



# DEMENTIA COLLABORATIVE RESEARCH CENTRES



**W**elcome to the November issue of the DCRC Newsletter. You will notice a newly designed format and less pages. We will be reducing the Newsletter to two issues a year but providing news and updates through E-Newsletters on a regular basis.

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## 2010 National Dementia Research Forum is a Resounding Success

**C**onference Chair, Elizabeth Beattie, DCRC QUT, was in her element, ensuring that the conference provided a very happy and fun environment.

In Elizabeth's welcome, she advised that since the 2009 Forum held in Sydney, the DCRCs have been successful in receiving ongoing funding from the Australian Government for a second triennium. This has enabled continuation of the vision for greater dementia awareness, earlier diagnosis, smarter prevention and treatment, more responsiveness, compassionate and flexible care and broader options in service provision and support. Part of this vision became a reality over the two-day Forum when a large number of speakers had the opportunity to tell the 300 plus audience what has taken place with regard to Early Diagnosis and Prevention; Assessment and Better Care; and Carers and Consumers.



Henry Brodaty AO; Elizabeth Beattie; Her Excellency the Governor, Penelope Wensley AO; Marc Budge; Sallyanne Atkinson AO

### Special Guests

Special guests included Her Excellency the Governor of Queensland, Ms Penelope Wensley AO, and the Federal Minister for Mental Health and Ageing, the Honourable Mark Butler MP.

Her Excellency had her own personal story to contribute of her grandmother who had suffered undiagnosed dementia. She spoke of the fact that the treatments and interventions available are too primitive to deal with the disease as is the language for describing the experience of living with it. She

## Translating Research Into Practice

stressed how urgent it was to have preventative measures, a cure and the importance of continued Government funding support. The dementia figures, as all know who work in the area, are frightening and the challenges are great. On the other hand, she spoke of the pleasure she has in signing hundreds of letters each year congratulating those in the Queensland community who have reached their 100th year and beyond.

Newly-appointed Minister for Mental Health and Aged Care, Mark Butler told the audience of his involvement in the aged care sector over the last 15 years, working closely on policy with providers and consumer groups. He spoke of his wish to be the Minister for Ageing because he strongly believed that one of the truest tests of a decent society is how it treats its seniors; the citizens who for years worked hard, paid taxes and raised families – and who now need our care and support. He went on to say that whilst Australia has a proud record in the areas of ageing and aged care, we can and should be doing better.

**Overseas Speaker**

This year’s overseas speaker Professor Lou Burgio, the Harold R Johnson Professor of Social Work and Research Professor, Institute of Gerontology, University of Michigan, spoke on “Lost in Translation: implementing dementia caregiver intervention programmes in community settings”.

Professor Burgio has, however, successfully developed a programme where community-based participatory research methods have been used to translate the REACH II RCT for feasible use in the community. Delegates were able to gain knowledge regarding the challenges facing translation efforts and see that one strategy for translation interventions can be defined. The results have shown that there is a decrease



**Michael and Jane D’Arbon - who feature in the film The Long Goodbye with Her Excellency Ms Penelope Wensley AO, Governor of Queensland**

in behaviour problems, an increase in social support, improved self care and a decrease in depression. The importance of the clinical trials is to focus on internal validity and not external validity.

As Prof Burgio acknowledged, there are no manuals for many projects, and this is certainly the case for Translational Research. There are no commonly accepted procedures - there is common terminology but no methodology. Focus groups have played an important role in the research and modules have been designed to include physician care communication and bereavement prior to death. After the patient has died, the program is followed up through family members. Formal certification is required to run the program and training is provided in a workshop format with retraining required after six months. Assessment of the outcome is mandatory – however the clinicians question why the assessment is required. Formal screening for burden is an entry criteria to the programme; 6 visits as home sessions over a period of 6 months are carried out and agency staff are taught that translation is a process and communication is of utmost importance. An

Action Guide to using REACH OUT is to be produced.

