive impairment, the results are significant. Further clinical studies

and research into the link between caffeine and dementia is now needed.'

Chronic stress is being investigated in an Alzheimer's Society funded research project as a risk factor for developing dementia. The study will involve 18 months' monitoring of 140 people aged 70 and over with mild cognitive impairment, compared with 70 people without memory problems. The participants will be assessed for levels of stress and any progression from mild cognitive impairment to dementia. About 60 per cent of people with mild cognitive impairment are known to go on to develop Alzheimer's disease.

Dr Anne Corbett, Research Communications Manager, explained, 'The study will look at the role chronic stress plays in the progression from mild thinking and memory problems – mild cognitive impairment – to Alzheimer's disease.'

'The results could offer clues to new treatments or better ways of managing the condition. It will also be valuable to understand how different ways of coping with stressful life events could influence the risk of developing Alzheimer's disease.'

A study has linked findings related to an antibody in the blood of people with Alzheimer's disease, and a vaccination for the same antibody in a mouse model of the

disease. The researchers found that in people with Alzheimer's disease with more antibodies against the protein ankyrin G (AnkG), symptoms progressed more slowly. The study also showed that if Alzheimer's disease model mice were vaccinated against AnkG, the level of amyloid-beta in their brains reduced and the health of their brain cells was improved. However, no improvement in symptoms was seen in the vaccinated mice.

Dr Corbett said, 'Finding a vaccine against Alzheimer's disease would be an exciting and life changing matter for people living with the condition. This study has identified an interesting new protein that appears to be linked to progression of symptoms, but this research is in its very early stages. The AnkG vaccination reduced levels of beta-amyloid in mice, but there was no improvement in symptoms of Alzheimer's disease. Therefore, further research is needed in mice, to see if AnkG can affect symptoms, before it could have the potential to be tested in humans.'

'Research like this is essential if we are to develop treatments and ultimately a cure. This spring the Prime Minister promised to double investment into dementia research. We must now ensure this money is used to make the biggest difference possible for people with dementia.'

# Research update: FITS project launched and event reports

## Project launched: Focused Intervention Training and Support (FITS) for person-centred care

Nicola Hart, Research Project Support Officer, Alzheimer's Society

Alzheimer's Society has launched the first stage of its government-backed staff training programme in care homes across the UK.

Alzheimer's Society has developed the Focused Intervention Training and Support (FITS) for care homes, an evidence-based training programme designed for care home staff. The programme trains staff to deliver person-centred care to safely help manage behavioural symptoms of dementia as an alternative to using antipsychotic drugs.

A person-centred approach to care is focused around recognising that each person with dementia is unique. This involves gaining a better understanding of individual residents, taking into consideration their personality, interests, skills and life history. The needs of each person should be central to all care planning to ensure they receive a supportive social environment and are able to experience activities that are meaningful to them. With this approach, staff can support people with dementia and their families to identify the 'triggers' that are likely to result in disruptive behaviour and therefore help to prevent them from occurring.

A research study previously funded by the Society was designed to test whether the FITS programme could reduce the need for people to be treated with antipsychotic drugs. The study was carried out over a nine-month period across 12 care homes. The training programme was shown to successfully reduce the use of antipsychotics by almost 50 per cent in comparison with usual care, without worsening behavioural symptoms. Additional improvements were also seen in residents' well-being and social engagement.

The programme is now being rolled out on a wider scale to 150 care homes across the UK, with the support of the Department of Health, the University of Worcester and HC-One care homes. The programme provides care staff with an understanding of the person-centred care framework as well as equipping them with the skills to train other

care staff. As two-thirds of people in care homes have dementia, it is estimated that the training programme could reach and benefit 3,000 people with dementia while also protecting those in the future. Care home staff receive 10 days of training to increase their awareness and understanding of dementia, and develop skills to deliver person-centred care and manage behavioural symptoms. Skills-based training will include positive care planning, awareness of environmental design, development of individualised interventions, active listening and communication, reminiscence techniques and the involvement of family members. The course will be followed by regular supervision sessions to ensure staff are confident to implement the skills they have learnt in their daily work and pass their knowledge and practice on to others around them.

There is strong evidence that this non-drugs-based intervention will reduce the inappropriate use of antipsychotic drugs and improve health outcomes, so helping to enable people to live well with dementia.



Care home staff will be trained in better person-centred care by the FITS programme.



## Antipsychotics focus group: A Research Network volunteer perspective

Susan Kelliher, Research Network volunteer

In May, I was privileged to join a focus group of nine carers and people with dementia to discuss the use of antipsychotics in the treatment of dementia. This group formed part of a European collaboration between the Netherlands, Norway and the UK to reach a consensus on guidelines for the use of antipsychotics in the treatment of dementia.