**The DCRCs**

Presentations were made by DCRC Directors and DCRC researchers addressing the work being carried out in each of the three DCRCs, together with an update by Professor Ralph Martins and Dr Simon Laws on the Blood and Brain Biomarkers for Alzheimer’s disease.

*Workshops were well received with topics discussing:*

- National Quality Dementia Care Network: Priorities, strategies and consumer involvement;
- Brokering the translation of research into practice through education; Australians love to drive: What do drivers over 55 say about dementia?;
- REACH OUT: an evidence-based caregiver support programme adapted for use in the community;
- Decisional capacity for people with dementia;
- Better understanding of behavioural and psychological symptoms of dementia through computer modelling;
- Intervention research – are you ready?;
- Dementia in Aboriginal and Torres Strait Islanders: do we yet know what we don’t know?;
- Hoisting the sail and tilling the rudder: navigating a clear course in practice-based dementia research;
- Communicating dementia prevention strategies: evaluation of a website for educating consumers and health professionals.

**“The Long Goodbye”**

One of the Forum highlights each year is the pleasure of coming together with Michael and Jane D’Arbon. Michael unfortunately has early-onset dementia and each year they give an update of how their year has gone for Michael, Jane and their family. Michael and Jane have, in the last twelve months, noticed some further deterioration in Michael’s condition



**Henry Brodaty and Lou Burgio**



Henry Brodaty AO; The Honourable Mark Butler MP; Sallyanne Atkinson AO; Elizabeth Beattie; Sue Pieters-Hawke; Marc Budge

and while Michael, at 52 years of age, is managing to conduct his life as best he can the frustrations and challenges are certainly there and concerning.

A 55-minute very moving documentary by Luminous Films Pty Ltd directed by Kaye Harrison and produced by Gina Twyble and titled "The Long Goodbye" was screened during the conference. The film features Michael and Jane together with two other older couples, each of whom have one spouse with advanced dementia, and the struggle they have to maintain their dignity and identity for those they love and care about. The film celebrates the capacity of the human spirit to search for meaning and hope when the end is inevitable. The documentary will be shown on ABC TV in 2011 and is available through Alzheimer's Australia Library – [www.alzheimers.org.au](http://www.alzheimers.org.au)

### A Lively Panel Discussion Session - Sexuality in Residential Care

Although many of us would not think about sexuality in residential care, it has proved to be an issue in older adults, particularly those in residential facilities. Unfortunately care staff can sometimes react to residents' expressions of sexuality in negative ways, as something that needs to be controlled or treated. What has been forgotten is that older adults continue to need some form of intimacy in their lives. A lively panel discussion session, expertly facilitated by Rhonda Nay, comprising a researcher, a clinical director, an expert in the care of older people and a clinical nurse consultant specialising in geriatrics and aged care, suggested that residential care facilities should be encouraging the appropriate expression of sexuality and intimacy. This can be done in many ways, for example visiting by partners, offering the privacy they deserve, or

providing companionship through the use of dolls and or pets. Clothing – soft to the touch and feel – could be offered to residents which encourages sensuality.

### Alzheimer's Australia Mind Your Mind Website

A visit to the Alzheimer's Australia *Mind Your Mind* Website is highly recommended – [www.mindyourmind.org.au](http://www.mindyourmind.org.au)

The website was launched at the Forum and is a ideal tool for increasing awareness of the measures that can be taken to reduce the risk of developing dementia. It is accessible, easy to navigate and includes news, quizzes and a blog layout explaining ways to reduce the risk of dementia by adopting a "brain healthy" lifestyle – including a look at YOUR brain, diet, body, health checks, social life, habits and head.

### Bonding Together

The Gold Coast prides itself on sun and fun. The sun was not always evident, but the fun was certainly there. The Queensland Committee had ensured that the Conference Dinner would be long remembered and for those who attended, it was a laugh a minute and an excellent team building exercise. Imagine spending nearly an hour on a "pineapple quiz". Whoever would have thought there was so much to learn about the PINEAPPLE!

If you have any feedback or require further information on the Forum, please contact Ruth Lilian, Editorial Assistant on [r.lilian@unsw.edu.au](mailto:r.lilian@unsw.edu.au)

## NEW PRODUCT

### Comorbidities of Dementia – Summary Report

*Authored by Susan Kurrle, Roseanne Hogarth and Jennifer Hill, Curran Ageing Research Unit, Division of Rehabilitation and Aged Care, Hornsby Ku-ring-gai Health Service, Hornsby NSW*

#### Introduction

Multiple comorbid medical conditions are common in the older population both with and without dementia. A number of these medical conditions may occur more commonly in people with dementia.

A review of the scientific literature has been conducted to understand more about these physical comorbidities which are associated with dementia, and this paper describes the results of the review. More information on this publication can be found at –

[www.dementia.unsw.edu.au/research/assessment\\_and\\_better\\_care](http://www.dementia.unsw.edu.au/research/assessment_and_better_care)

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## NEWS FROM THE CENTRES

### Early Diagnosis and Prevention

**Director: Marc Budge**

#### Recent Research Achievement(s)

Our initial 11 projects are all now up and running. During the National Dementia Research Forum held recently on the Gold Coast a number of these projects presented posters including the ANDI-II project conducted by ANU and the DAPHNE project conducted by the University of Queensland. The Mind Your Mind website was also launched at the forum and Dr Maree Farrow held a follow up workshop to create awareness of the website and gain important feedback into the value of its content from workshop attendees. For more information please visit the website at [www.mindyourmind.org.au](http://www.mindyourmind.org.au).

#### Research in the pipeline

A new and exciting project has been proposed by Professor Chris Rowe from Austin Health. The study will investigate the prevalence of brain amyloid in the older Australian community through PET and MRI imaging. Evidence shows that the accumulation of excess beta-amyloid in the brain is both the first and an essential step in the development of AD. Reports on the prevalence of brain amyloid in the healthy elderly vary from 15% to 55% in normal elderly persons over 60 years of age. The aim of this study is to clarify the prevalence of brain amyloid in the healthy elderly Australian population and look at the relationship to cardiovascular risk factors, brain atrophy and cognitive decline over time.

#### Other news

The DCRC-EDP has awarded three Post Graduate Scholarships to students completing higher research degrees focused on the early diagnosis and prevention of dementia. Dr Paul Yates has been awarded a scholarship to complete a Doctor of Medical Science at the University of Melbourne. Paul's project will use PET and MRI imaging to characterise patterns of B-amyloid and structural brain changes, and correlate these with cognition, and markers of vascular risk. Ms Sarang Kim was awarded a scholarship to complete a Doctor of Philosophy (PhD) at the Australian National University. Sarang's project aims to identify individuals who would benefit the most from an online dementia intervention and will also identify factors that

motivate and discourage people from changing their behaviour. Ms Rhona Creegan has been awarded a scholarship to undertake research towards the completion of a PhD. Rhona's project will utilise state-of-the-art electrospray ionization mass spectrometry (ESI-MS) to characterise lipid profiles of individuals with Alzheimer's disease and compare these to cognitively healthy individuals with the aim of identifying novel biomarkers.

### Assessment and Better Care

**Director: Henry Brodaty**

Since the last newsletter Katrin Seeher commenced her PhD scholarship on 1st July and the DCRC ABC awarded two new PhD scholarships to Kasia Bail and Jacqueline Wesson. Katrin will be examining the effects on supporters of people with Mild Cognitive Impairment. Kasia, a nurse and education graduate based at University of Canberra, will be supervised by Professor Diane Gibson and Dr Laurie Grealish. Kasia will be using nurse sensitive indicators' to examine hospital dementia services. Jacki, an occupational therapist, will commence her doctorate in January at the University of Sydney under the supervision of A/Professor Lindy Ciimsen. She will be investigating the use of the Large Allen's Cognitive Level Screen (LACLS) Tool to identify and manage functional impairment.