All participants had experience of caring for someone who has been prescribed antipsychotics, either currently or in the past. This meeting was facilitated by Professor Alistair Burns (National Clinical Director for Dementia, Manchester University) and Matt Murray (Alzheimer's Society).

I joined the group as my 87-year-old father has been on the antipsychotic amisulpride (trade name Solian) for the past five years, despite our attempts to have the drug reduced, then withdrawn, four years ago. Unfortunately, within three months it had been re-prescribed. I was interested to hear about others' experiences and to ascertain whether or not there were alternatives to antipsychotic use in the treatment of neuropsychiatric symptoms of dementia. Given there is only one antipsychotic, risperidone, licensed to be used in the treatment of dementia, it begs the question as to why other antipsychotics have been, and continue to be, prescribed.

We discussed whether there was any justification for the use of antipsychotics at any time; what, if any, would be the threshold for when prescription of antipsychotics could be justified; and issues surrounding consultation with the family caregiver regarding the use of antipsychotics. A lively and poignant debate ensued and the general consensus appeared to be that antipsychotics should not be prescribed at all, under any circumstances, but that alternatives should be explored.

Regarding outcomes, one would hope that suitable alternative treatments can be established that will lead to a better quality of life for all those living with dementia.

## Medicine and Me: a one-day conference

Matt Murray, Research Network Volunteer Co-ordinator, Alzheimer's Society

Alzheimer's Society staff, researchers and Research Network volunteers took centre stage at an event held at the Royal Society of Medicine on 29 May. The event, Medicine and me, is part of a series of meetings designed to bring together specialist healthcare professionals with patients and carers to discuss and learn about different chronic conditions.

An audience of over 60 delegates, including many people with dementia, appreciated the quality and range of all the speakers.

Highlights included some of our own leading researchers such as Professors Nick Fox, Carol Brayne, Clive Ballard and Dawn Brooker, who presented updates on treatment options, risk factors and the future direction of dementia research. Patient and carer perspectives were powerfully presented by Anne Johnson, Caroline Ogden and Barbara Woodward-Carlton, who is the Research Network Area Co-ordinator for Yorkshire. Leon Smith, Chief Executive of Nightingale and Jason Corrigan of Four Seasons also presented innovative ways of providing

better standards of residential care.

Although time for discussions was short, I was impressed by the consensus between researchers, carers, people with dementia and social care providers of the importance of providing high quality person-centred care and in reducing the prescription of antipsychotics. There also seemed to be a great appetite for developing better non-pharmacological treatments and improved diagnostic methods.

# Research into fronto-temporal dementia

Ryan West, PhD student, University of York

Working in the Sweeney lab at the University of York, my research predominantly focuses on the study of fronto-temporal dementia, using *Drosophila melanogaster* (fruit flies).

While the similarities between a fruit fly and ourselves don't seem particularly obvious and thus the idea of using a fruit fly to study human neurodegenerative diseases may seem convoluted, *Drosophila* have proven to be an invaluable tool in the study of disease. In fact we share around 60 per cent of genes with flies and 70 per cent of all genes and proteins implicated in neurodegeneration in humans have a counterpart in *Drosophila*. Furthermore *Drosophila* have a well-studied, intricate nervous system and are capable of displaying complex behaviours, including learning and memory. A toolbox for genetic manipulation unrivalled in any other organism, rapid generation times and short lifespan (allowing for fast study of age related disorders), mean that fruit flies are becoming the model organism for the study of genetic causes of neurodegeneration.

In our research we have developed two *Drosophila* models of fronto-temporal dementia in which we increase the amount of disease causing proteins in the fly eye. Because the fly eye is so regularly shaped and composed of repeating identical units any minor perturbations, induced by our manipulations, become amplified and visibly very obvious (see front cover image).

The disease related proteins we work with are human Chromatin modifying protein 2B (CHMP2B) and Valosin containing protein (VCP). Using these models we are able to ask which other proteins, encoded by the whole *Drosophila* genome, might be acting to trigger the disease. In this way we identify new novel factors that influence fronto-temporal dementia and unravel the biological pathways that drive disease progression, giving us greater understanding of the causes of neurodegeneration and potentially identifying targets for treatments. Through this approach we have identified a number of factors that influence neurodegeneration, including a

small protein called Rab8. Rab8 is one of numerous Rab proteins that act in all cells to regulate the traffic of cellular components around the cell. We have shown that mutations in Rab8 significantly increase toxicity associated with a disease-related form of CHMP2B that leads to fronto-temporal dementia. We also demonstrate that Rab8 disruptions lead to significant perturbations in normal neuronal development, identifying Rab8 and the biological pathways it is involved in as important to normal neuronal development and neurodegeneration, particularly in the context of fronto-temporal dementia.