We are very pleased that Claire Thompson is our first DCRC-ABC PhD student to have submitted her thesis. Claire investigated the use of prospective memory (i.e. remembering that you have to do something in the future such as keep an appointment, pick up the milk on the way home) as a diagnostic tool. Her research won the poster prize at the recent National Dementia Research Forum.

The three DCRCs are partnering with Alzheimer's Australia in the establishment of the National Consumers Dementia Research Network and are in large part funding the position of Dr Ellen Skladzien, the Consumer Network Coordinator. On 6th and 7th September Elizabeth Beattie and I participated in the Quality Dementia Care Summit in Sydney which decided on priorities for knowledge translation projects.

On 22nd September the NSW Dementia Services Framework was launched at Parliament House in Sydney by the Deputy Premier of NSW and Minister for Health, Carmel Tebbutt, and the Minister for Ageing, Peter Primrose, in conjunction with Alzheimer's Australia NSW. The framework was drafted by the NSW Dementia Policy Team which comprises Anne Cumming, Troy Speirs and myself and is supported by the DCRC-ABC. Further information visit [www.health.nsw.gov.au](http://www.health.nsw.gov.au)

We are pleased to welcome Dr Melissa Slavin as our new post-doctoral research fellow. Melissa, who has a wealth of experience in neuropsychology and neuroimaging, will be focussing on assessment of cognitive decline and dementia in the very old, i.e. those over 90 for whom most tests lack norms.

Finally, I would like to congratulate Elizabeth Beattie, Susie Wise and their colleagues at QUT on an outstanding National Dementia Research Forum.

### Carers and Consumers

**Director: Elizabeth Beattie**

Since the last newsletter DCRC: CC has hosted the national Forum, which was a first and challenging experience for us all! An aspect of the Forum I found exciting was to see some new faces amongst the attendees, evidence that we are extending our reach and attracting interest. Talking with many of the younger delegates I found myself a bit wistful – wishing I were just starting my career, young and vigorous with more years ahead than behind, because it is such a promising time to be involved in dementia research and evidence-based practice change. Never before has the demographic imperative been so clear and the stakes so high for those who will be diagnosed with a dementia in the next decade – in terms of caring and quality of life research, our focus in DCRC: CC, we need to generate evidence and improve many things fast. Yet we face the challenge that research done well with vulnerable people, especially in the real world of the community and residential aged care, takes time. Much as all of us want answers to persistent questions immediately, to prevent or ease suffering, we can't have them tomorrow.

I think it is fair to say that never before have we had the level of government commitment we have now, the critical mass of connected dementia-focused researchers we have now and the level of growing public awareness we have now. But

it is still not enough. While we work on answers to new questions what we can do is increase the speed and agility with which existing knowledge gets into practice and focus on some of the critical knowledge gaps and research with outcomes most relevant to the everyday lives of carers and consumers. To make this happen we will be working with the Quality Dementia Care Network, to get carer and consumer input and involvement for all phases of our research projects, from idea to outcomes dissemination.

DCRC: CC has new projects starting in the areas of caregiver support in acute care settings, the impact of the use of a robotic seal (PARO) in reducing selected behavioural and psychological symptoms of people with dementia, and sexuality and sexual expression in the context of residential aged care. Projects in planning focus on decisional capacity and informed consent for research participation, food and nutrition in residential aged care, caregiver support using positive-emotion focused training, and dyad (person with dementia and carer) focused interventions to improve rest, sleep and wayfinding. Soon we will be advertising for applications for our first post-doctoral Fellow position, with a focus on quality of life and care in dementia.

We are pleased to welcome Meredith Gresham to our group as the new representative from our partner HammondCare. Richard Fleming has moved into a new role with the University of Wollongong and will remain involved with DCRC: CC projects in his areas of interest. Sincere thanks to Susi Wise, centre manager, whom we farewelled at the end of Forum 2010. We welcome Sue White as our new interim Project Manager. Sue brings a wealth of expertise to the DCRC: CC from her previous managerial leadership role at Pfizer and enthusiasm to work in support of dementia research.

I would like to acknowledge the DCRC collaborating research partners for all that they did in reviewing abstracts, presenting and chairing sessions and bringing their expertise and commitment to Forum 2010, especially Rhonda Nay for being willing to look foolish alongside me for the cause. Finally we have wonderful staff at the DCRC: CC and the DTSC (Qld) who worked hard before, during and after the Forum as volunteers. I was horrified when I first saw their orange shirts - a bit out of sync with the 'pineapple' theme and, for me, orange is great, but it looks best on fruit. The 'Orange Brigade' certainly went above and beyond and were so easy to spot! Happy Spring - it was disappointingly dismal for Forum but Brisbane is now strutting Jacaranda blues.

## NEWS ON THE SYDNEY HOMEFRONT

### NSW Minister for Science and Medical Research Awards

NSW Minister for Science and Medical Research awarded **Professor Perminder Sachdev** the NSW Scientist of the Year prize in the Biomedical Sciences Category. Professor Sachdev is a CORE member of the DCRC based at the UNSW and we congratulate him on being a recipient of the award.

Professor Sachdev's research is in the areas of vascular dementia, Alzheimer's disease, dementia of Lewy body type and other dementias, Neuropsychiatric aspects of dementia and treatment of various neurological conditions.

### A three-year ARC Linkage and Discovery Grant

A three-year ARC Linkage and Discovery Grant has been awarded to **A/Professor Julian Trollor**, together with a number of neurological researchers, and in collaboration with Karitane, Sydney South West Area Health Service. The

project title is: Are neurobehavioural and neuromotor impairments associated with FMR1 gene expansion.

### The Dementia Collaborative Research Centre Assessment and Better Care –

#### Position Vacant Biostatistician (part-time)

An exciting opportunity exists for an enthusiastic biostatistician with research skills to contribute to various projects within the Dementia Collaborative Research Centre – Assessment and Better Care (DCRC-ABC) at UNSW. The successful applicant will be required to provide high level statistical and research design advice and mentoring to researchers in the Centre and in partner organisations.

Please visit <http://www.hr.unsw.edu.au/services/recruitment/jobs/05111011.html> for further details.

## POSTGRADUATE SCHOLARSHIPS

### The Sydney Centenarian Study, School of Psychiatry, University of NSW, Sydney

**The Project** - This scholarship provides the opportunity for a PhD student to undertake research into exceptional old age working on the Sydney Centenarian Study

**When:** The successful applicant would be expected to begin their doctoral studies in 2011 at the Brain and Ageing Research Program at the School of Psychiatry, University of New South Wales. The successful applicant must be enrolled through the UNSW's School of Psychiatry.

**Essential Criteria:** An honours degree in Science, Psychology, Health Sciences

or equivalent, or a degree in Medicine; demonstrated aptitude for research; excellent academic record.

**Application:** Available from the UNSW Graduate Research School website: [www.grs.unsw.edu.au/](http://www.grs.unsw.edu.au/)

Local and international applicants are encouraged to apply.

Further information is available from Charlene Levitan, Study Co-ordinator, Sydney Centenarian Study – [c.levitan@unsw.edu.au](mailto:c.levitan@unsw.edu.au) or Angie Russell, Administration Manager of the Brain & Ageing Research Program - [angie.russell@unsw.edu.au](mailto:angie.russell@unsw.edu.au)

**Closing Date:** 30 November 2010

## DATES FOR THE DIARY FOR 2011

### Alzheimer's Australia 14th National Conference

**Date:** 17 – 20 May 2011

**Venue:** Brisbane

**Further Information:**

[www.alzheimers2011.com/](http://www.alzheimers2011.com/)

### 2011 National Dementia Research Forum

**Date:** 22 and 23 September 2011

**Venue:** Wesley Centre, Sydney

**Further Information:**

[www.dementia.unsw.edu.au](http://www.dementia.unsw.edu.au)