We are making excellent progress in our research and I really enjoy the fact that I am working in a field that impacts so many people, both patients and carers. I also like that we are working on a relatively un-studied and under-appreciated disease, making any contributions that we can make even more worthwhile.

## Jargon buster: Fronto-temporal dementia

'Fronto-temporal dementia' covers a range of conditions, including Pick's disease, frontal lobe degeneration and dementia associated with motor neurone disease. All are caused by damage to the frontal lobe and/or the temporal parts of the brain - the areas responsible for our behaviour, emotional responses and language skills.

Fronto-temporal dementia is a relatively uncommon form of dementia. As a result, many people (including health professionals) may not have heard of it. Overall, it occurs less frequently than other conditions such as Alzheimer's disease. However, in younger people, specifically those under the age of 65, it is the second or third most common cause of dementia.

You can find out more about fronto-temporal dementia in Alzheimer's Society's factsheet 404, What is fronto-temporal dementia (including Pick's disease)?

# 60 seconds with...Ryan West

Ryan West is a PhD student in Dr Sean Sweeney's lab at the University of York. Ryan is in the second year of his project investigating fronto-temporal dementia.

What did you study at University?  
Biology

What led you into dementia research and why?  
During an industrial placement year at Eli Lilly I worked on developing models of Parkinson's disease. I think this year kindled my desire to stay working in research and swung my interest focus towards neuroscience.

What has been your biggest research achievement/most exciting moment of your career?  
The identification of severe neuronal overgrowth associated with mutations in Rab8. This is a significant characteristic, identifying Rab8 as a regulator of normal neuronal development.

What is the best/most surprising part of being a scientist?  
Science is about completing puzzles and the best part is probably when you bring all the seemingly disparate pieces together and can see with some clarity how it might go together.

What does Alzheimer's Society represent to you?  
As well as the funding it has already given me so many opportunities to develop as a researcher. From my colleagues in the department it is clear that not every funding body takes such an



Ryan West in the lab

interest in the development of its researchers.

What is the most difficult part of being a research scientist?  
One of the most important and frustrating lessons to learn is that things go wrong and experiments don't always go as you may have hoped or expected.

What is the best part of working with Alzheimer's Society?  
It has to be the opportunities to meet and liaise with the Research Network volunteers. They keep us grounded and remind us why it is we do what we do.

Name one place that you would like to go back to?  
I would love to go back to Iceland. The whole landscape and country is spectacular and a must visit if you ever get the opportunity.

How do you relax outside of work?  
I am currently in the process of renovating my first house with my long-suffering girlfriend. It's not always the most relaxing but it is very satisfying and keeps me occupied.

Favourite brain function?  
It would have to be sensory perception, in particular responses to music. I have always got my headphones in. I'm always amazed by the effect music can have on people and it's a great way to change a person's mood.

Favourite limerick?  
I'm the whole of my parts, so they say!  
And unique are my parts, DNA.  
They're tiny in size,  
But they sure humanize  
My nature and features, ôle!

Which superhero would you be?  
Probably Iron Man as he is a charismatic, genius, engineer and philanthropist rather than just having supernatural powers.

If you could take only one album to a desert island, what would it be?  
If I were forced to choose it would have to be between Wish you Were Here by Pink Floyd, Into the Wild by Eddie Vedder and the live album of David Bowie's Reality tour. But I don't know if I could choose.

What did you want to be when you grew up?  
I think this probably changed more times than I can remember. I know at one point I wanted to be in the RAF, another a surgeon, a vet and of course the obligatory want of a small boy to be a professional sportsman, either a footballer or rugby player.

## The Research Network

People with dementia and their carers are integral to our grants programme. We believe that they make a unique and valuable contribution to our work. Their knowledge and passion ensures our research funding is allocated to projects that address the real needs and concerns of people with dementia and their carers.

Research Network volunteers:

- set our research priorities
- prioritise and comment on grant applications
- sit on grant selection panels
- monitor ongoing projects funded by Alzheimer's Society
- tell others about the results of research.

If you have been a carer for someone with dementia or you have dementia and are interested in joining the Research Network, please contact Matt Murray, the Research Network Volunteer Coordinator and request an application form, or go online at [alzheimers.org.uk/researchnetwork](http://alzheimers.org.uk/researchnetwork)

If you are not a carer or a person with dementia, but you would like to learn more about our research and keep up to date, you are welcome to become a **Friend of Research**. Just fill in the form on the website (above) and you'll receive a monthly copy of the Research newsletter and information on all our research events.



Sunrise Senior Living is generously sponsoring the Research Network. Alzheimer's Society maintains editorial independence over this content.

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